

# Susceptibility and Vulnerability of Indian women to the impact of HIV/AIDS

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## Abstract

The objective of this thesis is to examine which socio-economic, structural and cultural factors may influence Indian women's propensity to contract HIV and later their ability to access the relevant healthcare services for their condition. The research draws on two theoretical frameworks, the first being Barnett and Whiteside's (2002) concept of social structural factors of disease transmission. Second, Anderson and Aday's (1981) model of access examines how a variety of structural and resource-based factors, e.g. area of residence, can influence usage of healthcare facilities.

Two stages of data analysis were undertaken, the first being secondary statistical analysis of the National Family Health Survey III. The survey provided state level estimates on the HIV sero-status of the general population in India and data on demographic and socio-economic determinants for family planning, nutrition, utilization of healthcare and emerging health issues. The second stage of analysis consisted of a set of qualitative interviews conducted in Andhra Pradesh, India. Thirty-three interviews were conducted with female sero-positive patients and ten with HIV-infected women who were providing social services to others with the same condition.

Statistical results on social structural determinants of HIV transmission illustrated that Indian women who were formerly married (OR=5.27, CI=3.07-9.04), lived in higher prevalence states (OR=3.48, CI=2.19-5.54), had a low level of education (OR=2.27, CI=1.40-3.68) and were employed (OR=1.45, CI=0.96-2.18) had significantly (<.05) higher odds of being HIV-positive in comparison to those who were not. Findings in the qualitative phase of analysis were similar but participants' narratives illustrated that their risk of contracting HIV begun before they even had the opportunity to seek a match as they seemed to live in communities with a high level of HIV prevalence. Many of the participants commented that

there were factors outside of their sphere of control, e.g. lack of education, which resulted in them having a narrow choice of potential partners.

Additionally, statistical results on female participants' access to healthcare services indicated the vast majority of HIV-positive respondents were almost certainly not aware of their sero-status as they had not undertaken an HIV test prior to the survey. As the sample of female HIV infected respondents was relatively small, it was difficult to ascertain which social factors had an impact on these participants utilisation of HIV testing services..

On the other hand, respondents' narratives from the qualitative stage of research highlighted on social structural factors which could potentially influence WLHA's continual utilisation of HIV-related healthcare services. It was found that participants experienced the most barriers to accessing healthcare facilities in the initial phases of their treatment. These barriers were mediated by the structure of healthcare services, culturally sanctioned medical practices (e.g. physicians refusal to inform the patient of their sero-status) and quality of services.

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## Table of Contents

<b>CHAPTER 1 INTRODUCTION.....</b>	<b>16</b>
<b>PART I.....</b>	<b>21</b>
<b>CHAPTER 2 LITERATURE REVIEW.....</b>	<b>22</b>
2.A INTRODUCTION.....	22
2.B THE EPIDEMIOLOGY OF HIV IN INDIA.....	24
2.B.I Gendered Factors in the transmission of HIV.....	29
2.C FACTORS WHICH COULD POTENTIALLY AFFECT ACCESS TO HEALTHCARE FACILITIES.....	34
2.C.I Cultural barriers to treatment.....	35
2.C.II Socio-economic barriers to treatment.....	42
2.C.III Structural barriers to treatment.....	45
2.D CONCLUSION.....	52
<b>CHAPTER 3 THEORETICAL UNDERPINNING TO THE THESIS.....</b>	<b>57</b>
3.A INTRODUCTION.....	57
3.B SUSCEPTIBILITY.....	59
3.B.I Biomedical Theories of Risk Behaviour related to HIV.....	59
3.B.II Social Structural Theories of HIV transmission.....	65
3.C VULNERABILITY.....	71
3.C.I Theoretical Frameworks used in research on HIV-positive patients' experiences of utilising treatment in India.....	72
3.C.II Sociological models of access.....	77
3.D CONCLUSION.....	84
<b>CHAPTER 4 METHODS.....</b>	<b>86</b>
4.A RESEARCH QUESTIONS.....	86
4.B MIXED METHODS.....	86
4.B.I Rationale.....	86
4.B.II Mixed methods model.....	89
4.C STAGE 1: SECONDARY QUANTITATIVE ANALYSIS OF NFHS-III.....	93
4.C.I Selection Criteria.....	93
4.C.II Sample Design.....	94
4.C.III Data Collection Procedures.....	96
4.C.IV Representativeness of NFHS-III data.....	97
4.C.V Ethical Procedures.....	98
4.D STAGE 2: QUALITATIVE RESEARCH.....	99
4.D.I Setting.....	99
4.D.II Sampling Technique.....	100
4.D.III Data collection.....	101
4.D.IV Translation Procedures.....	103
4.D.V Procedures to validate the data.....	105

4.D.VI	<i>Ethical Procedures</i> .....	105
4.E	INTEGRATION OF ANALYSIS .....	108
4.E.I	<i>Quantitative analysis</i> .....	108
4.E.II	<i>Qualitative analysis</i> .....	109
4.E.III	<i>Phase of Integration</i> .....	110
4.E.IV	<i>Limitations</i> .....	111
<b>PART II</b> .....		<b>114</b>
<b>CHAPTER 5 WOMEN'S 'SUSCEPTIBILITY' TO HIV IN INDIA ACCORDING TO DATA FROM THE NFHS-III</b> .....		<b>115</b>
5.A	INTRODUCTION.....	115
5.A.I	<i>Selection of variables to measure 'susceptibility'</i> .....	116
5.B	MACRO-ENVIRONMENTAL PREDICTORS OF HIV-STATUS.....	119
5.B.I	<i>Socio-demographic characteristics</i> .....	119
5.B.II	<i>Socioeconomic factors</i> .....	122
5.B.III	<i>Social Status</i> .....	126
5.B.IV	<i>Multivariate analysis of 'macro-environmental' predictors of HIV-status</i> .....	129
5.B	MICRO-SOCIAL PREDICTORS OF HIV-STATUS.....	134
5.B.I	<i>Gendered Discrimination</i> .....	134
5.B.II	<i>Attitudes to HIV</i> .....	140
5.B.III	<i>Geographical Mobility</i> .....	144
5.B.IV	<i>Multivariate analysis of 'micro-social' predictors of HIV-status</i> .....	147
5.C	BEHAVIOURAL PREDICTORS OF HIV-STATUS .....	150
5.C.I	<i>Sexual Behaviour</i> .....	150
5.C.II	<i>Multivariate analysis of behavioural predictors of HIV-status</i> .....	153
5.D	MULTIVARIATE ANALYSIS OF MACRO-ENVIRONMENTAL, MICRO-SOCIAL AND BEHAVIOURAL PREDICTORS OF HIV-STATUS .....	155
5.E	DISCUSSION .....	158
5.F	CONCLUSION .....	160
<b>CHAPTER 6 COMPARATIVE ANALYSIS OF DATA FROM THE QUANTITATIVE AND QUALITATIVE PHASE OF RESEARCH</b> .....		<b>162</b>
6.A	INTRODUCTION.....	162
6.B	MACRO-ENVIRONMENTAL DETERMINANTS .....	164
6.B.I	<i>Socio-demographic characteristics</i> .....	164
6.B.II	<i>Communal trends of HIV transmission</i> .....	172
6.C	MICRO-SOCIAL DETERMINANTS .....	178
6.C.I	<i>Gendered Discrimination</i> .....	178
6.D	BEHAVIOURAL DETERMINANTS .....	185
6.D.I	<i>Sexual behaviour</i> .....	185
6.E	DISCUSSION .....	188
6.F	CONCLUSION .....	191

<b>CHAPTER 7 EMERGING FINDINGS ON ‘SUSCEPTIBILITY’ FROM THE QUALITATIVE PHASE OF ANALYSIS .....</b>	<b>193</b>
7.A INTRODUCTION .....	193
7.B FACTORS WHICH CONSTRAIN A RESPONDENT’S CHOICE OF PARTNER ...	194
7.B.I <i>Familial factors</i> .....	194
7.B.II <i>Individual factors</i> .....	205
7.C COMBINING EMERGING AND CONVERGING RESULTS .....	209
7.D DISCUSSION AND CONCLUSION .....	212
<b>PART III.....</b>	<b>216</b>
<b>CHAPTER 8 UTILISATION OF HEALTHCARE FACILITIES AND HEALTH BEHAVIOUR OF PARTICIPANTS IN THE NFHS-III.....</b>	<b>217</b>
8.A INTRODUCTION .....	217
8.A.I <i>Selection of variables to measure ‘vulnerability’</i> .....	219
8.B CHARACTERISTICS OF HEALTH DELIVERY SYSTEM .....	223
8.B.I <i>Availability</i> .....	223
8.C CHARACTERISTICS OF POPULATION AT RISK.....	225
8.C.I <i>Need</i> .....	225
8.D SOCIO-CULTURAL PRACTICES .....	228
8.D.I <i>Health Behaviours</i> .....	228
8.D.II <i>Gendered discrimination</i> .....	234
8.E OBJECTIVE REALISED ACCESS .....	238
8.E.I <i>Use of HIV testing facilities</i> .....	238
8.E.II <i>Use of outreach and healthcare services</i> .....	242
8.F SUBJECTIVE REALISED ACCESS .....	248
8.G .DISCUSSION .....	251
8.H CONCLUSION .....	254
<b>CHAPTER 9 HIV-POSITIVE WOMEN’S ‘VULNERABILITY’ TO THE IMPACT OF HIV/AIDS- NFHS-III RESULTS ON ACCESS TO HIV TESTING FACILITIES .....</b>	<b>256</b>
9.A INTRODUCTION .....	256
9.A.I <i>Selection of variables to measure predictors of vulnerability</i> .....	257
9.B CHARACTERISTICS OF POPULATION AT RISK.....	260
9.B.I <i>Predisposing Characteristics</i> .....	260
9.B.II <i>Enabling Resources</i> .....	264
9.B.III <i>Need</i> .....	267
9.C CHARACTERISTICS OF HEALTH DELIVERY SYSTEM .....	270
9.C.I <i>Availability</i> .....	270
9.C.II <i>Organisation of services</i> .....	273
9.D SOCIO-CULTURAL PRACTICES .....	278
9.D.I <i>Gendered Discrimination</i> .....	278
9.E DISCUSSION .....	281
9.F CONCLUSION .....	283

<b>CHAPTER 10 HIV-POSITIVE WOMEN’S ‘VULNERABILITY’ TO THE IMPACT OF HIV/AIDS ACCORDING TO QUALITATIVE DATA FROM THE SECOND STAGE OF RESEARCH .....</b>	<b>286</b>
10.A INTRODUCTION .....	286
10.B FIRST ENTRY INTO HIV-RELATED CARE .....	287
10.C CURRENT TREATMENT .....	294
10.C.I <i>Non-governmental treatment</i> .....	297
10.C.II <i>Governmental treatment</i> .....	303
10.D CONCURRENT TREATMENT .....	308
10.E DISCUSSION AND CONCLUSION .....	311
<b>PART IV .....</b>	<b>315</b>
<b>CHAPTER 11 FINAL ANALYSIS .....</b>	<b>316</b>
11.A INTRODUCTION .....	316
11.B COMBINING QUANTITATIVE AND QUALITATIVE RESULTS .....	320
11.C WOMEN’S ‘SUSCEPTIBILITY’ TO HIV INFECTION.....	324
11.D WOMEN’S ‘VULNERABILITY’ TO THE IMPACT OF HIV/AIDS.....	329
11.E IMPLICATIONS FOR FUTURE SOCIAL INTERVENTIONS OR PROGRAMMES .....	337
11.F CONCLUSION .....	341
BIBLIOGRAPHY .....	345
APPENDIX.....	395

## Tables

Table 3.1: Barnett and Whiteside's (2002) model of social structural determinants of HIV transmission adapted for research.....	70
Table 3.2: Theoretical frameworks and methods used in studies on HIV-positive patients' utilisation of healthcare in India.....	73
Table 4.1: Structure of interview schedule.....	102
Table 5.1: The assignment of variables to measure dimensions of Barnett and Whiteside (2002) model of 'susceptibility'.....	117
Table 5.2: Female participants' sero-status and HIV prevalence by area of residence (weighted).....	120
Table 5.3: Female participants' sero-status and HIV-prevalence by level of education (weighted).....	123
Table 5.4: Female participants' sero-status and HIV-prevalence by work status, occupation and wealth (weighted).....	124
Table 5.5: Female participants' sero-status and HIV-prevalence by religion, caste or tribe identity, type of caste (weighted).....	127
Table 5.6: Female participants' sero-status and HIV-prevalence by marital status (weighted).....	128
Table 5.7: Couples' sero-status (weighted, n= 26230).....	129
Table 5.8: 'Macro-Environmental' predictors of HIV-status among female participants in the NFHS-III (weighted).....	131
Table 5.9: Female participants' experience of emotional violence according to their sero-status (weighted).....	135
Table 5.10: Types of violence that married female participants experienced and their HIV-status within their partnership (weighted).....	137
Table 5.11: Female participants' commonly held misconceptions about HIV according to their sero-status (weighted).....	141
Table 5.12: Female participants' knowledge of ART and mother-to-child transmission according to their sero-status (weighted).....	142
Table 5.13: Female participants' stigmatising attitudes towards HIV according to their sero-status (weighted).....	143
Table 5.14: Percent distribution of male and female participants aged 15-49 in the NFHS-III according to their history of mobility and their sero-status (weighted).....	145
Table 5.15: How many times male participants stay away from home for their work according to their sero-status (weighted).....	146
Table 5.16: 'Micro-social' predictors of HIV-status among female participants in the NFHS-III (weighted) (**<math> < .005</math>, **<math> < .01</math> and *<math> < .05</math>).....	148
Table 5.17: Female participants' previous sexual history and their HIV-status (weighted).....	150
Table 5.18: Multiple sexual partners and high risk sexual intercourse during participant's lifetime, including respondents who never had sex, in the last 12 months and their sero-status: Women and Men (weighted).....	151
Table 5.19: Correlates of 'behavioural' predictors of HIV-status (weighted).....	154
Table 5.20: Correlates of all predictors of HIV transmission (weighted).....	157

Table 6.1: Participants' characteristics in the qualitative stage of analysis.....	171
Table 8.1: Coverage of AWCs and sero-status of female participants (weighted).....	225
Table 8.2: Indicators of malnutrition and female respondents' sero-status.....	226
Table 8.3: Measurements of 'need' including indicators of chronic illness and STD symptoms according to participant's sero-status (weighted).....	227
Table 8.4: Social correlates of food consumption (weighted).....	230
Table 8.5: Multiple measures of female respondents' decision making capabilities and their sero-status (weighted).....	236
Table 8.6: Multiple measures of respondents' freedom of movement and their sero-status (weighted).....	237
Table 8.7: Female participants' use of HIV testing facilities according to their sero-status (weighted).....	238
Table 8.8: Multiple measurements of female respondents use of HIV testing facilities (weighted).....	240
Table 8.9: Indicators of female respondents' use of outreach services and their sero-status (weighted).....	243
Table 8.10: Types of issues that female respondents discussed with their outreach worker in the NFHS-III and their sero-status (weighted).....	244
Table 8.11: Multiple measurements of female respondents' use of healthcare facilities according to their sero-status (weighted).....	245
Table 8.12: Type of service female participants sought according to their sero-status (weighted).....	247
Table 8.13: Female participant's sero-status and multiple measures of quality of outreach worker services (weighted).....	248
Table 8.14: Female participants perceived level of quality of healthcare services according to their HIV-status (weighted).....	250
Table 9.1: Multiple measurements of female HIV-positive participants' 'predisposing characteristics' and whether they had taken an HIV test (weighted) (n=115).....	261
Table 9.2: Multiple measurements of female HIV-infected respondents' enabling resources and whether they had taken an HIV test (weighted) (n=115).....	265
Table 9.3: Multiple measurements of female HIV-positive participants' occupation and whether they had taken an HIV test (weighted) (n=115).....	266
Table 9.4: Multiple measurements of female HIV-positive participants' level of malnutrition and whether they had taken an HIV test (weighted) (n=114).....	267
Table 9.5: Any usual resident of the household suffers from TB and whether any female HIV-positive members of this household had taken an HIV test (weighted) (n=105).....	268
Table 9.6: Enumeration areas covered by AWC and whether female HIV-positive respondents had taken an HIV test (weighted) (n=115).....	270
Table 9.7: Years of coverage by AWC and female HIV-positive respondents' propensity to take an HIV test (weighted) (n=84).....	271
Table 9.8: Multiple measures of female HIV-infected respondents' control of financial resources and their propensity to take a HIV test (weighted) (n=115).....	279

## Figures

Figure 3.1: Barnett and Whiteside's (2002) model of social structural determinants of HIV transmission as displayed in their publication 'AIDS in the twenty-first century: disease and globalization' .....	69
Figure 3.2: Andersen and Aday's (1981) theoretical framework .....	81
Figure 3.3: Andersen and Aday's (1981) modified theoretical framework.....	83
Figure 4.1: Model of mixed methods.....	92
Figure 5.1: Distribution of ages by HIV-status of female respondents (weighted).....	119
Figure 5.2: Female participants' sero-status according to their level of wealth (weighted)..	125
Figure 6.1: Age distribution of female HIV-positive participants in the qualitative stage of analysis.....	166
Figure 7.1: Transmission dynamics in PF16's family .....	202
Figure 7.2: Stages of qualitative interview participants' narratives .....	212
Figure 8.1: Andersen and Aday's model of access with additional adjustments for data analysis.....	219
Figure 9.1: Andersen and Aday's model of access with additional adjustments for data analysis.....	258
Figure 10.1: PF1's pathway through treatment.....	289
Figure 10.2: PF22's pathway through treatment.....	291
Figure 10.3: Respondents' patterns of healthcare utilisation.....	295

## Appendix

Appendix 1: Demographics Sheet .....	395
Appendix 2: Telegu version of Demographics Sheet .....	397
Appendix 3: Service User’s Topic guide .....	399
Appendix 4: Peer Provider’s Topic Guide.....	404
Appendix 5: Telegu version of Peer Provider’s Interview Schedule.....	408
Appendix 6: Ethical Consent Form.....	413
Appendix 7: Telegu version of Ethical Consent Form .....	416
Appendix 8: Adverse Events Form.....	419
Appendix 9: Coverage of HIV testing by background characteristics: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to background characteristics, India 2005-06 .....	420
Appendix 10: Coverage of HIV testing by state: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to state, India 2005-06.....	421
Appendix 11: Coverage of HIV testing by religion: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to religion, India 2005-06 .....	422
Appendix 12: Married couples’ sero-status and their area of residence .....	422
Appendix 13: Female participants’ sero-status and prevalence by state .....	423
Appendix 14: Male participants’ sero-status and prevalence by state .....	424
Appendix 15: Couple’s sero-status by state.....	425
Appendix 16: Multiple measurements of agricultural work and female participants’ sero-status .....	425
Appendix 17: Men’s sero-status by marital status.....	426
Appendix 18: Duration of female respondents’ marriage in years and their sero-status.....	426
Appendix 19: Multiple measures of ‘controlling behaviour’ and female participants’ sero-status .....	428
Appendix 20: Multiple measures of ‘controlling behaviour’ and married female participants’ sero-status within their relations.....	429
Appendix 21: Multiple measures of attitudes towards domestic violence and female participants’ sero-status .....	430
Appendix 22: Multiple measures of justifications for domestic violence and couple’s sero-status (men) (weighted).....	431
Appendix 23: Multiple measures of justifications for domestic violence and couple’s sero-status (women).....	431
Appendix 24: Severity of violence experienced from spouse according to sero-status of female respondents.....	432
Appendix 25: Types of injuries incurred by domestic violence and female participants’ sero-status.....	432
Appendix 26: When domestic violence first started with spouse according to female participants sero-status.....	432
Appendix 27: Severity of violence experienced from spouse according to sero-status of couples .....	433

Appendix 28: Female participant's history of sexual violence according to their sero-status .....	433
Appendix 29: History of sexual violence according to couples' sero-status .....	433
Appendix 30: Female participants knowledge of the existence of HIV/AIDS according their sero-status .....	434
Appendix 31: Female participants' knowledge of the ABC method of HIV prevention methods according to their sero-status.....	434
Appendix 32: Female participants' sero-status and their knowledge of ways to avoid HIV (weighted).....	435
Appendix 33: Multiple measures of mobility of married female participants and their sero-status within their partnership.....	435
Appendix 34: Multiple measures of mobility of married male participants and their sero-status within their partnership.....	436
Appendix 35: Male participants' previous sexual history and their HIV-status.....	436
Appendix 36: The total lifetime number of sexual partners that married women had and their sero-status .....	436
Appendix 37: The total lifetime number of sexual partners that married men had and their sero-status .....	436
Appendix 38: Female and male participants' relationship to their last sexual partner and their sero-status .....	437
Appendix 39: Female participants' recent sexual activity and their sero-status.....	437
Appendix 40: Male participants' recent sexual activity and their sero-status .....	437
Appendix 41: Female and male participants used condom last sexual intercourse and sero-status .....	438
Appendix 42: The amount of wives male participants had according to their sero-status... ..	438
Appendix 43: Multiple measures of food consumption and female participants' sero-status .....	439
Appendix 44: Multiple measures of gendered barriers to healthcare and female participants' sero-status .....	441
Appendix 45: Multiple measures of female respondents' control over their financial resources and their sero-status .....	442
Appendix 46: Region of India which female HIV-positive participants lived in and whether they undertook a HIV test.....	442
Appendix 47: Religion of female HIV-infected participants religion and whether they undertook a HIV test.....	443
Appendix 48: Household ownership of a BPL card and whether female HIV-infected participants undertook an HIV test.....	443
Appendix 49: Years of coverage by AWC and female HIV-positive respondents propensity to undertake an HIV test .....	443
Appendix 50: Multiple measures of female HIV-positive respondents' decision making capabilities and if they have ever been tested.....	444
Appendix 51: Multiple measures of female HIV-positive respondents freedom of movement and if they have ever been tested .....	445

Appendix 52: Multiple measures of gendered barriers to healthcare and female HIV-infected propensity to undertake a HIV test .....446

## List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AIRTDS	Action for Integrated Rural and Tribal Development
AP	Andhra Pradesh
APPLE	Association of Positive People for Living Excellence
ARV	Antiretroviral
ART	Antiretroviral Therapy
AWC	Anganwadi Centre
BPL	Below Poverty Line
CCC	Community Care Centre
CHC	Community Healthcare Centre
CHES-plus	Cheytha HIV Infected People Empowerment Society
CSW	Casual Sex Worker
GIS	Geographic Information System
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
IIPS	International Institute for Population Sciences
IMF	International Monetary Foundation
LEPRA	British Empire Leprosy Relief Association
MOHFW	The Ministry of Health and Family Welfare
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NFHS	National Family Health Survey
NGO	Non-Governmental Organisation
OBC	Other Backward Classes
OI	Opportunistic Infection
PF	Participant Female
PHC	Primary Healthcare Centre
PLWHA	People Living With HIV/AIDS

PN	Positive Network
PP	Peer Provider
PSU	Primary Sampling Units
SC	Scheduled Castes
SHIP-Network	Society for Welfare of HIV Infected People
ST	Schedule Tribes
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
TN	Tamil Nadu
UNAIDS	Joint United Nations Programme on AIDS
UNICEF	United Nations Children's Fund
UP	Utter Pradesh
VMM	Vasya Mahila Mandali
WHO	World Health Organisation
WLHA	Women Living With HIV/AIDS
YRG CARE	YR Gaitonde Centre For AIDS and Education

## Chapter 1 INTRODUCTION

*"India is the single most important country with regard to the history of the global epidemic. If we lose the fight in India, we lose the fight globally"*  
Feachem (cited Cohen 2004b:509)

HIV is a devastating disease which has the potential to kill millions, impede the economic development of the South and change the structure of communities as it rapidly spreads across the world (UNAIDS, WHO 2009, Piot 2005, Ruxin, Paluzzi et al. 2005, De Cock, Mbori-Ngacha et al. 2002). In 2009 there were an estimated 33 million People Living With HIV/AIDS (PLWHA) globally, most of whom lived in Sub-Saharan Africa (Lubinski, Aberg et al. 2009). Around 2.2 million people die annually due to illnesses related to HIV/AIDS, with the majority of these individuals living in underdeveloped countries. Considering that the number of PLWHA who died in 2010 is almost equivalent to the population of Lesotho (DESA 2008), HIV/AIDS has generated a heavy burden on the healthcare services of developing nations with a high prevalence of HIV, countries which can barely afford to treat curable illnesses like tuberculosis (TB).

HIV-infected people can now live comfortably for long periods of time with the assistance of antiretroviral (ARV) medications (Kumarasamy, Solomon et al. 2005). In many underdeveloped countries, where the epidemic is most prominent, such medication is unaffordable for the average HIV-infected patient. Due to poor healthcare infrastructure and expensive medication, the majority of PLWHA worldwide may not have access to the appropriate treatment for survival (WHO 2009).

India is the epicentre of the HIV epidemic in Asia, with an estimated 2.31 million (1.8 – 2.9 million) PLWHA in 2008 (NACO 2008a). Over 90% of these PLWHA in India are between the ages of 15 and 45, usually the most economically productive age range (NACO 2010). PLWHAs' condition could affect the socioeconomic development of the country, as

the welfare of families and communities is impeded by loss of earnings and the high health costs of treating HIV-infected patients. Harris (2003) stated that:

*HIV/AIDs is 'shortening the life expectancy of working-age adults, dramatically increasing the number of infant and child deaths, shrinking the workforce, creating millions of orphans, widening the gap between rich and poor countries, and reversing developmental gains in third world nations' (p. 5).*

The Indian government has estimated that over a third of HIV-infected cases in India are women (NACO 2008a). Recent research has indicated that many Women Living with HIV/AIDS (WLHA) may have been infected by their husbands, the only sexual partner they have had in their lifetime (NACO 2010). The welfare of these WLHA could be crucial to the epidemic, because many act as gatekeepers to their families' healthcare and provide for them financially when the main breadwinner is unwell (D'Cruz 2003, Mehta, Sodhi 2008). Previous studies have illustrated that WLHA in India are responsible for care of in-laws, children and spouses, even when heavily afflicted with HIV (D'Cruz 2003, D'Cruz 2002, Duggan 2006, D'Cruz 2004). WLHAs' access to healthcare facilities and appropriate treatment could affect not only their health status but that of the rest of their family.

This thesis is a sociological examination of the social structural dynamics of HIV transmission among women in India and the influence of these factors on their ability to access healthcare services. The research for this thesis is informed by two theoretical frameworks, the first of which addresses the structural determinants of HIV transmission and the impact that it can have on these communities. According to Rhodes (1997), social structural theories of HIV transmission posit that:

*'Risk behaviour is thought to be the product of interplay between individuals, the actions of other individuals, their communities and social environments' (p. 210).*

The second conceptual framework specifically addresses factors which affect WLHAs' ability to access the necessary healthcare services. Andersen and Aday's (1981)

model of access explores how a variety of structural and resource-based factors (e.g. income), affect use of healthcare facilities.

This thesis seeks to fill a crucial gap in literature on HIV/AIDS in India through the use of the concepts of ‘susceptibility’ and ‘access’ to guide the research questions and the subsequent model of triangulation. These research questions firstly explore what structural determinants impact women’s predisposition to acquire HIV and how social processes may influence their ‘susceptibility’ in the Indian context, and secondly seek to examine what structural and social factors influence WLHAs’ use of healthcare facilities and the processes that participants undergo in choosing treatment.

A mixed methods approach is adopted to comprehensively investigate the complex social phenomenon of HIV/AIDS in India. The mixed methods model follows a ‘sequential explanatory design’ (Morse 2003), in which research is conducted in two stages with the quantitative analysis taking place first. The primary purpose of this research design is to ensure that the quantitative results can inform the qualitative phase of analysis. The initial stage of research comprises a secondary statistical analysis of the National Family Health Survey 3 (NFHS-III). The survey contains data on demographic and socioeconomic determinants for family planning and emerging health issues (IIPS 2008, IIPS, Macro International 2007). The second stage of research consists of a set of qualitative interviews carried out in Andhra Pradesh, India. Forty-three interviews were conducted with sero-positive women who were beneficiaries of or provided services for local NGO, governmental and Positive Network (PN) services in three different districts.

This thesis is divided into four parts, with Part I consisting of the literature review, theory and methods. The results chapters are presented in a format which reflects the mixed methods model and the theoretical frameworks guiding the research. As a consequence, the quantitative findings are presented first, in order to reflect the sequential rather than iterative

or ‘concurrent’ model of mixed methods research. Part II, which comprises chapters 5, 6 and 7, explores the social structural determinants of HIV transmission in India. Chapter 5 uses data from the NFHS-III to analyse statistically which social structural determinants of transmission influence Indian women’s propensity to HIV infection. The findings in this chapter indicate that women’s propensity to HIV infection could in part be a product of their social context rather than their own individual behaviour. Variables reflective of social structural forces (e.g. religion), had a greater impact on women’s predisposition to HIV infection than their sexual history prior to the survey.

Chapter 6 examines the social structural processes which could potentially influence findings in the previous chapter. These processes are classified through analysis of data from the qualitative phase of research. Particular attention is paid to participants’ narratives of their lives prior to being diagnosed as HIV-positive, in order to classify points where their accounts converged with findings from the quantitative phase of research. For instance, results from the NFHS-III indicated that female HIV-positive respondents tended to live in areas of high sero-prevalence, and participants’ narratives in the qualitative stage of research demonstrated that they lived in communities with a relatively dense concentration of HIV-prevalence and tightly-knit social/sexual networks. These findings illustrated that their social environment put them at elevated risk of contracting HIV prior to their even starting to search for a life partner.

In addition, chapter 7 investigates results which emerge purely from the qualitative phase of research. These findings illuminate social structural processes which may have impelled these women into partnerships with husbands who engaged in risky sexual behaviour, such as extramarital sexual relationships. These processes were driven at a communal and individual level through traditional gendered norms, sociocultural practices related to marriage and social inequality.

Part III, consisting of chapters 8, 9 and 10, examines HIV-positive women's access to healthcare facilities. Chapter 8 uses data from the NFHS-III to assess which social and structural factors affect WLHA's overall use of healthcare services. As participants in the NFHS-III were not asked their sero-status by the interviewer, it is not possible to ascertain whether female HIV-positive participants had used healthcare services with full knowledge of their condition. I therefore examine the differences in healthcare use between HIV-positive and HIV-negative respondents. The findings from this chapter highlight the fact that the majority of female HIV-infected participants may not yet be aware of their sero-status because they have not taken an HIV test.

In response to these findings, chapter 9 uses a combination of quantitative and qualitative data to further explore which factors influence female sero-positive respondents' use of HIV-testing facilities. Andersen and Aday's (1981) model of access is applied to assess which 'potential dimensions' of access influence respondents' use of HIV testing facilities.

As the NFHS-III is cross-sectional, it is not possible to analyse how different components of Andersen and Aday's (1981) conceptual framework of access may affect HIV-infected women's use of healthcare services at different stages of their illness. Chapter 10 therefore assesses respondents 'continual access' (Mechanic 1995) to healthcare providers through analysis of data from the qualitative phase of research. Findings in this chapter demonstrate that participants' access to healthcare services is a complex phenomenon dependent on the cultural practices related to diagnosis and the structure of healthcare services.

# PART I

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## Chapter 2 LITERATURE REVIEW

### 2.A Introduction

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In comparison to sub-Saharan Africa, there has been a dearth of research on prevention and treatment of HIV in South-East Asia. The foremost reason for this is that the prevalence of HIV in Asian countries (e.g. India and China), has been fairly low, less than 1 per cent (UNAIDS, WHO 2009). This hides the sheer scale of the HIV epidemic in these countries, which have sizeable numbers of PLWHA, given their very large populations. These HIV-infected populations are numerically larger than those of many sub-Saharan African countries with high rates of sero-prevalence (Cohen 2004a). Trends of HIV transmission within South-East Asian countries are often reflective of wider social dynamics related to rapid economic development, which displaces already vulnerable and stigmatised social groups (e.g. transsexuals) on the fringes of society (Wilson, Claeson 2009). These groups are particularly susceptible to HIV infection as they may have little awareness of HIV/AIDS or are constrained by their social setting from engaging in preventative behaviour.

One group susceptible to HIV infection and frequently overlooked by policy-makers in India is heterosexual female partners of HIV-infected men. It has been noted by researchers that the bulk of HIV-positive women in India are infected by their husband, usually their only lifetime sexual partner (Solomon, Mehta et al. 2010, Sri Krishnan, Hendriksen et al. 2007, Delpierre, Cuzin et al. 2006, Steen, Mogasale et al. 2006). Recent literature on this topic indicated that a set of social factors mediated by gendered norms, including domestic violence and low economic bargaining power, may possibly increase these women's propensity to contract HIV (Avert 2010b). Nonetheless, many women in India experience gendered discrimination on a daily basis and yet never contract HIV, indicating that other social structural factors may also influence these women's susceptibility to the

virus. This thesis therefore explores how gendered discrimination works in unison with other structural determinants of transmission, through the use of a combination of qualitative and quantitative data.

Due to the large numbers of PLWHA in India, sustained access to relevant treatment is crucial for containing the epidemic. Piot, Bartos et al. (2001) argue that HIV/AIDS needs to be accepted as a unique disease, and thus ‘the response to AIDS needs to be equally exceptional’ (p.2). It has therefore been posited by leading experts in the field that, unlike other illnesses, HIV needs to be tackled from multiple platforms in order to deal with the social consequences of the condition (Piot 2005, Amaro, Raj et al. 2001).

Currently very little research directly addresses female HIV-positive patients’ access to healthcare facilities. Literature on WLHAs’ experience of their condition indicates that they may potentially suffer from many sociocultural, economic and structural impediments to access (Break Through 2003, Amin, Bentley 2002, Sinha, Peters et al. 2009). Some of these impediments are associated with gendered inequalities and sociocultural practices (e.g. caste) inherent in traditional Indian society which restrict their freedom of movement and earning potential. These social factors could later be exacerbated when they are diagnosed with HIV.

The first objective of this chapter is to critically engage and identify the gaps in the current body of literature on HIV transmission in India. Historical trends of the HIV epidemic in South-East Asia are complex, as transmission involves disparate groups of individuals displaying different types of risk behaviours (Babu, Kar 2010, Bojko, Schensul et al. 2010, Weiss, Patel et al. 2008, Chandrasekaran, Krupp et al. 2007). Epidemiological study of the epidemic is further mired in the difficulty inherent in estimating the true level of infection in such a large and diverse population (Wilson, Claeson 2009, Over 2009). I initially examine, therefore, epidemiological trends of HIV transmission, paying particular attention to

government policy on prevention and research into gendered determinants of HIV transmission in India.

The second objective of this chapter is to assess sociocultural, economic and structural factors that could potentially influence HIV-positive women's long-term use of healthcare. Currently, literature on sero-positive women's use of HIV-related treatment in India remains relatively sparse. Although recent research conducted by the World Bank has identified widowed HIV-positive women as one of the groups most vulnerable to extreme poverty (Over, Heywood et al. 2004, Binswanger 2000), very few studies have sought to address how these women learn to cope with their condition (Das, Mukhopadhyay et al. 2009, Haacker 2009, Haacker, Claeson 2009). The following section of this chapter therefore explores hypothesised barriers to access that are based on previous research on gender, labour and the structure of public and private healthcare facilities in India. Particular attention is paid to the effects that recent changes in healthcare policy may have had on WLHAs' ability to access healthcare services.

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## 2.B The Epidemiology of HIV in India

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The first cases of HIV in India were detected in 1986 amongst Commercial Sex Workers (CSWs) in Chennai, Tamil Nadu (TN) (Cowley 2003, O'Neil, Orchard et al. 2004). It was noted that contact with foreign visitors had played a role in the initial infections (Avert 2009). This fuelled the common perception that it was not possible for HIV to spread over wide areas of India as 'ordinary' people held 'traditional' values that prohibited sexual relations outside marriage (Nag, NCEPH 1995). Consequently, the National AIDS Control Organisation (NACO), a governmental body that coordinates HIV/AIDS prevention and treatment programmes in India, was not established until six years after the virus was initially detected (Over, Heywood et al. 2004). The first phase of the National AIDS Control Policy,

conducted in 1992-1998, encompassed few programmes of prevention or treatment of HIV in India. Few financial resources were channelled towards social interventions addressing HIV-related risk behaviours. NACO concentrated on monitoring trends of HIV transmission and implementing procedures to ensure safety of blood products used by public healthcare providers (Mehta, Sodhi 2008).

By the turn of the 21<sup>st</sup> century HIV had rapidly spread across India to the extent that it was detectable in every state. Similar to other South-East Asian countries, India was undergoing what was identified by UNAIDS and WHO (2003) as a ‘concentrated epidemic’<sup>1</sup>, whereby HIV-prevalence was high amongst groups displaying risk behaviour but low in the general population. According to UNAIDS (2006):

*India was ‘experiencing a highly varied HIV epidemic which appears to be stable or diminishing in some parts while growing at a modest rate in others’ (p. 27).*

Unlike many countries heavily afflicted with HIV in Sub-Saharan Africa (e.g. Kenya), which has a uniformly high sero-prevalence spread over a large area of the population (Doherty 2011, Gregson, Todd et al. 2009, Chen, Jha et al. 2007, HELLERINGER, Kohler 2007), India had localised pockets of HIV prevalence concentrated in small areas (UNAIDS, WHO 2007a). Two thirds of the infections were concentrated in six states situated in the industrial southern areas and the North East<sup>2</sup> of India (Maharashtra, TN, Karnataka, Andhra Pradesh, Manipur and Nagaland) (UNAIDS, WHO 2003). Hence, experts in the field of HIV/AIDS have posited that the epidemic in India is best analysed as a ‘continent’ ‘given...(its) size and complexity... some of whose states are larger than many African countries’ (Wilson, Claeson 2009: 15).

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<sup>1</sup> The numeric proxy for a concentrated epidemic is that HIV prevalence consistently over 5% in at least one sub-population at highest risk, and prevalence below 1% in the general adult population in urban areas (UNAIDS, WHO 2003).

<sup>2</sup> A state is categorized as high if prevalence of HIV infection in pregnant women attending antenatal clinics is 1% or more (NACO 2010).

In the north-eastern states of Manipur and Nagaland, the spread of HIV infection was fuelled by unsafe practices associated with drug-injecting use, e.g. sharing needles and failure to adequately sterilise apparatus (Kumar, Virk et al. 2008, Mahanta, Borkakoty et al. 2009, Mahanta, Medhi et al. 2008, Panda, Bijaya et al. 2001, Solomon, Celentano et al. 2010). According to Gajendra, Jagadish et al. (2011) these states bordering Myanmar were part of the 'Golden Triangle', a route in South-East Asia infamous for trade in illegal drugs. Few studies record women's drug-injecting behaviours in India, and some researchers have argued that injecting drug use was relatively rare among women (Panda, Kumar et al. 2005, Panda, Kumar et al. 2007). Nevertheless, it is possible that female Injecting Drug Users (IDUs) were difficult to sample, being even more marginalised than their male counterparts. Panda, Bijaya et al. (2001) reported that female IDUs in Manipur were impelled to migrate from their natal homes after ethnic clashes and were forced through poverty and drug addiction to engage in sex work.

On the other hand, studies conducted in North-eastern states and large cities reported that wives of male IDUs were predisposed to HIV through their partner's risk behaviour (Grassly, Lowndes et al. 2003). Panda, Kumar et al. (2005) found that none of the spouses of male IDUs in their sample in Chennai had reported partaking in any form of drug use or sexual risk behaviour. Conversely, most male IDUs reported having more than five sexual partners in their lifetime. It was not possible to conduct any fieldwork for this thesis in the North Eastern regions of India as this area has a recent history of terrorism conducted by separatist Maoist groups (Suykens 2010). Nevertheless, it was feasible to quantitatively analyse risk behaviours and access to healthcare services of WLHA residing in the north-east of India through using data from NFHS-III.

In the southern states of India HIV was typically transmitted along mobile labour routes used by truck drivers and industrial workers (Halli, Blanchard et al. 2007, Nagelkerke,

Jha et al. 2002). Previous studies have suggested that heterosexual sexual transmission was driven by male migrant labourers and truck drivers visiting CSWs along the highway<sup>3</sup>. Many CSWs belong to economically deprived backgrounds and have little education, so may not know of routes of HIV transmission (Thappa, Singh et al. 2007). For instance, Dandona, Dandona et al. (2006) demonstrated that condom requirements were not met for three-fifths of a sample population of CSWs in Andhra Pradesh (A.P.). Hence, research on HIV transmission in Southern and North-Eastern states of India indicate that populations displaying risk behaviours are geographically located, meaning that some people living in the same area could be at heightened susceptibility of contracting HIV if they are in a sexual relationship with someone belonging to a high-risk group.

In response to the rapid spread of HIV across these areas of India, the second phase of the National AIDS Control Policy was conducted in 1999-2005. The main objectives of this phase of policy were to ensure safety of blood products in both public and private healthcare services, increase awareness of HIV in the general population and decrease risk behaviours. These types of measures may have reduced iatrogenic transmission of HIV from medical procedures. During this time around 660 NGOs in India were funded by the government and other donors to deliver social interventions targeted at high risk groups, e.g. truck drivers and CSWs (Over, Heywood et al. 2004), with the intention of changing their behaviour. Some of these interventions involved social marketing of condoms, needle exchange programmes for IDUs and peer education for CSWs (Mehta, Sodhi 2008).

By around 2005, it was estimated that India had an HIV-infected population of around five million, making it the largest group of PLWHA in the world (NACO 2008a, NACO 2008c). However, research indicated that the HIV surveillance techniques used by NACO produced inaccurate estimates of sero-prevalence in the general population. Dandona,

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<sup>3</sup> It was estimated that there are between 1.0 and 16.2 million CSWs in India and that they are visited on average by 1.6 to 13 clients per day (Venkataramana, Sarada 2001).

Lakshmi et al's (2006) study of research techniques used by the Indian government shows that the HIV burden in the Indian population had been overestimated because data was collected from sentinel sites located in urban public health clinics, which are only attended by the poorest. The majority of the Indian population used private healthcare, meaning that it was difficult to specify from these statistics overall prevalence in the general population.

In 2006, estimates of the prevalence of HIV were improved by expanding surveillance and enhancing the quality of data, including the NFHS-III, which began to physically test participants for HIV by gathering blood samples as part of the data collection process. Estimates of HIV prevalence in India were revised to 0.36% (0.27%-0.47%), meaning that the size of the population of PLWHA would be around 2.47 million (2.0-3.1 million) (UNAIDS, WHO 2007a, NACO 2008c, Pandey, Reddy et al. 2009). This confirmed that earlier population-based data collected from sentinel sites may have significantly overestimated the extent of the epidemic in India.

Current population-based data collected from sentinel sites and surveys indicate that the HIV epidemic may have peaked in states with a high sero-prevalence (NACO 2010)<sup>4</sup>. According to data from the Behavioural Surveillance Survey<sup>5</sup> conducted in 2009, over 90% of CSWs reported using a condom the last time that they had sex with an occasional client in AP, Karnataka and TN. This data indicates that interventions targeted at populations displaying high-risk behaviour could have halted the further spread of HIV (Steen, Mogasale et al. 2006).

Nevertheless, other findings from the Behavioural Surveillance Survey indicate that coverage of targeted interventions can vary by risk group and state. It was reported that over

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<sup>4</sup> This trend in HIV prevalence in India perhaps reflects the worldwide trajectory of the virus, whereby the global incidence rate peaked around late 1990s.

<sup>5</sup> The Behavioural Surveillance Survey is conducted by NACO and the Ministry of Family and Welfare. The purpose of the survey is to assess the success of social interventions targeted at risk populations. It collects data on hazardous behaviours within high risk populations, e.g. CSWs. This survey was conducted in 2001 and 2006 at a national level and in 2009 in six high prevalence states (Pillai, Sehgal et al. 2011).

75% of MSM (Men who have Sex with Men) were covered by preventative interventions, whilst less than a quarter of labour migrants were covered. Due to the limited coverage of these interventions, HIV-prevalence is increasing in states which have districts with a high incidence of HIV, e.g. Bihar and Punjab (NACO 2010).

The recent history of the HIV epidemic illustrate that it is still an important issue in the Indian context. Although research on current trends in HIV transmission has indicated that it is declining in areas that previously had a high rate of sero-prevalence, it appears to be rising in other states with a low prevalence of HIV. This is attributable to two factors, namely the limited effect of targeted interventions on groups that are difficult to access (e.g. economic migrants), and the failure of governmental policy to address the susceptibility to HIV infection of other groups, such as the female partners of HIV-infected men. There is currently very little literature relating to social structural factors that could lead to these female partners being at risk of contracting HIV. The following section of this chapter aims to tackle gendered components of HIV transmission apposite to the Indian context.

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### *2.B.1 Gendered Factors in the transmission of HIV*

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According to recent research, 85% of HIV transmission in India is estimated to be through heterosexual sexual contact (Avert 2010b, Over, Heywood et al. 2004). Literature on HIV transmission indicates that many women's susceptibility to HIV is heightened by their partners' risk activities. Some experts have therefore argued that the dissemination of HIV has taken on a gendered dimension as men who move to urban areas for work leave their spouses behind to look after their children and the elderly, whilst they remain away from the family for long time periods, potentially engaging in high-risk activities like unprotected sex with CSWs (Gupta, Vaidehi et al. 2010, Verma, Saggurti et al. 2010). Previous studies have illustrated that living away from the family can be an independent predictor of HIV

acquisition in men (Sri Krishnan, Hendriksen et al. 2007). In some cases, they may carry the infection back to their spouses.

It has even been argued that women married to a partner from a high-risk group should also be classified as belonging to a 'risk' category (Break Through 2003, Newmann, Sarin et al. 2000). Experts have noted that these women do not engage in risk behaviour, e.g. sexual relationships with multiple partners. Nonetheless, their ability to prevent transmission of HIV could be severely inhibited by a host of social, cultural and biological factors. Go, Sethulakshmi et al. (2003) stated:

*'In many societies, women's economic and social freedoms are constrained, leading to powerlessness to engage in these HIV/STD-preventive behaviours'. (p. 263)*

Many WLHA could be economically dependent on their husbands as the main breadwinner of the household, and thus do not have the power to protect their own interests (Solomon, Mehta et al. 2010, Decker, Seage et al. 2009). Studies of the risk behaviours of women experiencing domestic violence in urban slum dwellings and rural areas have illustrated that they were unable to leave their husbands even if they knew that their spouse had repeatedly had relations with multiple sexual partners, because they did not have the economic resources to survive independently (Decker, Seage et al. 2009).

Recent research has shown an association between domestic violence and HIV-positive status for women living in developing countries. Domestic violence has been shown to increase women's risk of HIV infection through three routes: firstly, women with a history of physical or sexual abuse are more likely to engage in sexual risk behaviour (Raj, Silverman et al. 2000); secondly, they could be forced to have sex with their partner (Stephenson 2007); and thirdly, it limits their ability to negotiate condom use (Solomon, Subbaraman et al. 2009).

Research on domestic violence and HIV transmission in India has demonstrated that the two latter routes affect female partners of HIV-infected men the most severely. In Go, Sethulakshmi et al.'s (2003) study of domestic violence in slums, one female participant was informed by her doctor that her husband should use a condom until he had fully healed from gonorrhoea. She was unable to negotiate condom use with her spouse, however, as she feared violent retaliation. Other studies have shown that for many women asking for a condom to be used is perceived as an act of insubordination (Weiss, Patel et al. 2008, Panchanadeswaran, Johnson et al. 2008). It is therefore possible that many sero-negative housewives are unable to negotiate sexual behaviour with their HIV-infected husbands, leaving them at a disproportionate level of risk of contracting HIV.

Furthermore, many women in India are expected to tolerate sociocultural 'double standards' as regards premarital sexual behaviour. Single women are almost always expected to remain virgins until married, to maintain their 'purity' (Bailey, Hutter 2006). Some women from impoverished backgrounds, meanwhile, may marry older sexually experienced men at a young age, leaving them open to infection from STDs. After marriage, they are still expected to maintain their 'pure' status through obedience and discipline, lest they are labelled prostitutes (Solomon, Mehta et al. 2010).

In contrast, men are permitted to engage in premarital sexual activity to gain experience and prowess. Some studies reported that it is socially sanctioned for married men to partake in relations with multiple sexual partners (Solomon, Mehta et al. 2010, Mishra, Swain et al. 2008, Thomas, Chandra et al. 2009)<sup>6</sup>. Thus, Amaro, Raj et al. (2001) argue that women from marginal sections of society are at high risk of contracting HIV because of their low status and lack of sexual autonomy.

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<sup>6</sup> Becker, Ramesh et al. (2007) study of prevalence and determinants of HIV infection in south India illustrated that significantly more men (12.2%) than women (1.7%) reported ever having had multiple sexual partners.

Moreover, women have the direct biological mediator of being more physiologically predisposed to HIV infection than men. They have 2–3 times higher risk of infection from sexual contact with a man than vice-versa according to epidemiological studies in developing countries. Although the probability of HIV transmission through vaginal intercourse is low at 1 or less per 1,000 sex exposures (Mehta, Sodhi 2008, Over, Heywood et al. 2004), the risk of HIV transmission increases if one partner is exposed to repeated and frequent unprotected sexual acts with an HIV-infected individual over a long period of time. It was estimated that due to this factor the probability of transmission of HIV infection from an infected person to his/her spouse is between 64% (Bhave, Lindan et al. 1995) and 85% (Mohamed, Ravinathan et al. 1990).

Nevertheless, Unterhalter, Boler et al. (2008) argue that research on HIV transmission with an emphasis on women's vulnerability to infection supports 'essentialist' assumptions that associate women's behaviour with the epidemic, whilst neglecting to question men's role. This encourages monolithic depictions of women in developing countries as being victims in these societies of patriarchal structures that perpetuate the transmission of HIV (Mohanty 1988). Men are perceived to be vectors of the virus by conforming to masculine gendered norms of 'sexual promiscuity' and 'violence'. This type of research therefore fails to note that:

*'Not all men and women conform to these stereotypes, that it is not tradition, but history and social relations at work in forming relationships with these characteristics, and that many women and men question and contest identities of vulnerability or violence'* (Unterhalter, Boler et al. 2008: 30).

Literature on HIV transmission among women in India has tended to support the 'essentialist' view, which posits that women living in developing countries are susceptible to HIV infection because of culturally-sanctioned gendered norms. Findings from the NFHS-III demonstrated that 35% of all married female participants had experienced some form of

physical violence from their husband prior to the survey (IIPS, Macro International 2007), but few women who experienced domestic violence in the NFHS-III were sero-positive. This indicates that other social structural factors (e.g. level of prevalence of HIV in area of residence), could act in unison with gendered discrimination to encourage further transmission of HIV.

One of these social structural factors may be caste, as previous epidemiological studies have illustrated that people belonging to lower castes are more at risk of HIV due to lack of education, risky sexual behaviour and economic deprivation (Priya, Sathyamala 2007, US Department of State 2006, Becker, Ramesh et al. 2007). Naik, Karpur et al. (2005) identified rural tribal Indian communities as an emergent high-risk group, as many members have a low awareness of HIV/AIDS and some engage in unique marriage practices that allow them to change spouse every four to five years. Furthermore, Schneider, Saluja et al. (2007) noted in their study on the dynamics of HIV infection in rural Andhra Pradesh that there were an increased number of concurrent sexual relationships among respondents belonging to certain tribal backgrounds.

Other researchers have identified traditional practices among lower-caste individuals which may predispose women to HIV infection (Dandona, Dandona et al. 2006, Ghose, Swendeman et al. 2011, Swendeman, Basu et al. 2009). The Devadasi system dedicates some young unmarried women from lower-caste backgrounds to gods in Hindu temples (Gupta, Reed et al. 2011). These women are often expected to provide sexual services to temple priests and pilgrims. In 2007 it was estimated that around 10,000 young women from impoverished families in Karnataka were dedicated to the Goddess Yellama (Thappa, Singh et al. 2007), and Ramesh, Moses et al. (2008) found that unmarried female sex workers from the Devadasi tradition showed higher odds of being HIV-positive than their counterparts.

Unfortunately, few studies explicitly analyse the dynamic between gendered discrimination and other social structural determinants of HIV transmission in the Indian context. As noted by Unterhalter, Boler et al. (2008), it is often assumed that gender works in isolation in the transmission of HIV among women. Nevertheless, literature on caste illustrates that certain sociocultural practices, such as marriage systems, which may predispose lower-caste women to HIV infection. In order to fill this gap in research, this thesis uses a combination of qualitative and quantitative methods to investigate the complex dynamics of HIV transmission in the Indian context. For instance, in chapter 7 qualitative interview data is used to map temporal pathways of HIV infection of participants, which in turn emphasises factors that both constrain women's ability to prevent infection and restrict their capacity to take action to resist harmful sociocultural norms.

## 2.C Factors which could potentially affect access to healthcare facilities

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The previous section of this chapter addressed historical trends of HIV transmission in India. Research on this topic indicated that the rate of HIV transmission had plateaued or declined in states that previously had a high sero-prevalence (NACO 2010). Nevertheless, there remains a large population of PLWHA who are not receiving any HIV-related healthcare and may not even know of their sero-status (Zala, Rustad et al. 2008, Balarajan, Selvaraj et al. 2011, Avert 2010a). Despite the urgent need to provide these PLWHA with HIV-related care, literature charting social structural factors influencing PLWHA's utilisation of healthcare remains relatively sparse.

Recent research on how female HIV-infected patients cope with their condition indicates that many could suffer from cultural impediments to accessing healthcare providers. Most of these impediments are associated with gendered inequalities inherent in traditional

Indian society which predispose women towards HIV infection and later are exacerbated when they are diagnosed with their condition. However, there are other factors that are embedded in Indian culture which could severely affect women's ability to access the relevant treatment, e.g. HIV-related stigma.

Hence, the following section of this chapter, firstly, investigates hypothesised cultural barriers to HIV-related healthcare, which include gender, caste and stigma. Secondly, it explores socio-economic barriers to treatment, e.g. poverty. Finally, structural barriers to services including healthcare policy are examined.

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### *2.C.I Cultural barriers to treatment*

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#### *2.C.I.i Gender*

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Recent research has indicated that some WLHA might not have adequate knowledge to make effective health-seeking decisions, as they are not aware of what type of treatment is required for their condition (Ramchandani, Mehta et al. 2007, Chomat, Wilson et al. 2009). This is because some WLHA may either not know of HIV or perceive their personal risk of contracting it as low, and are therefore shocked to learn of their condition (Chatterjee, Hosain 2006). For instance, in Samuel, Srijayanth et al's (2007) study on pregnant women undergoing voluntary counselling and testing for HIV in south India, approximately one third had heard of HIV or AIDS. The majority of these respondents learnt of their condition either through a routine HIV test during pregnancy or after their husband was diagnosed with the condition.

Furthermore, once these women are diagnosed as sero-positive they receive little or no psychosocial support from their family. Recent research highlighted that many WLHA are perceived as vectors for HIV infection by their parents-in-law, who often blame them for transmitting the virus to their son (Cowley 2003). Rogers, Meundi et al. (2006) study of HIV-related attitudes of pregnant women in rural southern India illustrates that many respondents

were apprehensive of taking an HIV test, as they were worried their husband might accuse them of being unfaithful. Other studies have demonstrated that many WLHA are ejected from their homes by their parents-in-law after their HIV status is discovered, (Pallikadavath, Garda et al. 2005, Pallikadavath, Foss et al. 2004, Bharat, Aggleton et al. 2001). Qualitative research for this thesis uses interview data from WLHA to determine whether this is indeed the case and to examine how family social support may later affect access to HIV-related healthcare services.

Finally, many WLHA might be obliged to care for their severely ill partner in times of hardship. In many cases this is due to their spouse having contracted HIV earlier than they did, resulting in their being at a later stage of the infection (Das, Mukhopadhyay et al. 2009). Literature on the plight of WLHA has highlighted the fact that many sero-positive women conduct most household duties for other members of the family even when they are suffering from HIV-related symptoms (Duggan 2006, D'Cruz 2004, D'Cruz 2002). This caring role is attributed to gendered inequalities inherent in Indian society, whereby women are expected to adopt the culturally-ascribed role as the caring mother/wife.

This could result in many HIV-infected women being burdened with the triple responsibility of housework, care of their children and elderly members of their families, and working in a manual occupation. This physically demanding workload would be stressful and tiring even without an illness, especially as they are not remunerated for their work within the household (Alex 2011). However, this triple burden is even more stressful for HIV-infected women, who need to balance their caring tasks with their ability to earn money for treatment. Some of these women may need to try to increase their income, which means working more hours because they need enough money to pay for their own, husband's or child's treatment<sup>7</sup>. There is currently little research on the impact that such caring activities can have on

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<sup>7</sup> Some WLHA may sacrifice their health in order to pay for treatment of their husband, e.g. eating one meal a day to increase the amount of money going towards therapy (Das, Mukhopadhyay et al. 2009).

WLHAs' ability to access healthcare facilities. This thesis addresses these issues by eliciting participants' narratives on their caring duties during the qualitative phase of analysis. The following section will examine the impact of caste on WLHAs' ability to access the necessary healthcare services.

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### 2.C.I.ii Caste

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According to the 2001 census 16% of the Indian population consisted of scheduled or lower castes (Ministry of Home Affairs, Government of India 2001). People from these castes usually belong to the poorest sections of the Indian population due to widespread discrimination practised by those in higher castes (Banerjee, Knight 1985). In the past, this system relegated lower caste people to performing low status tasks for upper caste proprietors often without monetary remuneration (Bosher, Penning-Rowell et al. 2007, Reddy 2005, Fliegel, Rao 1978).

Moffatt (1975) illustrated that South Indian villages were often physically segregated on a caste framework whereby the highest and the purest castes, i.e. Brahmins, would live at the centre and the lowest castes would be relegated to hamlets outside the village. People from the lowest castes were physically separated from the rest of the village because of their status as being spiritually impure as they partake in 'polluting' activities, e.g. eating contaminated food such as beef (Michelutti 2008), and partaking in unclean occupations, such as cleaning toilets. This system could isolate those from the lowest caste from important facilities located inside the villages (e.g. water) since their presence is deemed polluting for people of higher castes (Thorat 2002).

Recently, urbanisation and economic development has subdued the rigidity of the caste system (Banerjee, Knight 1985). Social forces associated with industrialisation have resulted in the decline of traditional caste occupations through the migration of workers from

rural to urban areas. Discrimination against Dalits<sup>8</sup> is not so often openly practised in urban areas as it is difficult to instil spatial boundaries between castes as has been done within small villages (Thorat 2002, Moffatt 1975, Jodhka, Shah 2010).

Nevertheless, the historical precedence of caste discrimination does still exist and may define educational opportunities for people from low-caste backgrounds (Nagamani, Sharma 2011, Pada 2010). Van de Poel, Speybroeck (2009) found that people belonging to the government-designated categories of ‘scheduled castes’ and ‘tribes’ had a lower level of education than that of the general population. Consequently, people from lower-caste backgrounds may have little awareness of HIV, meaning that they may not know how to avoid HIV infection or what type of treatment to seek if diagnosed as sero-positive<sup>9</sup>.

Finally, recent research has highlighted the fact that many people belonging to lower-caste backgrounds are relegated to manual occupations due to lack of education and caste-based discrimination (US Department of State 2006, Dunn 1993). Ito (2009) demonstrated that people from lower-caste backgrounds experience difficulties in accessing regular employment. The types of occupation they do perform are often precarious, as work is irregular and employees are often granted few rights. People in such occupations often experience extreme poverty, with their income barely covering their living costs. Taking these factors into consideration, it was calculated that in 2002-3 between-caste inequality accounted for around 13% of overall wealth inequality in India (Zacharias, Vakulabharanam 2011).

Literature on caste-based inequality in India suggests that WLHA from lower-caste backgrounds could face substantial difficulties in finding regular employment, leading to

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<sup>8</sup> According to the Oxford English Dictionary (2011) Dalit is ‘a person who does not belong to one of the four Brahminic castes; spec. a member of the scheduled castes, an untouchable’. People belonging to this group have been historically excluded from areas of villages occupied by people of higher castes and excluded from well-paid professions.

<sup>9</sup> Recent research highlighted that people in India with a low level of education often have little awareness of HIV as sexual education is usually taught in secondary school (McManus, Dhar 2008).

impoverishment, which is in turn likely to result in financial restraints on their use of healthcare services. As Kurian (2007) stated:

*'Socially backward sections, especially scheduled castes and tribes... have gained little from the new prosperity which rewards disproportionately those with assets, skills and higher education... (they) have often been victims of development as a result of displacement.'* (p. 374).

Unfortunately, there are few studies directly addressing the impact that caste status can have on WLHA's ability to access healthcare facilities. This thesis addresses this gap in literature through using quantitative data to test assumptions that caste status can influence women's propensity to HIV infection and their ability to later access facilities. The following section will examine the impact of HIV-related stigma on WLHA's ability to access healthcare services.

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#### 2.C.I.iii HIV-related Stigma

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Goffman (1968) identifies stigma as 'an attribute that is deeply discrediting within a particular social interaction' (p.3). From an objective standpoint this 'attribute' should not hold a moral value, and Goffman (1968) therefore stipulates that stigma is socially constructed. The labelling of the attribute as stigmatising partially arises from existing cultural norms and social expectations on what a person should be and how they deviate from these norms. According to Bond, Chase et al. (2002), then, stigma is a process of devaluation wherein certain 'attributes' are identified as 'un-creditable' and 'unworthy'. This process legitimises negative behaviour (e.g. social ostracism) towards those who are stigmatised (Green, Devi et al. 2007).

According to experts, HIV as an illness has a uniquely stigmatising status for a variety of reasons (Bharat, Aggleton et al. 2001, Bond, Chase et al. 2002, Herek 1999). Firstly, previous research has illustrated that HIV is perceived as the bearer's responsibility, especially when sexually acquired (Lee, Kochman et al. 2002). Participants in Bond, Chase et al's (2002) study of stigma in Zambia believed that CSWs deserved to contract HIV as a

result of their sexually promiscuous behaviour. Secondly, it is a commonly held misconception in developing countries that HIV is contagious and terminal as an illness. In some clinics in India, hospital staff burn sero-positive patients' clothes out of fear of contracting HIV (Mahendra, Gilborn et al. 2007), and thirdly HIV-related stigma is layered with pre-existent forms of stigma associated with marginalised groups (e.g. IDUs). These marginalised groups often have a history of engaging in activity which is deemed as deviant<sup>10</sup>.

Previous research has identified how HIV-related stigma can negatively affect WLHAs' access to healthcare facilities. Many PLWHA experience 'perceived stigma', which is 'manifested in the fears that people have around being stigmatised if they are HIV-positive' (Bond, Chase et al. 2002:348). Some PLWHA in India may be reluctant to disclose their HIV status to their partner out of fear of rejection (Bharat, Aggleton et al. 2001). It is therefore possible that WLHA suffering from 'perceived stigma' may be unwilling to seek the support of communal networks or seek treatment for their condition, as they are worried that others will learn of their sero-status.

The other type of HIV-related stigma that could negatively affect WLHAs' access to services is 'enacted stigma', which is 'when people are actually discriminated against because they have, or are thought to have, HIV' (Bond, Chase et al. 2002:348). Recent research highlighted that PLWHA suffer from stigma in healthcare settings. Many PLWHA in India are denied therapy in private clinics because doctors managing these facilities do not want people living locally to learn that they were treating HIV-infected patients (Mahendra, Gilborn et al. 2007).

In public clinics, patients are offered treatment but face discriminatory practices on the part of hospital staff (Chakrapani, Newman et al. 2009, Kumarasamy, Safren et al. 2005,

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<sup>10</sup> It has been reported that the transsexual population have a high prevalence of HIV in India (NACO 2008c). As many transsexuals in India participate in sex work, they are perceived as 'dirty' (Bharat, Aggleton et al. 2001).

Kurien, Thomas et al. 2007). Participants in Tarakeshwar, Krishnan et al's (2006) study of HIV-infected patients' perception of their treatment reported in the same study that they had discontinued treatment in these clinics due to being stigmatised by hospital staff. These results indicated that stigmatisation of HIV-infected patients in a hospital setting could seriously affect their access to care by reducing their options for treatment.

Due to stigma, many female HIV-infected patients may be offered a lower level of treatment than their male counterparts (Datye, Kielmann et al. 2006). Although ethical guidelines have been established for the treatment of PLWHA, it is difficult to fully regulate such a diverse and heterogeneous health market in India, and it is therefore possible that many doctors may not follow ethical guidelines on the treatment of HIV-infected patients. Bharat, Aggleton et al.'s (2001) study of stigmatising attitudes towards HIV among healthcare providers in India highlighted the fact that many physicians informed newly-married women's parents-in-law of their HIV status, as they did not think that the patients themselves were able to understand the serious nature of HIV. These doctors assumed that their female patients lacked the mental facilities to understand the intricacies of their condition because of their low level of education. Due to these factors, female HIV-infected patients may experience delays in access to medication, and in general have considerably less access to treatment than their male counterparts.

This section illustrates how WLHA in India suffer from a combination of cultural barriers that are inherent to Indian society. Current literature on female HIV-infected patients' use of healthcare facilities has not taken into account how these cultural components of access could interact with one another to inhibit the use of treatment. One of the objectives of this thesis is to fill this gap in research by looking at how caste- and HIV-related stigma could affect HIV-positive women's use of healthcare services. The following section will examine how WLHA's socioeconomic status may affect their experience of accessing treatment.

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## 2.C.II *Socio-economic barriers to treatment*

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Recent research on the socio-economic impact of HIV in India demonstrated that HIV-positive women are the most vulnerable group of all PLWHA with respect to poverty (Das, Mukhopadhyay et al. 2009, Haacker 2009, Haacker, Claeson 2009, Das, Mukhopadhyay et al. 2006). The reasons for these findings are related to the limited opportunities for stable employment in the casual labour sector and the gendered dynamic of HIV transmission in the Indian context. According to data collected by Pradhan, Sundar et al. (2006) on HIV affected households, the majority of WLHA were widowed. Many of these WLHA were forced to seek employment after their partner was unable to work. As these women have little experience of work prior to infection, their bargaining power within the manual labour sector could be very low. Hence, Pradhan, Sundar et al. (2006) noted that half of all households headed by a female HIV-positive widow had an overall income of less than Rs. 20,000 (£244.24) per annum, which is below the poverty line.

Another explanation for these findings could be that women suffer from discrimination within the casual employment sector in India. Many women are paid less for casual manual work than their male counterparts (Olsen, Mehta 2006a, Olsen, Mehta 2006b, Thangamani, Rani 2005). The assumption behind this system of differential wages is that men are physically stronger and undertake more work than women, and therefore are entitled to higher wages. Many WLHA, who may have replaced their husbands as the main breadwinners, are likely to be severely discriminated against in the workplace, resulting in their earning wages that may barely cover their living costs, let alone pay for their treatment needs.

It is important to note that some WLHA may earn money in the informal economy as part of their family business or from subsistence agriculture. Current literature on agricultural work has demonstrated that this type of labour is becoming feminised as men leave villages

for more lucrative forms of employment (Olsen, Mehta 2006a, Olsen, Mehta 2006b)<sup>11</sup>. A few WLHA may informally contribute to the family business in the private sphere by tending small plots of land with leafy vegetables for subsistence or to sell at a small profit in the market. These small plots of land offer women an opportunity to earn a small income to bolster the family earnings because all procedures from ploughing to harvesting can be operated by them without the assistance of other male relatives and tending the plot does not require much skill (Fliegel, Rao 1978).

Nevertheless, in many instances the income that women generate may be controlled by male members of their family, who collect money from selling other types of produce, e.g. milk (Chattopadhyay 1982, Agarwal 1997). In most families male relatives are appointed as the main decision-makers as they can move freely in the public sphere, meaning that they may be able to sell crops at a higher profit than their female relatives would be able to in the local market. It is often, therefore, assumed by the family that male members should act as the main breadwinners, while the income of female relatives is considered only as a small contribution, particularly for financially difficult times<sup>12</sup>.

Finally, recent research has highlighted that PLWHA find it physically demanding to conduct daily tasks even when they are in the asymptomatic phase of their condition<sup>13</sup> (Evans, Atim 2011). In western settings PLWHA could easily lessen their workload to ensure that it is less physically demanding (Gaidhane, Zahiruddin et al. 2008). However, in the Indian context, it would be difficult for PLWHA to adapt their workload according to their condition, especially if they are illiterate and the only work available for their skills is in

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<sup>11</sup> Prasad, Abraham et al's (2005) study of women with reproductive tract infections in Tamil Nadu recorded that fifty-five percent were housewives, 32% worked as agricultural labourers in other farms, and 9% farmed their own land.

<sup>12</sup> This informal system places women in a disadvantageous position because any income that a WLHA earns from selling their crops will be a fraction of what their husbands are paid for selling other higher yielding products (Venkateshwarlu, da Corta 2001).

<sup>13</sup> Debilitating symptoms of HIV include fatigue (Barroso, Hammill et al. 2010) and dementia (Deshpande, Patnaik 2005).

manual labour. It is possible that PLWHA would be less economically productive in manual labour as they are unable to work for many days (Das, Mukhopadhyay et al. 2009, Gupta, Trivedi 2009). Pradhan, Sundar et al. (2006) found that 37% of PLWHA who were able to retain employment reported an income loss of 9%.

There could be other WLHA who withdraw from the labour market due to extreme HIV-related symptoms. Recent research highlighted that a higher proportion of PLWHA are unemployed than their HIV-negative counterparts (Das, Mukhopadhyay et al. 2009, Das, Mukhopadhyay et al. 2006). According to Pradhan, Sundar et al. (2006) PLWHA who withdrew from the labour market experienced an income loss of 66% in urban areas and 75% in rural residences. This substantial loss of income could inhibit WLHA's ability to financially support their family, let alone cater to their own basic needs. Some WLHA could be compelled to borrow large sums of money in order to survive. Recent research highlighted that many HIV affected households are heavily indebted<sup>14</sup>.

In summary, research on women's participation in the informal and formal labour market suggests that WLHAs' income generated from small businesses and other types of employment may not be enough to pay for their own treatment needs, let alone to help to support the rest of the family. These findings suggest that the economic constraints they suffer, which in some cases prevent them from engaging in HIV prevention activities, might be exacerbated once they have acquired the virus. Previous studies on patients' access to HIV treatment facilities have illustrated that women 'feel' economic constraints more keenly than their male counterparts, often worrying how they will be able to afford treatment if their husband dies (Chakrapani, Newman et al. 2009, Kumarasamy, Safren et al. 2005). These studies, however, do not examine how HIV-positive women cope with a series of economic

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<sup>14</sup> Pradhan, Sundar et al. (2006) found that many HIV affected households had taken loans of around Rs. 11,000 (£140), which far exceed that of households with no sero-positive members.

shocks related to their condition in order to access healthcare services. The thesis used a combination of quantitative and qualitative data to address this issue.

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### 2.C.III *Structural barriers to treatment*

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It has been noted that continued transmission of HIV at its current rate could adversely affect the Indian healthcare system because of the high cost of testing and treatment facilities (Gupta, Trivedi 2009). India has a large heterogeneous population, meaning that even a small prevalence of 1% could have a detrimental effect on the Indian healthcare service. Maniar, Kamath et al. (2006) argues that once India reaches this level of infection, HIV would no longer be only a health problem, but a social, economic and developmental crisis and a national calamity.

There are a few studies which have estimated the future cost to the Indian economy of treating HIV-positive patients (Poudel, Okumura et al. 2003, Pais 1996). These studies indicate that the Indian public health system does not have the resources to cope with the requirements of treatable diseases such as cholera, and so it may not be able to deal with the needs of poor patients who have chronic illnesses (Over, Heywood et al. 2004). This is due to a combination of factors, which include: inefficient allocation of resources, external pressures exerted by the world economy and donor policies, and the dominance of the private health sector in India (Qadeer 2000). PLWHA may not therefore have vital healthcare services located close to where they live, and so will not have facilities that cater for their basic needs, let alone provide ART (Anti-Retroviral Therapy). The following section will examine the impact of the structure of healthcare services on WLHA's access to HIV-related medical facilities.

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#### 2.C.III.i Service Provision

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Currently, the Indian healthcare system is a complex and vertically controlled organisation designed to provide preventative, curative and rehabilitative services to large

sections of the population. These services are supplied through a three tier referral system, which offers primary care, e.g. family planning facilities, through small healthcare units located close to villages, secondary care through intermediate hospitals and tertiary care through large medical college hospitals (Shaikh, Kadir et al. 2006, Jeffery 1986). Health-workers attached to Primary Health Centres target isolated rural areas to promote preventative health measures, e.g. immunization (Mavalankar, Vora 2008). For most patients services are free at the point of delivery but they are expected to pay for drugs (Peters, Rao et al. 2003). Therefore, this system should in principle be able to spread a broad range of health services over large sections of the population through an efficient referral system which sufficiently allocates medical resources to the local population.

Nevertheless, this system has been insufficient at providing basic medical services to patients. According to Qadeer (2000), India's healthcare system has undergone a series of changes due to external pressures exerted by donor driven policies. International organisations have been concerned about the rapid rise of the population and have spearheaded national programmes to implement family planning facilities in isolated rural areas (Banerji 2005, Kabeer 1994). Due to these donor driven policies, local Primary Health Care (PHC) services now only offer family planning facilities and basic medication for common epidemics, e.g. malaria, without taking consideration of localised epidemics, for instance HIV (Ager, Pepper 2005). This could adversely affect HIV-positive women who may need services located close to their home due to cultural barriers associated with their gender (e.g. child caring activities). As there is a limited supply of public medical services at the local level, HIV-positive women will be forced to demand services from private clinics that may incur further costs.

Public services have also declined due to external pressures exerted by heavy loan repayments to international organisations like the World Bank and the International Monetary

Fund (IMF) (Whitehead, Dahlgren et al. 2001). In the early 1990s India suffered from an economic crisis due to a drop in foreign exchange reserves, decrease in foreign private lending, low industrial growth and the burden of loan repayment. This resulted in the Indian government implementing 'Structural Adjustment Programmes' in return for loans from the IMF (Patil, Somasundaram et al. 2002). These policies involved phasing out budgetary support for failing public enterprises, encouragement of foreign investment and liberalisation of the Indian economy. 'Structural Adjustment Programmes' have been detrimental for the public healthcare sector, due to a 20% cut in the health budget in 1992-3 without a recent increase in expenditure<sup>15</sup>. This has resulted in the decimation of various areas of the public health services.

Access to the public health sector has been affected by scarce resources, lack of beds for patients and insufficient equipment in PHCs, For instance, much of the health budget is allocated to doctors' salaries and high prevalence diseases instead of equipment and preventative medicine (Bajpai, Goyal 2005). In addition, internal errors and flawed planning procedures influenced people's utilisation of healthcare services. It has been argued that the Indian government has allocated more financial resources towards clinics in urban areas, ignoring the fact that most of the population live in rural areas (The Centre for Health Research and Development 2003). Consequently, most female HIV-infected patients living in isolated rural areas may not have any treatment facilities close to their vicinity. If there were any facilities available, these healthcare providers could be inadequately equipped and staffed which means that they will receive a low level of care (Bhatia, Cleland 2001, Balgir 2006, Blackstone Market Facts, Family Health International 2001).

Researchers have argued that a combination of 'Structural Adjustment Policies' and poor government management of the health sector has weakened the public sector supply of

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<sup>15</sup> According to Bajpai and Goyal (2005) spending on public health remains 2% of the government budget whilst loan repayments are almost 30%.

facilities, which has increased demand for healthcare in the private sector. Currently, 80% of the population's healthcare expenditure goes to the private sector (Sheikh, Porter et al. 2006). The healthcare market has responded to demands for care resulting in a high density of private clinics (Quazi, Nimbarte et al. 2010), which cater for the needs of manual labourers, who want fast effective treatment.

Currently, the Indian private healthcare system is unregulated resulting in drugs being sold on the 'black' market without the need for a prescription from a doctor (Blackstone Market Facts, Family Health International 2001, Madan 1981). This gives patients the freedom to choose practitioners from different disciplines (Vissandjee, Barlow et al. 1997). These patients are 'smart consumers' who maximise their options by trying many treatments (Moshabela, Pronyk et al. 2010, Kunstadter 1980, Cant, Sharma 1998). This type of consumer will be likely to use treatments that they perceive as effective. Lambert (1998) illustrated this in their study of the health seeking strategies of CSWs in Bombay. They recorded that participants often seek the fastest and most effective treatment by biomedicine and/or traditional therapy, which resulted in practitioners prescribing the most potent therapy to retain patients.

Findings in Lambert's (1998) study suggest that some female HIV-infected patients may choose to use alternative or traditional medicine if no other type of treatment is available or biomedical treatment is too expensive (Fritts, Crawford et al. 2008, Baban, Ikeda et al. 2006). HIV-infected patients using this type of treatment could be vulnerable to exploitation from unscrupulous practitioners. Chomat, Wilson et al. (2009) noted that many PLWHA utilised alternative treatment for their condition because they believed that it would cure them, illustrating that alternative medication could be potentially dangerous to the health of HIV-positive patients.

Other studies on the healthcare utilisation patterns of patients using alternative treatment illustrated that female patients use alternative or traditional medicine as a form of self-medication for ‘mild’ illnesses (i.e. a flu) as part of a normal lifecycle to keep the elements of their body in balance or to treat mental ailments (Jacob, Jayakaran et al. 2003, Kurup 1983, Lambert 1992). There is a possibility that female HIV-infected patients may use traditional medicine either in conjunction with modern medication or as an alternative to ART. This means that alternative medication could be an important component of access because it might be the only type of treatment that some HIV-positive women use. Information on female HIV-positive participants’ utilisation of alternative healthcare practitioners is recorded as part of the NFHS-III. This data was used to examine whether female HIV-positive participants may have sought alternative forms of treatment.

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#### 2.C.III.ii Provision of healthcare for HIV-positive patients

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Governmental organisations (e.g. NACO), International Organisations (i.e. World Bank) and NGOs have tried to overcome structural barriers for patients seeking HIV treatment through funding initiatives that would increase the availability of ART. Almost \$3 billion was allocated towards prevention and treatment of HIV in India under NACO’s third five year phase of programmes (NACO 2010, Steinbrook 2007b, Steinbrook 2007a). One sixth of these funds were assigned to the treatment of HIV-positive patients. Under this phase of policy HIV-positive pregnant women, HIV- infected children under 18 years old, and patients with a CD4 count of less than 200 were offered free ARVs<sup>16</sup>.

HIV-positive patients were offered medical services via a three tier referral system similar to the one described earlier. In the first stage of treatment seeking, before their sero-status was known, patients were offered pre- and post-test counselling in Integrated Counselling and Testing Centres (NACO 2008c, NACO 2008b). Those who were exhibiting

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<sup>16</sup> NACO aimed to provide 300,000 PLWHA ART in 250 treatment centres by 2010 (MOHFW, NACO 2007).

HIV-related symptoms were referred to ART centres. PLWHA who were enrolled into a regime of ART were supposed to undergo ‘adherence counselling’, periodic CD4 testing and routine laboratory investigations (MOHFW, NACO 2007). Health-workers were utilised in rural areas to ensure that patients adhere to treatment regimens (Dallao 2008). Asymptomatic HIV-positive patients were referred to a Community Based Organisation that offered care and counselling on how to maintain their health until it was deemed necessary for them to undertake ART. This new phase in Indian HIV policy was a departure from the previous phases which ignored the needs of PLWHA and allocated few resources to their treatment (Deodhar 2003).

Most of these policies were conducted with assistance of local NGOs. In AP, where qualitative data was collected for this thesis, many NGOs under the guidance of HIV/AIDS Alliance have implemented initiatives to reduce structural barriers to antiretroviral treatment through programmes which have encouraged dialogue between HIV-infected patients and medical providers (HIV/AIDS Alliance 2004). NGOs in AP have combined efforts to implement accessible ‘drop in’ centres for people living in rural areas, increase medication available for those who cannot afford it and build communities of AIDS activists (VMM, International HIV/AIDS Alliance 2004). Vasya Mahila Mandali (VMM)<sup>17</sup> has implemented a scheme to offer female HIV-positive patients loans to start their own business or to assist them with living expenses (VMM 2008). Thus, efforts by grass-root NGOs and new governmental policy could significantly improve women’s access to HIV treatment.

Furthermore, there are programmes in areas with a high HIV prevalence offering social services and care to families with sero-positive members. In Andhra Pradesh local NGOs, governmental organisations and international organisations are following the Balasahyoga programme to provide integrated HIV care, support and treatment for HIV-

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<sup>17</sup> Some participants were sampled from this NGO in the qualitative phase of research.

infected children and their families<sup>18</sup> (Coutts-Buys 2007, Honoured 2007). This programme provides medical care, psychosocial support, economic assistance and shelter for 30,000 households containing PLWHA<sup>19</sup>. Although there are unofficial reports generated by NGOs which describe their programmes to other service providers' currently, there are no known academic studies which comprehensively analyse how such programmes affect PLWHAs' ability to access services (Blackstone Market Facts, Family Health International 2001, NACO 2007b, Panos (India) 2007). My study addresses this gap in research by collecting qualitative data recording patients' accounts of the effects of NGO programmes on their access to healthcare services.

However, recent studies have illustrated that HIV-positive patients still suffer significant barriers due to poverty, stigma and unavailability of services. Ramchandani, Mehta et al. (2007) illustrated in their study of HIV-infected patients' health-seeking patterns that participants experienced distance to clinic, family responsibilities and loss of wages as barriers to accessing HIV treatment. The study also indicated that patients who could afford medication in the private sector received better treatment and were more likely to be prescribed ARVs.

In light of these structural barriers, Steinbrook (2007b) argued that a multifaceted approach needs to be taken to ensure that treatment is available to HIV-positive patients. NACO needed to make a commitment to provide appropriate testing facilities to generate CD4 blood cell counts and second line treatment. Sujatha Rao, the former director of NACO, said that a policy of covering additional drugs to that of basic first line treatment is 'a big responsibility' which the government would have to commit to in the long term (Steinbrook 2007b:1200).

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<sup>18</sup> Balasahyoga was monitored and managed by three lead partners: Family Healthcare International focused on Community Based Care, The Clinton Foundation monitored family-based clinical services, and CARE addressed patients' nutritional needs (Honoured 2007).

<sup>19</sup> St. Paul Trust (a local NGO) in Andhra Pradesh provided loans and home-based care for HIV-infected patients struggling with poverty (Dallao 2008).

Moreover, healthcare services will have to be scaled up to deal effectively with two simultaneous epidemics: HIV and tuberculosis. Currently, India has the largest population of tuberculosis patients in the world and this number will rise as PLWHA contract the disease. It is estimated that 23% of HIV-positive patients are co-infected with tuberculosis (Steinbrook 2007a). Hence due to the nature of HIV/AIDS as an illness, in which HIV-infected patients are left vulnerable to infection from other viruses, governmental policies on HIV-related healthcare would need to take into account the treatment of other illnesses.

This section has illustrated that female HIV-positive patients may face considerable structural barriers. Currently, there are few public facilities available to patients living in rural areas and private healthcare is often unregulated and expensive. There have been a few relevant studies on male patients' access to HIV-related facilities in urban areas conducted by NGOs (Shah, Walshe et al. 2007, Kamalika, Madhu et al. 2010). However, there are no known studies on women's access to healthcare providers. This thesis explores access to private, public and alternative medical health facilities for HIV-positive women, addressing an important gap in research.

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## 2.D Conclusion

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This chapter has illustrated that the HIV epidemic in India is a complex phenomenon as India has a large heterogeneous population. India is undergoing a 'concentrated epidemic', whereby HIV-prevalence was high amongst groups displaying risk behaviour but low in the general population. The two main modes of transmission were heterosexual sexual risk behaviour in southern states and drug injecting use in north-eastern regions of India. Literature on HIV transmission in India indicated that many WLHA were infected by their husbands, their only lifetime sexual partner. These findings suggest that research concentrating purely on individuals' risk behaviours may not be sufficient for addressing

social factors which may increase these women's propensity to contract HIV in the Indian context.

There is currently some research on social, cultural and biological factors which could mediate women's risk of contracting HIV in India. Findings in these studies suggest that their susceptibility to HIV infection is facilitated by gendered assumptions on female sexuality in which most young single women's sexual behaviour is regulated in order to ensure that they maintain their virginity prior to marriage. This results in these women being given little information on STIs, meaning that they could have a low awareness of HIV. These women's risk could be further exacerbated by domestic violence, which severely inhibits their ability to negotiate condom use with their spouse.

These studies have been criticised by Unterhalter, Boler et al. (2008) for encouraging a narrow depiction of women in developing countries as being victims of traditional patriarchal structures of society. As there is such a strong focus on these women's status of being 'victims', these studies often fail to address the fact that many women in India experience domestic violence and gendered discrimination yet may not ever contract HIV.

Findings from studies on gendered determinants of risk suggest that other social structural factors, e.g. caste, could act in unison with gendered discrimination to encourage further transmission of HIV. There are currently few studies which sufficiently address the complex manner in which gender could impact women's susceptibility to HIV infection in India. This thesis contributes to the literature of HIV amongst women in India through analysis of the NFHS-III, which collected data on sexual behaviour of respondents. Furthermore, qualitative interview data is used to trace socio-cultural processes that led to HIV infection. This type of analysis emphasises social factors which constrained their ability to prevent infection.

Recent research on epidemiological trends of HIV in India illustrated that the rate of transmission had declined in states that had a high sero-prevalence (NACO 2010). There remains a large population of HIV-infected individuals in need of treatment. These PLWHA would have diverse treatment needs and may experience substantial barriers to accessing the necessary healthcare facilities. Although many of these PLWHA need medical care there is very little research examining social structural factors affecting female HIV-infected patients' utilisation of healthcare services.

These social structural factors could be driven by gender, socioeconomic status, HIV-related stigma and caste-based inequalities which are embedded in traditional Indian society. Recent research conducted by the World Bank on the economic impact of HIV on Indian households demonstrated that HIV-positive women are the most vulnerable group to poverty (Das, Mukhopadhyay et al. 2009, Gupta, Trivedi 2009). Many WLHA suffer from discrimination in the casual employment sector, in which female employees are paid less than their male counterparts. Moreover, jobs in manual labour are often physically demanding and employees have few workers' rights, such as sick leave. Some WLHA in the symptomatic phase of their illness may not be able to work to their full capacity resulting in a substantial loss of income.

In addition, HIV-related stigma could severely inhibit WLHA's utilisation of services. Literature on HIV-related stigma in India illustrated that it negatively affected WLHA by restricting their sources of social support (e.g. familial networks) and lowering the quality of healthcare they received. Some WLHA could be reluctant to disclose their sero-status to family members and co-workers out of fear of stigma. This could have a negative impact on their well-being as they would be unable to draw on financial resources of other family members. Chandra, Deepthivarma et al. (2003) noted that WLHA who disclosed their illness to close relatives have a better quality of life and were less likely to suffer from depression.

The degree of shared confidentiality between family members enhanced the role of those close to the HIV-infected individual.

These studies reveal that HIV-positive women suffer from a combination of economic and socio-cultural barriers to healthcare facilities. There is little research on how these socio-cultural factors could interact with economic components of access to inhibit female HIV-infected patients' usage of treatment. This thesis addresses this gap in the literature through using data from the NFHS-III to examine which social and cultural factors may impact female HIV-positive patients' utilisation of HIV testing facilities.

Finally, structural barriers to treatment are attributed to donor-driven policies, inefficient government planning, the dominance of the private sector, stigma from healthcare providers and the unregulated nature of the Indian healthcare system. Literature on this topic indicated that many female HIV-infected patients may not have access to affordable treatment close to their vicinity. In many cases if these women manage to reach any healthcare facility, they will receive a varied quality of care. It is possible that many WLHA would face considerable structural barriers which they may not be able to overcome.

In conclusion, the most pertinent issue highlighted in this chapter was that the same social structural factors that predispose women to HIV infection, could be exacerbated after they contract the virus. Previous studies have illustrated that many WLHA belonging to poor socioeconomic backgrounds suffer from domestic violence but this is increased when their HIV-status is known within their family. It is often difficult to examine HIV-positive women's experiences of utilising healthcare without addressing their susceptibility prior to infection. This multifaceted social phenomena needs to be analysed from a cultural viewpoint relevant to Indian society. This thesis contributes to the literature of HIV/AIDS in India by using a mixed methods approach to examine women's 'susceptibility' and 'vulnerability' to

HIV infection in India. The following chapter describes how the theoretical underpinning to the research conducted for this thesis permits the examination of both these topics.

## Chapter 3 THEORETICAL UNDERPINNING TO THE THESIS

### 3.A Introduction

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The previous chapter illustrated that the nature of the Indian epidemic is complex and difficult to define. One feature of HIV transmission in India is that many women are probably infected by their husband, usually their only lifetime sexual partner (Mehta 2008). These women are difficult to identify as they do not engage in drug injecting use and/or sexual risk behaviour. Recent research demonstrated that these women may experience gendered discrimination and economic constraints to such an extent that they have difficulties in preventing their own infection (Nayak, Korcha et al. 2010). This highlights that HIV is a ‘social disease’, which is driven through a host of social structural factors. Zierler, Krieger (1997) stated:

*‘Women living with and at high risk of HIV infection by and large have borne the brunt of persistent, and also deepening, forms of economic and social inequality’* (p. 411).

In response to the global plight of WLHA, experts in the field of HIV/AIDS, such as de Bruyn (2004), Berer (2004) and De Cock, Fowler et al. (2000), have called for more access to healthcare for female HIV-positive patients living in developing nations. This is in order to reduce infant mortality through vertical transmission from mother-to-child and improve health outcomes for families. New programmes established in NACO’s third phase of policy<sup>20</sup> were designed to improve HIV-positive patients’ access to treatment as they no longer have to pay vast sums of money for medication. Nonetheless, few of these interventions specifically address the gendered dynamics of HIV transmission in India, which continue to reduce WLHA’s chances of utilising treatment relevant for their condition. There

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<sup>20</sup> In this phase of policy HIV-positive pregnant women, HIV- infected children under 18 years old, and patients with a CD4 count of less than 200 were offered free ARVs.

has been considerable research on social interventions to reduce barriers for women wishing to access healthcare facilities in Sub-Saharan Africa (Hunter 2010, Parkhurst 2010, Marseille, Dandona et al. 2007) but few known studies on such programmes in India. Therefore, it is pertinent to research female HIV-positive patients' access to healthcare services in the Indian context.

The two primary objectives of this thesis are to identify the socio-economic and demographic characteristics that increase Indian women's predisposition to contract HIV and then examine how these factors may later affect their utilisation of services. Most worldwide study of HIV concentrates on either prevention or treatment of the virus, as if they are two mutually exclusive categories that rarely influence one another. Nevertheless, recent research highlights that HIV-related treatment can be a crucial component of prevention (AVERT 2012, Granich, Crowley et al. 2010, Cohen, Chen et al. 2011). Das, Chu et al. (2010) found that the rate of transmission of HIV in San Francisco, USA, between 2005 and 2008 fell when an increased number of HIV-infected patients enrolled in ART treatment. It was possible that these patients may have a low viral load, decreasing the likelihood of HIV transmission.

As a product of the dichotomy between the study of prevention and treatment of HIV, there are few known theories that address both topics simultaneously. Barnett and Whiteside (2002) established in their seminal study of the global impact of AIDS in the twenty-first century that disease transmission is part of a wider spectrum of the possible effects that HIV/AIDS can have on Southern nations' socio-economic development. They propose that social researchers should adopt a semi-historical interpretation of the HIV epidemic by assessing its long-term impact on nations and communities. It was noted that the transmission of HIV could deeply affect the lifetime trajectory of those belonging to the most vulnerable

sections of society through reducing their lifespan and restraining their economic opportunities<sup>21</sup>.

Barnett and Whiteside (2002) and Loevinsohn and Gillespie (2003) draw a clear distinction between factors which increase an individual's 'susceptibility' to HIV infection and 'vulnerability' to the negative impact of being sero-positive. They demonstrate through innovative research that it is possible to chart the systematic relationship between drivers of 'susceptibility' and sources of 'vulnerability' by examining communities' response to different stages or 'waves' of the epidemic. These concepts are crucial for shaping the research for this thesis as it provides the basis for the holistic analysis of causes and outcomes of the HIV epidemic on women in India.

The concepts of 'susceptibility' and 'vulnerability' are used to guide the selection of theoretical models for this thesis, which the remainder of this chapter examines. First, conceptual frameworks currently utilised in research on transmission of HIV in Northern and Southern countries are evaluated. Particular attention is paid to the advantages and disadvantages of using these types of theories in order to identify characteristics of susceptibility amongst women in India. Furthermore, an account is given on how these models are used for the purposes of this thesis. Finally, there is a similar analysis of theories which will be used to measure 'vulnerability' of WLHA in terms of their ability to reach appropriate HIV-related healthcare services.

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## 3.B Susceptibility

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### 3.B.I *Biomedical Theories of Risk Behaviour related to HIV*

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Researchers initially used the biomedical model of risk behaviour when the first cases of AIDS were identified in 1981 amongst young male patients who were suffering from

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<sup>21</sup> Recent research has highlighted that tight knit prosperous communities are more able to address the needs of PLWHA than impoverished communities with low levels of social capital (Gupta, Parkhurst et al. 2008, Dean, Fenton 2010, Evans, Lambert 2008).

Pneumocystis Carinii Pneumonia and Kaposi Sarcoma in USA. AIDS was at first labelled the 'gay plague' as a large section of the male homosexual population was suffering from it (Mehta, Sodhi 2008). Fee and Krieger (1993) commented that the advent of AIDS 'seemed to resurrect the true meaning of epidemic: a disease that spreads like wildfire, consumes lives, and then burns out, leaving devastation in its wake' (p. 1478). Sociologists demonstrated through social network analysis that most of the first AIDS cases were linked by sexual contact (Klov Dahl 1985); they focused on the 'exotic' lifestyle choices of young gay men at the time (e.g. 'promiscuity' and 'anal sex') that were later labelled as 'risk behaviours'. They at first failed to notice other sections of the population who were also heavily afflicted by AIDS, e.g. heroin users, as they did not fit the model of the 'gay plague'.

This framework of research followed the traditional approach to disease control in which groups of those who are infected are identified then quarantined or other social measures are undertaken to reduce transmission. In the case of HIV/AIDS 'risk groups' were identified by epidemiologists through their common identity or 'risk behaviours'. These groups of individuals were labelled in supposedly neutral scientific terms, e.g. MSM. However, the popular perception was that these 'risk groups' were potentially infectious as they previously participated in behaviour that was deemed as immoral, such as extra-marital sex (Lupton, McCarthy et al. 1995). Moreover, these individuals were often depicted by the media as being responsible for their own infection. Other groups of PLWHA who had not contracted HIV through their own behaviour were considered to be 'innocent victims' of the epidemic, e.g. haemophiliacs.

Critics of the early epidemiological model of research on risk behaviour have argued that scientists cloaked their own normative assumptions behind biomedical terminology. This type of language disempowers those affected by HIV through discounting their viewpoint and placing them as objects of medical research (Harding 1988, Harding 1987, Harding 1982).

Scientists are perceived as possessing knowledge and expertise to conduct research, thus were believed to be more able to decipher the ‘truth’ (Oakley 1999, Oakley 1998). Fee and Kreiger (1993) stated:

*‘Working under the rubric of "objectivity" as defined by the biomedical model, scientists have failed to see how social biases affect the type of research questions they ask.’ (p.1481).*

These types of normative assumptions are still apparent in epidemiological literature on HIV-related risk behaviours in developing countries. According to NACO’s terminology there is a three tier gradation on levels of risk within the Indian population with those at the greatest risk of contracting HIV belonging to the ‘high Risk Group’ (NACO 2008a, NACO 2010, NACO 2008c, NACO 2007b). The prominent members of this group are CSWs and IDUs as they were the first individuals to be identified as being HIV-positive in the early stages of the epidemic in India. The next risk category are those belonging to the ‘bridge group’, e.g. clients of sex workers. People belonging to this category engage in slightly less risk behaviour than those in the ‘high risk group’ but could still potentially transmit HIV to those in the ‘general population’, e.g. their long term sexual partners.

This terminology places individuals on a spectrum of risk based on their ability to act as vectors of HIV transmission. Individuals who belong to ‘high risk groups’ retain the most responsibility for contracting and transmitting HIV to others, making them ‘guilty culprits’. At the other end of the spectrum of risk those belonging to the ‘general population’ are perceived as ‘innocent victims’, since they did not contract it through their own risk behaviour. This categorisation of risk is less helpful in the Indian context as even those belonging to ‘high risk groups’ may not engage in these activities out of their own free will. Mahanta, Borkakoty et al. (2009) illustrates that IDUs in North East India are compelled to share needles if there is not a needle-exchange vendor available within their local area.

This conceptualisation of HIV-related risk has been attributed to the biomedical model, also known as ‘biomedical individualism’ (Fee, Kreiger 1993:1477), which posits that people have the freedom to choose their own health behaviours. The individual’s assessment of risk is based on the cognitive processes involved in evaluating the perceived costs and benefits of partaking in potentially hazardous behaviour (Rhodes 1997). Someone’s risk of contracting HIV is conceived as the outcome of their own choices and actions (Rhodes, Singer et al. 2005). Most social interventions in Northern and Southern countries operate with the objective of preventing further transmission of HIV by attempting to alter the individual’s behaviour through increasing their awareness of the virus or provision of prophylaxis (Blankenship, Friedman et al. 2006, Gupta, Parkhurst et al. 2008). These programmes are deemed as successful if beneficiaries engage in positive behaviours proven by medical research to prevent transmission of HIV, e.g. condom use. Individuals who wilfully engage in risk behaviour after participating in these interventions are perceived as ‘irrational’, thus might be later blamed for their sero-status (Rhodes 2002).

Research based on this model of risk has been criticised for ignoring the social context in which hazardous behaviour exists (Poundstone, Strathdee et al. 2004). It has been argued that according to the biomedical paradigm biological explanations of disease transmission are perceived as primary to any other possible factors. Within this paradigm social determinants of risk, e.g. poverty, are deemed as secondary to the aetiology of the disease if not irrelevant. It is often assumed within biomedical research that the study of the social factors related to HIV transmission is ‘unscientific’. Many scientists prefer to reduce accounts of HIV transmission to being attributable to a few ‘risk behaviours’ that are easy to document and follow rather than examine the social determinants of these actions, which are less directly observable.

Recent social research has highlighted that HIV-related risk behaviour can be specific to context. Rhodes (1997) illustrated through ethnographic research on IDUs residing in London that the individual's perception of risk can be 'socially situated'. Respondents in Rhodes' (1997) study believed that they were more at 'immediate risk' of dying from an overdose of heroin rather than contracting HIV.

Other studies demonstrated that CSWs did not use condoms when they last had sexual contact with a client despite knowing that they could potentially acquire HIV (Verma, Saggurti et al. 2010, Moses, Ramesh et al. 2008, Subramanian, Gupte et al. 2008). These CSWs often experienced difficulties in negotiating condom use with their clients, who could potentially act violently towards them (Ghose, Swendeman et al. 2011). In these extreme circumstances, social interventions that focus purely on changing individual CSWs behaviour may not be sufficient in preventing the transmission of HIV. These interventions fail to address the social context of risk behaviour, which leave marginalised sections of the population relatively powerless to prevent infection from HIV (Pronyk, Hargreaves et al. 2006). As Farmer, Léandre et al. (2001) stated:

*'Many of those at greatest risk already know that HIV is a sexually transmitted pathogen and that condoms could prevent transmission. Their risk stems less from ignorance and more from the precarious situations in which hundreds of millions live.'* (p. 404)

Currently, much research on transmission of HIV in developing countries is still informed by the biomedical model of risk. The research within this field mostly focuses on the behaviour of individuals who are deemed as having a higher propensity towards HIV infection, e.g. male mobile labourers (Gupta, Vaidehi et al. 2010, Greenfield, Nayak et al. 2010, Deering, Vickerman et al. 2008). Some of the methods in these studies seem to be guided by normative assumptions already held by the researcher. There is a plethora of studies on the sexual risk behaviours of MSM and transsexuals in India (Solomon, Mehta et al. 2010, Schneider, Saluja et al. 2007, Newman, Chakrapani et al. 2008), although most

sexual transmission of HIV occurs within the heterosexual population (Avert 2010b, Over, Heywood et al. 2004).

Most of these studies fail to address the fact that many women living in developing countries do not contract HIV through their own sexual risk behaviour. It was stated in a UNDP report (1992) that, 'For most married women, the major risk factor for HIV infection is being married' (Farmer, Lindenbaum et al. 1993:387). Moreover, a large proportion of women at risk of HIV infection in India may not have been able to choose their husband under the system of 'arranged marriage', whereby their parents coordinate their partnership (Ghimire, Axinn et al. 2006). Hence, in the study of Indian women's propensity towards HIV infection it is inappropriate to conceptualise risk as being mostly located within the individual's behaviour. As Barnett and Whiteside (2002) stated:

*'An atomistic individualised perspective does not sit easily with a consideration of the causes and consequences of HIV/AIDS epidemic. If an epidemic is not mere chance but susceptibility... then it follows that the social and economic impacts are not chance events either.'* (p.76)

This thesis adopts a theoretical approach which examines an individual's 'susceptibility' rather than 'risk' of contracting HIV. As mentioned earlier, the concept of 'risk' perceives the probability of one acquiring HIV as being mostly dependent on the ability of the individual to make a rational decision based on appropriate knowledge. This concept is not reflective of the reality for many of those with a heightened predisposition towards HIV infection nor does it take account of how the illness could later affect their lives. In contrast, the term 'susceptibility' refers to social environments and factors that may increase the individual's propensity to contract HIV and could act as a source of 'vulnerability' for PLWHA (Barnett, Whiteside 2002, Loevinsohn, Gillespie 2003). The following section will evaluate theoretical frameworks on social structural factors affecting HIV transmission.

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### 3.B.II *Social Structural Theories of HIV transmission*

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In the late 1990s there was a new body of literature on HIV transmission in developed and developing countries which focused on the social determinants of the epidemic. Research in many of these studies was guided by Farmer's (2004) concept of 'structural violence'<sup>22</sup>. Within this theoretical framework the definition of 'violence' encompasses the processes and forces that conspire to constrain the agency of the individual (Galtung 1990, Galtung, Høivik 1971, Galtung 1969). According to Farmer (2010) this type of violence is inherent in unequal social structures, therefore, historically given. He stated:

*'Suffering is structured by historically given (and often economically driven) processes and forces that conspire... to constrain agency' (p. 263).*

Farmer (2004) argued that the conceptual framework of 'structural violence' can be used in ethnographic research to identify social structures which perpetuate HIV and TB in the population. These methods were used to document how HIV/AIDS spread amongst families in Haiti who were forced to relocate after the construction of a hydroelectric dam caused the flooding of their agricultural land (Farmer, Lindenbaum et al. 1993, Farmer 2001). Female members of these families forged sexual relationships with wealthy men who could offer them an alternative to destitution. Farmer (2004) recounts the biography of Acephie Joseph, who died of AIDS-related illnesses after her sexual partner abandoned her when pregnant. It is argued that her biography is representative of social mechanisms involved in HIV transmission for Haitian women from rural areas who were compelled by poverty to seek employment in large cities. Her narrative called into question the level of agency these women had when they were exchanging sex for monetary compensation. Farmer stipulates

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<sup>22</sup> The theory of 'structural violence' was originally utilised by Latin American liberation theologians to examine the social structures and mechanisms that generate oppression on large sections of the population. They stipulated that it was the researchers' moral prerogative to analyse the social structures which perpetuate the widespread systematic 'violence' of poverty on large sections of the global population in order to 'denounce' it.

that the transmission of HIV is a product of complex political and historical forces in Haitian society which leaves marginalised groups vulnerable to considerable suffering.

The theory of 'structural violence' has been well received by other experts in the field of HIV/AIDS, who commented that it was a useful tool for examining the social causes of epidemics. As Heggenhougen (2004) states, 'if we are to make a dent in the prevalence of the diseases... (we) must attend to the matrix of fundamental causative factors that disproportionately condemn the majority of (marginalized) humanity to disease and death' (cited Farmer 2004:320).

On the other hand, the concept of 'structural violence' has been criticised by Bourgois and Scheper-Hughes (2004) and Wacquant (2004) for being conceptually limited. The definition of 'violence' encompasses a wide range of direct and indirect actions which have the outcome of perpetuating human suffering (cited Farmer 2004). Under this terminology 'structural violence' is conflated with income inequality, political strife and gendered discrimination. Consequently, the narratives of the participants in Farmer's studies become linear and deterministic, indicating that their suffering was already predetermined through social and historical processes. It has been proposed by Bourgois and Scheper-Hughes (2004) that the concept of 'structural violence' could be improved as a tool for research by distinguishing between different forms of violence as Galtung (1969) did. They commented that 'violence' should be conceptualised as being part of a continuum which ranges from direct assault to the more commonly experienced routinized structures of oppression.

Various interdisciplinary social researchers have since adapted Farmer's (2010) conceptual framework of 'structural violence' to encompass the changes proposed by Bourgois and Scheper-Hughes (2004). The common features of these models are that they measure how structural factors and social context can influence people's 'susceptibility' by reducing their capability to control their own health behaviours (Gupta, Parkhurst et al.

2008). These models can be used as an effective tool for analysing the contextual and socio-cultural determinants of the HIV epidemic in India.

Researchers have effectively used the social structural model of ‘susceptibility’ in order to illustrate the economic and cultural mechanisms involved in transmission in societies experiencing transition or upheaval (Hunter 2010, Parkhurst 2010, Poundstone, Strathdee et al. 2004, Parkhurst, Lush 2004, Sumartojo 2000). As Loewenson (2007) stated:

*‘The epidemic feeds on and worsens unacceptable situations of poverty, gender inequity, social insecurity, limited access to healthcare and education, war, debt and macroeconomic and social instability’ (p. 2).*

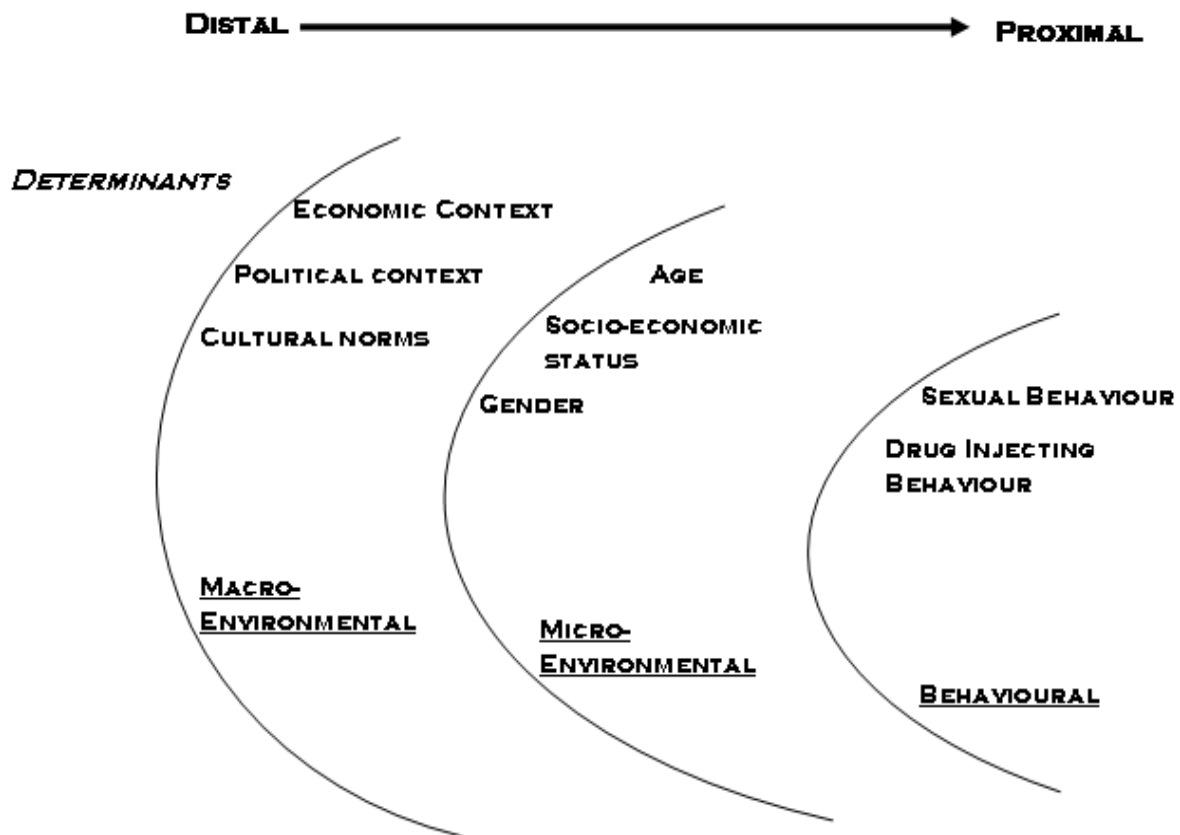
The social structural model of assessing susceptibility has been used with great success in informing social interventions aimed at preventing further transmission of HIV in India (Blankenship, Friedman et al. 2006). One of the most internationally renowned structural interventions is the Sonagachi Project (Ghose, Swendeman et al. 2011), in which CSWs in the Kolkata red light district were trained to educate their peers on condoms and collectivise other female sex workers to mobilise against harassment and other forms of violence. Currently, this project provides a wide range of services for around 20,000 sex workers in its local vicinity. Data from longitudinal studies have indicated that beneficiaries’ levels of HIV knowledge, autonomy, financial security, and rates of condom use have significantly increased compared to their counterparts in other areas of India. Researchers have attributed the success of the intervention to the creation of an ‘enabling environment’ that has empowered CSWs to make their own decisions. In response to these findings other organisations, e.g. the Bill and Melinda Gates Foundation, have implemented similar structural social interventions with the objective of providing ‘enabling environments’ for CSWs across India (Steen, Mogasale et al. 2006, Bill and Mellinda Gates Foundation 2008, Chandrasekaran, Dallabetta et al. 2008, Chandrasekaran, Dallabetta et al. 2006). This new trend in HIV-related interventions indicate that social structural theories of risk could be

fruitfully utilised to research women's propensity towards HIV infection in the Indian context.

Many complex two dimensional models have been proposed by experts for assessing social structural factors associated with susceptibility (Blankenship, Friedman et al. 2006, Sweat, Denison 1995). Rhodes, Singer et al. (2005) suggested that structural determinants of risk should be ranked according to their 'type' and 'level' of environmental influence. They proposed the 'type' of environmental influences which would assess the impact of physical, social, and economic and policy factors on the individual's risk of contracting HIV. Meanwhile, the 'level' of environmental influence measured the impact that these factors had on a micro, meso and macro level. Unfortunately, this model is difficult to apply to mixed methods research as it encompasses social structural factors, such as the micro-level physical environment, which are difficult to operationalize in statistical data.

Research on Indian women's susceptibility to HIV infection in this thesis is informed by Barnett and Whiteside's (2002) model for assessing social structural factors of disease transmission. This conceptual framework places social determinants on a spectrum based on their distance from 'susceptibility'. 'Distal' determinants of HIV-related risk affect the individual's behaviour through a long chain of events, whereas 'proximal' factors more directly influence one's propensity towards HIV infection. In some social contexts these 'proximal' causes of disease transmission can also act as mechanisms through which more 'distal' factors operate (Blankenship, Friedman et al. 2006). These determinants of 'susceptibility' are further ranked according to their structural components. The most 'distal' determinants are 'macro-environmental' which encompass the economic and political context. 'Behavioural' factors are more 'proximal' as they directly influence the individual's risk of contracting HIV, such as sexual behaviour. Figure 3.1 shows Barnett and Whiteside's

(2002) model of ‘susceptibility’ as displayed in their publication ‘AIDS in the twenty-first century: disease and globalization’.




**Figure 3.1:** Barnett and Whiteside's (2002) model of social structural determinants of HIV transmission as displayed in their publication ‘AIDS in the twenty-first century: disease and globalization’.

Based on literature on the dynamics of the HIV epidemic in India (Gupta, Reed et al. 2011, Rajesh, Sanjay et al. 2011, Beattie, Shetty et al. 2009) the dimensions in the Barnett and Whiteside (2002) model of ‘susceptibility’ will be adapted to be more reflective of social structural determinants driving disease transmission in the South-east Asian context. Determinants of ‘susceptibility’ will be allotted according to their structural and distal capabilities for the purposes of mixed methods research. Determinants chosen for the ‘macro-environmental’ structural component have been proven through research to act on a distal level to perpetuate environments that inhibit the individual’s ability to avoid acquiring HIV.

The ‘macro-environmental’ dimension of ‘susceptibility’ encompasses: a) female respondents’ *social status*, that is their religion and caste; b) *socio-demographic factors*, e.g. female respondents’ age and area of residence; and c) female participants’ *socio-economic factors*, for instance their level of wealth. These social structural components are assigned to the ‘macro-environmental’ dimension as they are reflective of wider developmental issues and may create environments which leave the individual at a greater risk of acquiring HIV. For instance, Becker, Ramesh et al. (2007) illustrated that women from lower caste backgrounds in Karnataka were at elevated risk of contracting HIV<sup>23</sup>. Table 3.1 displays how social structural determinants of ‘susceptibility’ are adapted for the Indian context.

**Table 3.1:** Barnett and Whiteside's (2002) model of social structural determinants of HIV transmission adapted for research

*Distal*  *Proximal*

<b>Macro-Environmental determinants</b>	<b>Micro-social determinants</b>	<b>Behavioural Determinants</b>
Socio-demographic characteristics	Gendered Discrimination	Sexual Behaviour
Socioeconomic factors	Awareness and Attitudes towards HIV	
Social status	Geographical Mobility	

Intermediary determinants have a ‘micro-social’ structural component of ‘susceptibility’. This dimension of ‘susceptibility’ comprises: a) female respondents’ experience of *gendered discrimination*, e.g. domestic violence; b) participants *awareness and attitudes towards HIV*, such as their knowledge of possible routes of transmission; and c) their *geographical mobility*, such as female participants’ and their spouses’ movement across India in search of work. It is important to note that it could be argued that a few of the factors

<sup>23</sup> Examples of macro-environmental and micro-social determinants were selected according to their relevance to the Indian context.

assigned to the ‘micro-social’ component of susceptibility may equally belong to the ‘macro-environmental’ dimension, such as *geographical mobility* which could be caused by wider structural changes in society<sup>24</sup>.

Lastly, the most ‘proximal’ determinants are deemed as having an individual ‘behavioural’ structural component of ‘susceptibility’, e.g. their sexual behaviour. This model is used to evaluate ‘susceptibility’ in Part II of this thesis, comprising chapters 5, 6 and 7, which analyses the social structural determinants of HIV transmission in India on a qualitative and quantitative level.

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### 3.C Vulnerability

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The second issue that this thesis seeks to address is women’s vulnerability to the impact of HIV/AIDS. This issue is tackled through exploring how female HIV-positive patients in India reach relevant healthcare services for their condition. Previous research illustrated that WLHA may suffer from substantially more barriers to healthcare services than their male counterparts (Baghdadi 2005, Kumari 2011, Preetika 2011). Das, Mukhopadhyay et al. (2009) found that HIV had a disproportionately more detrimental effect on women’s economic status in comparison to men’s. One possible reason for this result was that many WLHA contracted HIV from their husbands, who died of HIV-related symptoms leaving them widowed. Consequently, these women were left with the burden of care of dependents and as the sole earner in their family. This indicated that the same social structural dynamics which led to these women contracting HIV, later negatively affected them after diagnosis. Therefore, it is pertinent to find a theory on healthcare utilisation which encompasses factors which predispose the individual to HIV infection and then later affects their ability to access medical treatment.

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<sup>24</sup> Some people move to urban areas in search of work due to large scale industrialisation of production (Kurian 2007, Shah 1974).

Until fairly recently, there was a dearth of research on HIV-positive patients healthcare seeking patterns and their experiences of utilising treatment. Most literature on HIV/AIDS in India has focused on the sexual behaviour of ‘risk groups’ in southern states (Thomas, Chandra et al. 2009, Deering, Vickerman et al. 2008, Munro, Pradeep et al. 2008, Pandey, Benara et al. 2008). After 2006 a plethora of research emerged on HIV-positive patients’ utilisation of healthcare services (Safren, Kumarasamy et al. 2006, Kumarasamy, Safren et al. 2005). This was in response to changes instilled in NACO’s third phase of policy, in which all PLWHA are offered some form of free curative care by public healthcare providers (NACO 2008c, MOHFW, NACO 2007). The remainder of this section examines theoretical frameworks currently being used in research on HIV-positive patients’ experience of utilising healthcare services. The strengths and weaknesses of these studies are discussed. Finally, the theoretical framework later used in this thesis to measure WLHA’s access to healthcare services is described.

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### 3.C.I *Theoretical Frameworks used in research on HIV-positive patients’ experiences of utilising treatment in India*

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Currently, most social research on HIV-positive patients’ experiences of utilising healthcare services is concentrated in three areas; these are: a) the economic impact of paying for healthcare services on HIV affected households; b) HIV-positive peoples’ expenditure on healthcare; and c) HIV-infected patients’ adherence to ARV medication. Table 3.2 shows the theoretical frameworks and methods used in studies on HIV-positive patients’ utilisation of healthcare in India.

**Table 3.2:** Theoretical frameworks and methods used in studies on HIV-positive patients' utilisation of healthcare in India.

Subject area	Theoretical models	Methods	Author(s) (year)
The economic impact of paying for healthcare services on HIV affected households	None	Econometric analysis of survey data	Haacker (2009), Dandona, Kumar et al. (2009), Murthy (2008), Freedberg, Kumarasamy et al. (2007), Das, Mukhopadhyay et al. (2009) and Over (2009)
HIV-positive peoples' expenditure on healthcare	None	Econometric analysis of survey data	Nagelkerke, Jha et al. (2002), Gupta, Trivedi (2009) and John, Rajagopalan et al. (2006)
HIV-infected patients adherence to ARV medication	Adherence defined as having taken >95% of the prescribed doses over the past 4 days	A variety of methods were used. Most of the studies were quantitative.	Shah, Walshe et al. (2007), Sharma, Singh et al. (2007), Chomat, Wilson et al. (2009), Kamalika, Madhu et al. (2010) and Maru, Khakha et al. (2007)
	Semi-theoretical	Qualitative methods	Kumarasamy, Solomon et al. (2005) and Safren, Kumarasamy et al. (2006)
	Psychological theories	A variety of methods were used. Most of the studies were qualitative	Ramchandani, Mehta et al. (2007), Solomon, Mehta et al. (2010), Tarakeshwar, Srikrishnan et al. (2007) and Tarakeshwar, Krishnan et al. (2006)

The majority of research on the economic impact of HIV was carried out in collaboration with the World Bank (Wilson, Claeson 2009, Over, Heywood et al. 2004, Haacker 2009, Haacker, Claeson 2009, Nagelkerke, Jha et al. 2002, Gupta, Trivedi 2009). The objective of these studies was to assess the potential long-term effect that HIV could have on the Indian economy and whether it would be sustainable for the government to continually fund curative care for HIV-infected patients. Das, Mukhopadhyay et al's (2009) household survey on HIV affected families collected data on participants' socio-economic status, their mental health and their expenditure on healthcare. This data was used to predict the potential income loss of PLWHA in India.

These studies are useful as they illustrate the possible economic constraints that HIV-positive patients could face. Bhat and Saha (2006) calculated that the cost of ART, including the required tests, for patients attending a private clinic in Gujarat was Rs. 668 (£8.65) on a monthly basis (cited in Gupta, Trivedi 2009). Considering that the weekly earnings of an agricultural labourer are estimated to be Rs. 199 (£2.31), it is likely that many PLWHA would experience very great difficulties affording to continually use ART treatment.

There is a more substantial body of literature on HIV-positive patients' adherence to ART treatment in India (Ramchandani, Mehta et al. 2007, Chomat, Wilson et al. 2009, Chakrapani, Newman et al. 2009, Kumarasamy, Safren et al. 2005, Tarakeshwar, Krishnan et al. 2006, Safren, Kumarasamy et al. 2006, Shah, Walshe et al. 2007, Sharma, Singh et al. 2007, Wanchu, Kaur et al. 2007, John, Rajagopalan et al. 2006, Kamalika, Madhu et al. 2010, Maru, Khakha et al. 2007, Solomon, Venkatesh et al. 2008a, Tarakeshwar, Srikrishnan et al. 2007). Research on this subject area is driven by the success of ART treatment being so reliant upon patients' adherence to the medical regime. This is affected by a wide range of factors including the appropriate ART regimens being prescribed, regular laboratory monitoring and physicians' level of knowledge on HIV-related treatment (Munro, Lewin et al. 2007).

Many studies on adherence to ARV medication in India were conducted by physicians at hospitals providing antiretroviral treatment to HIV-positive patients. A large proportion of these studies did not have any explicit theoretical framework guiding the research. The methods were led by the premise that adherence was defined as the patient consuming >95% of the prescribed doses over a period of 4 days (Chomat, Wilson et al. 2009, Sharma, Singh et al. 2007, Kamalika, Madhu et al. 2010, Maru, Khakha et al. 2007). Patients' reported level of adherence was measured against their socio-demographic characteristics. Shah, Walshe et al. (2007) conducted a survey on HIV-positive patients' adherence to medication in three private

clinics in Mumbai. They reported that respondents' adherence to medication was positively associated with age and the existence of opportunistic infections.

The second type of research on HIV-positive patients' adherence to ARV medication was semi-theoretical (Kumarasamy, Safren et al. 2005, Safren, Kumarasamy et al. 2006). These studies utilised qualitative methods to investigate what patients defined as perceived 'barriers' and 'facilitators' towards full adherence to the strict regimens of ART. Adherence in these studies was conceived as a cognitive process influenced by the patient's own perception of their ability to continually consume medication. The results from these studies could demonstrate barriers that some PLWHA face in reaching healthcare services. Safren, Kumarasamy et al. (2006) illustrated that respondents' perceived illiteracy and HIV-related stigma acted as obstacles to treatment.

The third type of research on HIV-positive patients' experiences of ART treatment utilised clearly defined psychological theories on adherence to medication (Ramchandani, Mehta et al. 2007, Tarakeshwar, Krishnan et al. 2006, Solomon, Venkatesh et al. 2008a, Tarakeshwar, Srikrishnan et al. 2007). Tarakeshwar, Krishnan et al. (2006) used the Social Cognitive Model of Health to assess how HIV-infected patients who had access to care provided by the Tamburam clinic managed their condition. This model examined how personal, environmental, and behavioural domains influenced patients' experience of their condition. It was reported that many female participants expressed less optimism for ARV treatment. Some of these respondents had discontinued ART due to the side-effects of medication, lack of motivation, and treatment costs. There were a few female HIV-infected participants who displayed optimism towards their treatment as they felt supported by members of their natal family and religious community. Hence, they orientated their goals for therapy towards their children and parents.

The studies listed within this section contribute to literature on HIV-infected patient's experiences of using healthcare in India through highlighting how economic and psychological factors can potentially impede their ability to continually use medication. Unfortunately, many studies on adherence may not be representative of HIV-infected patients as they were conducted by physicians at governmental and NGO healthcare facilities specifically providing ART treatment. This meant that these studies were reflective of the needs of a small proportion of PLWHA who were continually using their services. Kamalika, Madhu et al. (2010) commented that the vast majority of their participants were late presenters as they had sampled from a tertiary clinic wherein most patients are treated for severe illnesses, such as TB. Moreover, the overwhelming majority of participants within these studies were men. For instance, in Shah, Walshe et al's (2007) study almost three quarters of the participants were male. Considering that according to NACO (2010) 40% of all PLWHA are women, it is possible that many WLHA were unable to reach these services due to lack of financial resources.

Furthermore, the scope of these studies was conceptually limited as they focused purely on the patients' consumption of ARV medication. Medical research has highlighted that HIV is a very complex illness that can change over time from being dormant to extremely debilitating, especially when patients have opportunistic infections (Stallard 1991). During the course of their illness HIV-positive patients may require a wide range of treatment, which may not pertain to ART. Hence, this type of adherence research fails to acknowledge the needs of many HIV-positive patients who are using some type of HIV-related healthcare facility but were not yet in need of ART under the NACO guidelines for initiation of ARV treatment (Lubinski, Aberg et al. 2009, Bongaarts, Over 2010, Walensky, Wood et al. 2010), in which the patient has a CD4 count of less than 200. These patients may

experience debilitating symptoms, such as fatigue, which inhibits their ability to work (Barroso, Hammill et al. 2010).

Another pertinent theoretical limitation of the concept of adherence was that it was perceived as an activity entirely dependent upon the individual, similar to that of the biomedical concept of risk. Social and structural dynamics of adherence either were ignored or relegated to a lesser position. In Kumarasamy, Safren et al. (2005) study HIV-positive patients' reported 'barriers' to adherence were defined as 'perceived', perhaps indicating that these problems were experiential rather than outside the individual's sphere of control. The reality was that prior to NACO's third phase of policy the vast majority of HIV-positive patients would not have had access to ART treatment unless they were able to afford it.

Finally, the most striking aspect of the findings in most adherence studies was that many of the difficulties HIV-positive respondents experienced with *adherence* to medication were actually related to patients' *access* to care. Tarakeshwar, Krishnan et al. (2006) reported that many female HIV-positive respondents were acutely affected by financial barriers to healthcare facilities. These participants stated that they were concerned about their ability to afford ART treatment as their husbands were also utilising the same services and there were many other costs associated with healthcare, e.g. travel. Therefore, the concept of access acts as a more effective measure of WLHA's ability to reach services, as most obstacles that patients experience in continually utilising care are related to the structure of healthcare facilities and their ability to afford the direct and indirect costs of treatment.

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### 3.C.II *Sociological models of access*

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According to the U.S. Institute of Medicine 'access is the timely use of personal health services to achieve the best possible health outcome' (cited in Gulzar 1999: 16). There are currently many theories which either measure access on a spatial, economic or socio-behavioural level (Young 2004). This thesis follows McKinlay's (1972) taxonomy which

divides various theoretical approaches used in studies of healthcare access or utilisation into the categories of: organisational, economic, socio-demographic, socio-cultural, micro-social and geographic.

I concentrate on socio-demographic and micro-social theoretical frameworks as studies that use geographic measures tend to lack theory. Most of this type of research utilises Geographic Information System (GIS) technology to chart the populations' utilisation of healthcare according to their area of residence (Hare, Barcus 2007, Luo 2004). This conceptual framework is useful for assessing structural and spatial elements of access. However, it is insufficient for examining socio-cultural and financial factors which could affect HIV-positive patient's ability to reach services.

Socio-behavioural models of access are often adopted in developing countries to measure population's usage of health services or the impact of insurance policies on patterns of health service consumption (Wolff 2006). These models were formulated in western nations, e.g. the U.S.A, where the health system is highly regulated by the government and infrastructure of services is strong (Guagliardo 2004, Norris, Aiken 2006, Wagner, Austin et al. 1996, Bond, Lauby et al. 2005). Nevertheless, in many under-resourced countries impoverished patients may not be able to afford health insurance (Ruxin, Paluzzi et al. 2005, Balarajan, Selvaraj et al. 2011, Kumari 2011, Posse, Meheus et al. 2008, Kumar 2004). Patients' access to essential treatment facilities could be affected by poor infrastructure, e.g. in mountainous areas of India it is sometimes not possible for patients to reach hospitals by car because roads may be dangerous or difficult to travel (Ensor 2004).

There are a few theories which operationalize components of access. Khan and Bhardwaj (1994) stipulated that the 'use of services, or the actual entry into the system, is dependent on barriers and facilitators that reflect dimensions of both the service system and the potential users' (p.66). Different components of access are assessed in terms of their

ability to incur ‘potential’ and ‘realised’ utilisation of services. These dimensions are further divided into barriers, facilitators, costs and opportunities. Barriers are classified as factors which impede the utilisation of services, e.g. stigma, whilst facilitators have the opposite effect. Cost measures the monetary and social expense of seeking and using treatment. Opportunity describes factors which create advantageous circumstances for those in search of care (e.g. local support networks). It is taken into account that opportunities for utilisation of services can incur extra costs. These components of access are measured on a spatial and social level. This typology emphasises the relative nature of access by taking into account that for some patients cost and distance to treatment facilities are insurmountable whilst for others it presents few difficulties.

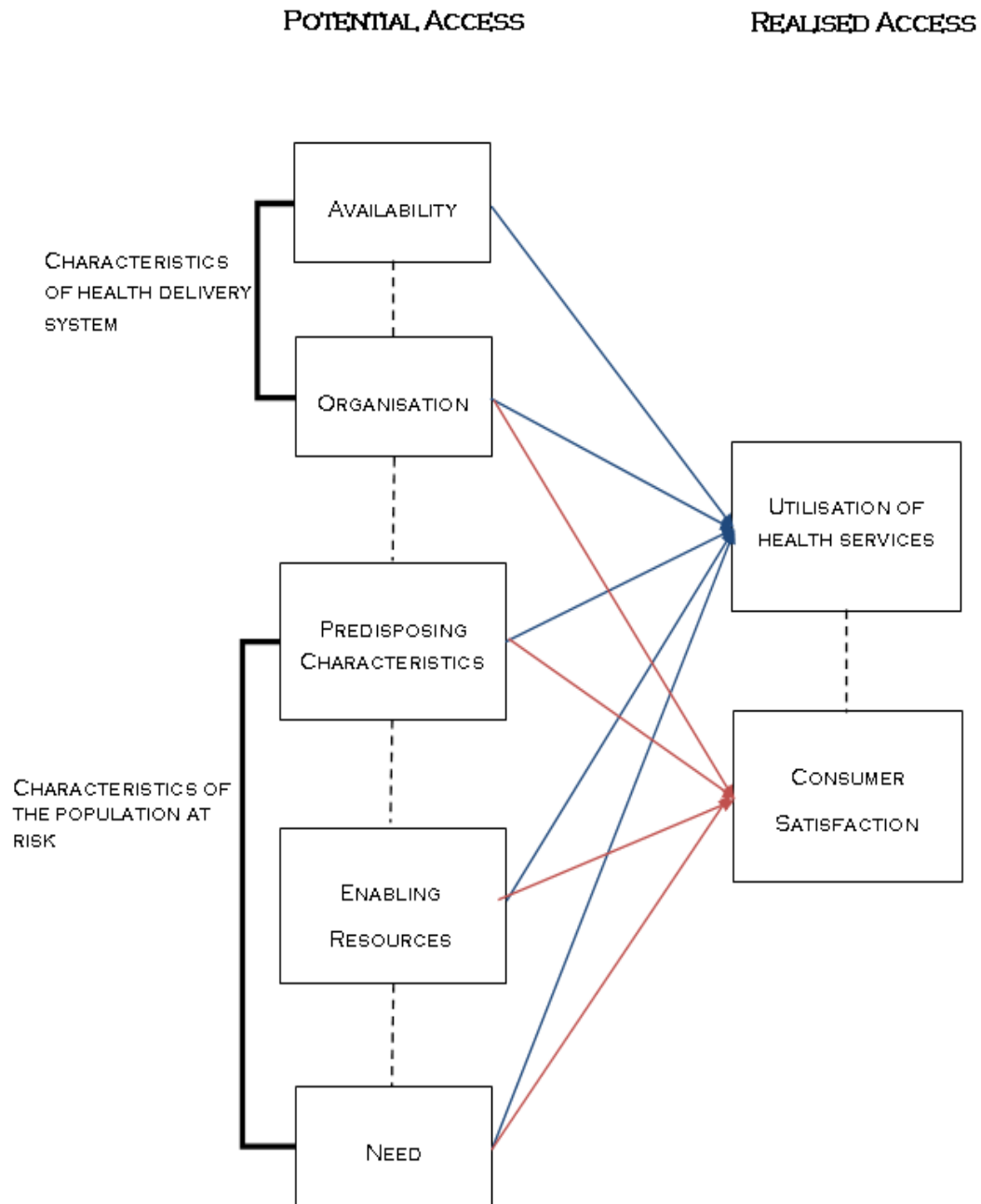
Khan and Bhardwaj’s (1994) theory has been fruitfully used to measure the interaction between spatial and aspatial barriers or facilitators of access on patients’ ability to use the necessary services. Fullerton, Bader et al. (2006) used this concept of access to determine barriers and facilitators to healthcare services for early and adequate antenatal care of women residing on the American/Mexican border. They identified facilitators to receiving timely prenatal care as being personal health beliefs in the value of these types of services and having a strong social network which supported and encouraged utilisation of these facilities. This illustrates that it is possible to use Khan and Bhardwaj’s (1994) concept to identify determinants of access inherent to the setting, such as the participants’ culturally-specific beliefs on healthcare. Unfortunately, this theoretical framework was not used to guide the research in this thesis as it was not possible to operationalize these dimensions of access in the NFHS-III dataset. For instance, the NFHS-III did not record the distance of healthcare facilities from participants’ homes, making it difficult to examine ‘spatial barriers’ to healthcare services.

On the other hand, Aday and Andersen's (1981) model of access has been used in many contexts to examine whether services are distributed according to the needs of patients or if there are barriers to access due to race, gender or income by measuring how structural and population factors combine to affect patients' access to healthcare services. Andersen, McCutcheon et al. (1983) state:

*'Access may be defined as those dimensions which describe the potential and actual entry of a given population group to the health care delivery system.'* (p. 51).

Access is evaluated by examining how 'potential' dimensions affect 'realised' utilisation of services (Andersen, McCutcheon et al. 1983, Phillips, Mayer et al. 2000, Aday, Andersen 1981, Aday, Andersen et al. 1980). 'Potential' dimensions of access are further sub-divided into 'characteristics of health delivery system' and 'characteristics of population at risk', in order to evaluate whether the structure of the healthcare system is delivering the relevant services to those most in need of treatment. The 'characteristics of health delivery system' is measured through examining the *availability* of facilities locally and overall *organisation* of healthcare services.

Meanwhile, 'characteristics of population at risk' is evaluated through looking at *predisposing characteristics, enabling resources* and *need*. *Predisposing characteristics* describe features which existed before the onset of the illness (i.e. level of education). *Enabling resources* are the means to which patients' obtain access to services (e.g. healthcare insurance). The population's *need* for healthcare is evaluated by looking at their perceived health status and level of illness. By contrast, actual or realised access to services is defined as the patients' utilisation of facilities and the quality of care they received. Figure 3.2 depicts Andersen and Aday's (1981) theoretical framework.



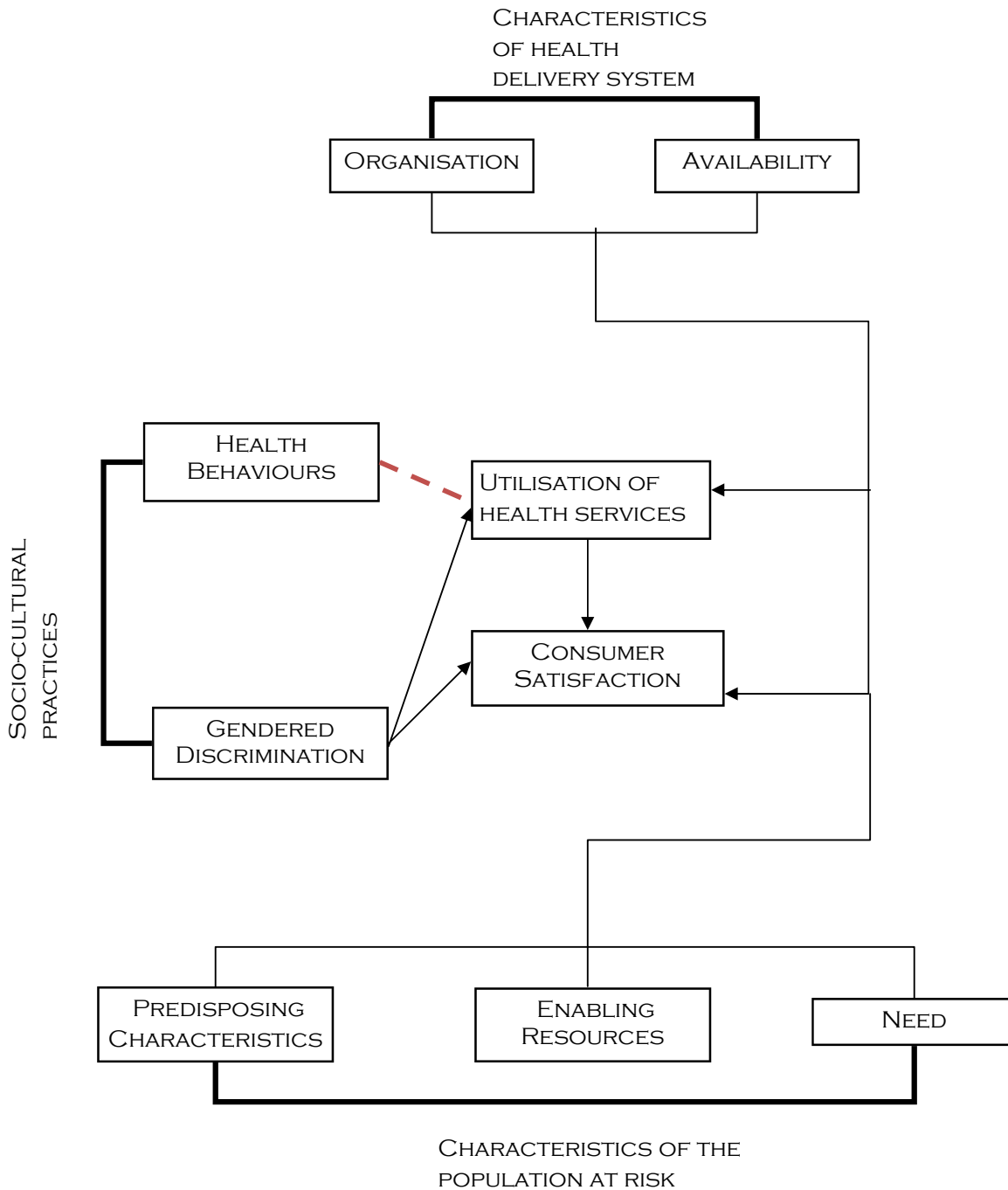
**Figure 3.2:** Andersen and Aday's (1981) theoretical framework

This model is useful in the Indian context because it measures how socio-cultural factors combine with structural factors to prevent access to care. It also evaluates patients' access to care on a qualitative and quantitative level, acknowledging that patients' access to care is affected by their experience of the condition as well as the availability of services. Wong, Ann et al's (2006) study of CSWs' used Andersen and Aday's model to illustrate that

participants suffered barriers to healthcare due to predisposing factors, such as the stigma of their profession. Moreover, this model has been used for studying utilisation of healthcare in India. Chakrapani, Newman et al. (2009) employed Andersen and Aday's conceptual framework of access to assess CSW's usage of healthcare facilities providing ART. They reported that participants experienced obstacles to reaching services on an individual, healthcare system, programmatic and social level. Therefore, this model could be used fruitfully to measure structural and population components of access for HIV-positive women in India.

In consideration of the findings from Chakrapani, Newman et al's (2009) study, Andersen and Aday's (1981) model of access will be altered to address the complexity of HIV/AIDS as an illness. *Gendered Discrimination* will be added to the conceptual framework of access as previous research has indicated that social inequalities can affect the health outcomes of HIV-positive patients in developing countries (Baghdadi 2005, Kanniappan, Jeyapaul et al. 2008, Mawar, Joshi et al. 2007, Joseph, Kielmann et al. 2010). This dimension was difficult to place on Andersen and Aday's model of access as it does not neatly fit into the criteria of being part of 'characteristics of the population at risk' or 'characteristics of health delivery system'. Moreover, it is possible that 'characteristics of the population at risk' could influence how women experience gendered discrimination; for instance, an impoverished woman from a low caste background may experience more sexual harassment in comparison to their richer high caste counterparts. In consideration of these social dynamics, gendered discrimination will be added to a new overarching dimension of socio-cultural practices.

Figure 3.3 depicts how Andersen and Aday's (1981) theoretical framework will be utilised for research in this thesis<sup>25</sup>.



**Figure 3.3:** Andersen and Aday's (1981) modified theoretical framework

<sup>25</sup> Please see p.214 and p.253 for a more detailed description of how the adapted model will be used to measure participant's access to healthcare.

Finally, research on the treatment outcomes of ART has highlighted that success is heavily dependent on patients' adherence to strict regimens of the medication (Munro, Lewin et al. 2007), indicating that self-care practices could be a crucial component of continual access to healthcare. Andersen (1995) further refined his model by adding 'health behaviours' to the potential dimensions of access. This was in order to recognise the impact that personal 'Health behaviours', such as diet, can have on long-term utilisation of services and the well-being of patients.

*Health behaviours* are used for the purposes of this thesis to measure participants' diet as it could have a negative impact on their adherence to the strict ART regime. Similarly to *gendered discrimination*, health behaviour is affected by socio-cultural practices, such as dietary requirements associated with religion. For instance, it is customary for high caste Hindus to adhere to a strict vegetarian diet (Michelutti 2008), which could be detrimental for PLWHA who have higher protein requirements than their HIV-negative counterparts (Ivers, Cullen et al. 2009). Therefore, 'health behaviours' are added to the over-arching dimension of socio-cultural practices. This model is used to evaluate access in Part III, comprising chapters 8, 9 and 10, which analyse social determinants of HIV-positive women's utilisation of healthcare in the Indian context.

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### 3.D Conclusion

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This chapter reviewed literature on theories of social factors related to disease transmission and health seeking behaviours. It was found that most theories tend to treat these social phenomena as separate rather than affecting one another. The only theory that dealt with transmission and treatment simultaneously was Barnett and Whiteside's (2002) conceptual framework of 'susceptibility' and 'vulnerability'. Within this theoretical framework, social structural determinants of disease transmission were conceptualised as

effecting the individual's 'susceptibility' rather than 'risk', as people belonging to vulnerable groups may not be able to ensure that they do not contract HIV.

Barnett and Whiteside (2002) demonstrate in their seminal study of the global impact of AIDS in the twenty-first century that disease transmission is part of a wider spectrum of the possible effects that HIV/AIDS can have on developing nations' social and economic development. They propose that researchers should investigate sections of the populations' ability to cope with the socio-economic consequence of HIV/AIDS. This means that it is possible to measure this aspect of HIV/AIDS by exploring people's 'vulnerability' to its negative impact on their social welfare.

Barnett and Whiteside's (2002) concept of 'vulnerability' encompasses a wide range of possible outcomes for HIV-positive women, such as the intergenerational impact of HIV on families, meaning that it is difficult to fully use this concept in a doctoral thesis. Hence, it was decided that the remainder of this doctoral study would focus purely on female HIV-infected respondents' access to healthcare facilities. Andersen and Aday's (1981) model of access was used to assess whether services were distributed according to the needs of patients or if there were barriers to access due to gender or poverty, by measuring how structural and population factors combine to affect patients' access to healthcare services. The following chapter will describe how these theoretical frameworks will be used to guide the methodology.

## Chapter 4      METHODS

### 4.A Research Questions

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Based on an understanding of social structural determinants of women's 'susceptibility' and 'vulnerability' to the impact of HIV/AIDS in India, this doctoral thesis explores the following questions:

1. What are the social structural determinants of HIV transmission among women in India according to Barnett and Whiteside's (2002) model of 'susceptibility'?
2. What social structural processes influence women's susceptibility towards HIV/AIDS?
3. What effects do theoretical 'potential' dimensions of access, such as availability of services or level of income, have on 'realised' use of facilities for HIV-positive women in India?
4. What are the processes that HIV-infected women undertake in choosing treatment?

### 4.B Mixed methods

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#### 4.B.I *Rationale*

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As noted in the literature review, in chapter 2, the HIV epidemic in India is complex and relatively little is known about the impact it has had on women. Using a combination of qualitative and quantitative methods allows one to both *measure* and *explain* the sources of 'susceptibility' and 'vulnerability' to HIV/AIDS for women in the Indian context. It is difficult to mix methods without a comprehensive understanding of the paradigms which shape and to a certain extent represent qualitative and quantitative research (Bowker 2001, Kleining, Witt 2001, Westmarland 2001). This section examines the paradigmatic foundations for each method and provides an explanation to why they have been combined for the purposes of this thesis.

Quantitative methods (e.g. surveys) occupy a dominant position within the hierarchy of social research methodologies in terms of ‘hard’ science<sup>26</sup>. Drawing on the philosophy of natural sciences, the positivist paradigm claims that social phenomena could be affected by universal laws (Comte 1868, Popper 2002). Knowledge is generated through a process of deductive reasoning, whereby the role of the researcher is to ‘test theories or hypotheses, gather descriptive information, or examine relationships among variables’ (Creswell, Klassen et al. 2011:6). Within this process the researcher is expected to adopt an objective stance (Curry, Nembhard et al. 2009) further reinforced by various procedures to certify that the data is ‘reliable’ and ‘valid’, such as randomisation (Doyle, Brady et al. 2009, Creswell 2003, Sale, Lohfeld et al. 2002). This ensures that research is conducted in a ‘value-free’ framework intended to separate social phenomena from context (Johnson, Onwuegbuzie 2004).

Quantitative research has played a crucial role in highlighting the prevalence and distribution of a social issue (Reinharz 1992)<sup>27</sup>. Nonetheless, some researchers have questioned whether it is possible for the investigator to approach their subject area in a truly objective manner, given that they are embedded in their social context (Harding 1987, Harding 1982, Oakley 1998). Quantitative data was used in this thesis to identify groups affected by HIV, the relationships between different types of social phenomena and behavioural patterns that could be generalised across the population (McDowell, MacLean 1998). The inclusion of qualitative methods mitigated the methodological limitations of the quantitative research assumption of presumed ‘objectivity’ by using participants’ narratives to shape the hypotheses to better suit the Indian context (Elshtain 1981). In this manner, I

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<sup>26</sup> Some researchers consider quantitative research as the benchmark for research on HIV and other health-related issues (Pronyk, Hargreaves et al. 2006, Fung, Guinness et al. 2007, Kumarasamy, Flanigan et al. 2007).

<sup>27</sup> Researchers and policy-makers have fruitfully employed quantitative tools to highlight the impact of widespread gendered discrimination on women (Friedan 1963, Kaplan, Marks 1995, Allen, Myhill 2002). Experts in the field of HIV/AIDS research have used quantitative methods to illustrate that domestic violence can increase the likelihood of HIV transmission amongst women through inhibiting their ability to engage in protective behaviours, e.g. condom use (Chandrasekaran, Krupp et al. 2007, Garcia-Moreno, Jansen et al. 2006).

adopted a simultaneously emic (insider) and etic (outsider)<sup>28</sup> perspective (Hollway, Jefferson 1997, Starks, Trinidad 2007, Wray, Markovic et al. 2007), a multiple perspective which allowed one to see that knowledge, especially in marginalised groups, is situated in socio-historical processes and environments (Mills 1959).

The interpretivist paradigm, commonly used in qualitative research, posits that knowledge is generated through human beings engaging with their world and attempting to comprehend it through their own socio-historical lens (Denzin, Lincoln 2000, Richardson 1994, Crotty 1998, Lincoln, Guba 2000). Social reality is constructed through the act of interpretation, which is often ‘transitory and situational’ (Gall, Borg et al. 1996:28), meaning that context-free enquiry is never wholly possible. Qualitative studies are often exploratory in nature, seeking as they do to generate theories on meaning in social interaction or identify complex causal mechanisms. Creswell, Klassen et al. (2011) suggest that:

*‘A salient strength of qualitative research is its focus on the contexts and meaning of human lives and experiences for the purpose of inductive or theory-development driven research’ (p.6).*

Qualitative methods were employed in this thesis for a variety of reasons, the foremost being to expand on quantitative findings by identifying possible causal mechanisms (Greene 2008). For example, in chapters 5, 6 and 7 a mixture of quantitative and qualitative methods was used to investigate the impact of caste on women’s susceptibility to HIV/AIDS. Quantitative analysis highlighted the fact that women’s caste-status had little or no apparent influence on their propensity to contract HIV. Nevertheless, respondents’ narratives from the qualitative phase of research illustrated that caste acted as an aggregated proxy indicator of risk for those in relationships with a husband from outside their caste/ethnic community. Some of these respondents experienced such discrimination from relatives that they received little support when their partner was physically abusive.

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<sup>28</sup> The terms ‘emic’ and ‘etic’ are used by anthropologists and social scientists to describe different approaches that researchers adopt to investigate a social issue. Researchers adopting an ‘emic’ perspective usually explore knowledge and interpretations already existing within a culture, meaning that they act as an insider. Meanwhile, those with an ‘etic’ perspective attempt to provide generalisations on human behaviours, resulting in them acting as an ‘outsider’.

In conclusion, qualitative and quantitative methods were both used with full acknowledgement of the paradigmatic assumptions and philosophical foundations of each methodology (Creswell, Plano Clark et al. 2003). This thesis combined methods for a variety of reasons, namely to comprehensively research a complex social phenomenon using multiple viewpoints, to mitigate the weaknesses of each methodology and to elaborate upon findings (Sale, Lohfeld et al. 2002, Creswell, Fetters et al. 2004, Morgan 1998). The following section will describe the mixed methods model adopted in this thesis.

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#### 4.B.II *Mixed methods model*

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Currently, researchers use mixed methods in their studies not only to validate their data but also to enrich it through the use of a wide range of viewpoints. Creswell, Plano Clark et al's (2003) definition of multi-method analysis is used for the purposes of this thesis. They stipulate that:

*'Mixed methods study involves the collection or analysis of both quantitative and/or qualitative data in a single study in which the data are collected concurrently or sequentially, are given priority, and involve the integration of the data at one or more stages in the process of research'* (p. 212).

There are currently several typologies of designs for mixed methods research, most of which are similar and follow set criteria (Creswell 2003, Sale, Lohfeld et al. 2002, Creswell, Miller 2000, Tashakkori, Teddlie 2003). According to Creswell, Plano Clark et al. (2003) the main standard for mixing methods should be that the research question determines the selection of methods. The directional drive of the research questions establishes the implementation of data collection, the priority of a given method and stages of integration of analysis. The directional drive of the research questions in this thesis is *deductive*, as a set of theories inform the collection and analysis of the data. The mixed methods model chosen is therefore a 'sequential explanatory design', in which the quantitative component of the research has heavier weighting than that of the qualitative. In this model the research is

conducted in two stages of data collection with the initial stage being quantitative followed by qualitative (Newman, Ridenour et al. 2003).

The first stage of research consisted of a secondary quantitative analysis of the National Family Health Survey (NFHS-III), a cross-sectional multi-round survey conducted on a nationally representative sample of households in India (IIPS, Macro International 2007). Findings from the NFHS-III have been previously used by the Indian Government to provide national and state level data on demographic and socioeconomic determinates of family planning, nutrition, use of healthcare, maternal and child health indicators and emerging health issues.

This phase of analysis addressed research questions 1 (the social structural determinants of HIV transmission among women in India according to Barnett and Whiteside's model of susceptibility) and 3 (the impact of 'potential' dimensions of access on female HIV-positive patients' use of services). The first research question was examined by identifying variables which measured women's propensity to contract HIV in the Indian setting, through the use of Barnett and Whiteside's (2002) typology of structural determinants of 'susceptibility'. Associations between these variables were tested through bivariate and multivariate analyses. The outcomes of these tests are displayed in chapter 5. The third research question was analysed in a similar manner, except that variables were allotted according to their ability to evaluate dimensions of access stipulated by Andersen and Aday (1981). These analyses are reported in chapters 8 and 9. Findings from this stage of analysis informed the interview schedule and coding framework in the second qualitative phase of research.

The second stage of research consisted of a small set of qualitative narrative interviews with female HIV-positive patients conducted in NGOs and Positive Networks (PNs) based in Andhra Pradesh (A.P). The purpose of this phase of analysis was to address research questions 2 (the social structural processes influencing women's susceptibility to HIV/AIDS) and 4 (the processes that HIV-infected women undergo in choosing treatment).

Both research questions were addressed using the ‘illness narrative’ approach in chapters 6, 7 and 9. This concept has been used in medical sociological research to examine the personal and social dimensions of chronic illness through the recording of participants’ biographical narratives (Bury 2001, Bury 1982, Rosenfeld, Charmaz 2010, Charmaz 1995, Charmaz 1983, Williams 1984, Williams 2000). This type of narrative in-depth interview was beneficial because it depicts from the participant’s viewpoint the order and context of temporal events before and after diagnosis.

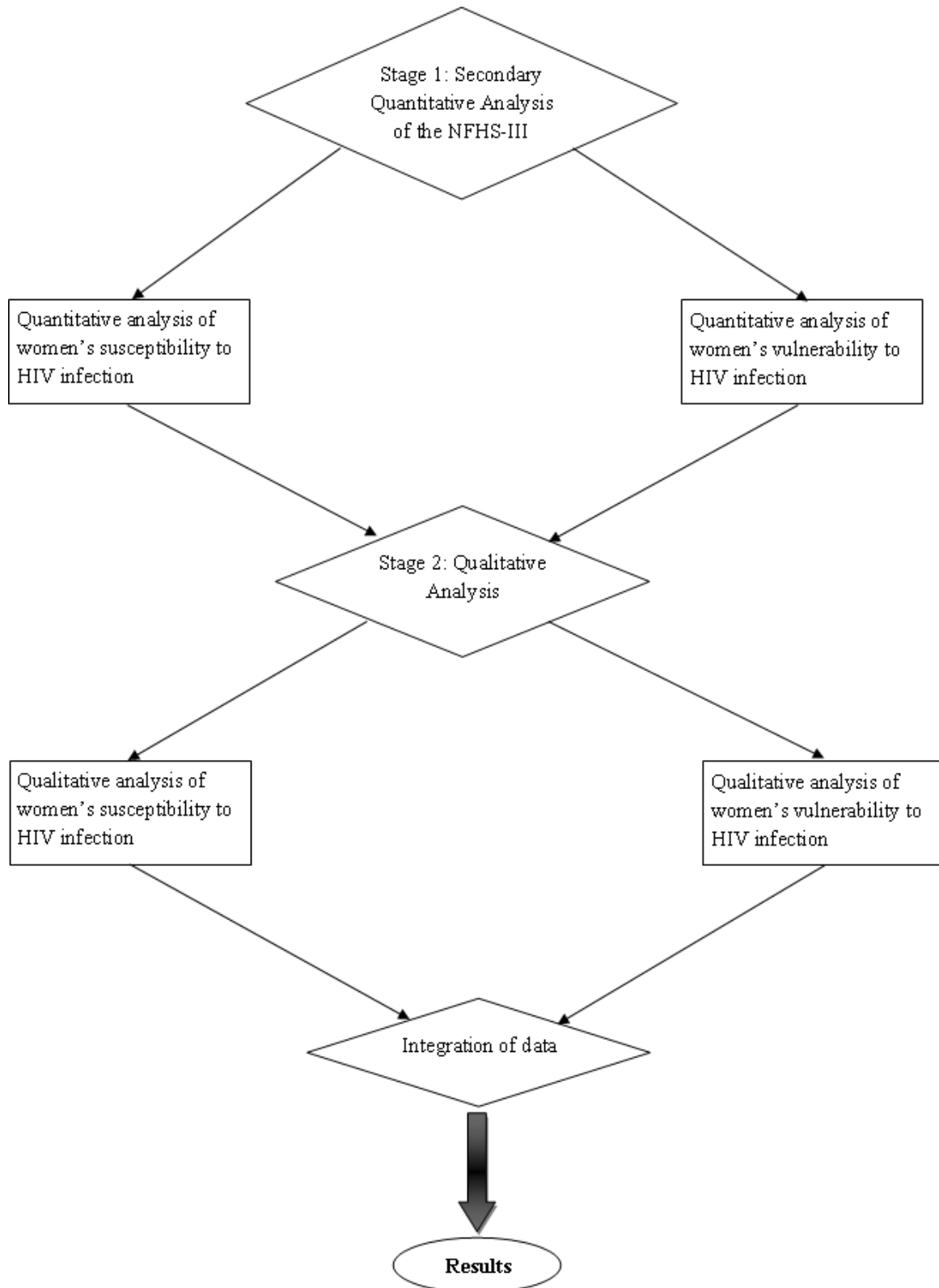
Qualitative and quantitative data was fully integrated when the findings of both phases of research were analysed and reported. At this point in the analysis, I was able to expand on the quantitative findings by using qualitative interview participants’ narratives to highlight potential processes leading to relationships between independent and dependent variables. Rogers (1995) posits that:

*‘In order to explore the nature of the innovation-decision process one needs a dynamic perspective to explain the causes and sequences of a series of events in time’ (p.189).*

This form of analysis allowed me to test hypotheses emerging from the qualitative data using statistical tests. For example, participants’ accounts in the qualitative phase of analysis revealed that female outreach staff at Anganwadi Centres (AWCs) guided women to the necessary healthcare services. This converged with findings from the quantitative stage of research, which indicated that the availability of AWCs might influence female HIV-positive respondents’ use of HIV testing services.

The remainder of this chapter is designed to be reflective of the mixed methods model used for this thesis. I initially outline the selection criteria, sample design and data collection used in the quantitative phase of research. Then I describe the fieldwork setting, sampling technique, data collection, translation and ethical procedures used in the qualitative stage of research. Thirdly, I explain how qualitative and quantitative data is separately analysed in each phase of research. Finally, I illustrate how these forms of analysis are integrated. Figure

4.1 shows the model for combining quantitative and qualitative methods used in the research for this thesis.



**Figure 4.1:** Model of mixed methods

## 4.C Stage 1: Secondary Quantitative Analysis of NFHS-III

The first stage of research consisted of a secondary analysis of the National Family Health Survey (NFHS). The NFHS was initiated by the Ministry of Health and Family Welfare (a department of the Indian Government) in order to produce accurate data on issues related to health. Implementation and design of this survey was guided by the International Institute for Population Sciences (IIPS), a non-profit research organisation in Mumbai (India), and ORC Macro, a market research and consultancy company based in the USA (DHS 2008).

Data from the 2005-6 NFHS-III was used for the purposes of this thesis, as it contains a large set of variables especially relevant for researching access to healthcare facilities of HIV-positive women, e.g. the sero-status of the participants, their knowledge of the virus and the ability of female respondents to enact healthcare decisions (IIPS 2008, IIPS, Macro International 2007). The objective of this stage of analysis was to determine women's sources of 'susceptibility' and 'vulnerability' to the impact of HIV/AIDS in India.

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### *4.C.I Selection Criteria*

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The NFHS-III used a stratified sampling technique, in which households were selected according to variables pertinent to the survey, e.g. HIV-prevalence<sup>29</sup>. This level of stratification can reduce the reliability of data, given that the NFHS-III was not a simple random survey (Marsden, Wright 2010). However, as the Indian population is large and heterogeneous, this was the most valid method for targeting economically deprived populations relevant to the survey.

The selection criteria for female participants were that they had to be 15-45 years old and residents of the sample households or had stayed in the house the night before the

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<sup>29</sup> The 2001 Census list of villages was used as a sampling frame. The first level of stratification was by districts in each state and their level of prevalence of HIV. Then villages within each of these regions were further divided by their size, percentage of men working in the non-agricultural sector, proportion of those belonging to the most deprived caste groups, and female literacy.

interview (IIPS 2006a). This survey covered an age demographic proven by previous research to act as a proxy indicator of risk since it comprised the duration of women's reproductive cycle, meaning that participants were likely to be sexually active (Quazi, Nimbarte et al. 2010, Beattie, Shetty et al. 2009, Chaudhuri, Mundle et al. 2010).

A similar stratified sampling technique was used for the selection of participants to take an HIV test as part of the survey. The purpose of this technique was to create a national and state representative estimate of HIV prevalence in the Indian population. All adult participants living in Uttar Pradesh and the six high prevalence states as identified by NACO (A.P., Karnataka, Maharashtra, Manipur, Nagaland and T.N.) were eligible for an HIV test. Meanwhile, a sub-sample of adult participants was tested for HIV in the remaining states.

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#### 4.C.II *Sample Design*

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Target sample sizes in each state were approximated by IIPS according to the number of ever-married women who needed to be interviewed and the size of the population living in the state (IIPS, Macro International 2007, IIPS 2006b). The initial target size was 4,000 completed interviews with ever-married women in each state with a 2001 census population of more than 30 million. The target sample sizes were reduced for states with a smaller population<sup>30</sup>. The sample size was then adjusted according to estimated HIV-prevalence and the number of people living in slum and non-slum areas of selected cities. Sample sizes in some states were therefore in excess of initial criteria. Since sample sizes were tailored to the population needed for this study, the survey provided a rich and detailed source of data that may not have been possible to obtain through an attempt to conduct a survey purely on a sample of HIV-infected patients, due to logistical constraints and stigma associated with the condition.

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<sup>30</sup> The rural and urban samples in each state were selected in two stages. Firstly, Primary Sampling Units (PSU) were selected by probability proportional to size. Then households were randomly selected within each PSU. The difficulty with this type of sampling framework was that each stage of selection incurred a different level of sampling error. However, it would have been logistically almost impossible to target the populations required for this survey with a simple random sampling framework due to the fact that the Indian population is large and heterogeneous and the prevalence of HIV is relatively low.

Inflationary weights were provided by ORC Macro for the NFHS-III dataset to produce estimates of HIV prevalence in the Indian population at a national and state level (DHS 2008). These inflationary weights were also designed to compensate for possible biases incurred by the stratified sampling technique described earlier. This stratified sampling technique resulted in participants in low prevalence states being under-sampled, and therefore, cases in low prevalence states were upweighted, and those in high incidence states downweighted.

The inflationary weights increased the size of the sample to such an extent that most bivariate analyses would have had statistically significant results. The standard procedure recommended for NFHS-III was to divide the sample weights by 1,000,000 in order to return the number of cases to that of the original unweighted sample. On the advice of my supervisor, George Smith, and two experts in quantitative research methodology in the Social Policy department, Kenneth Macdonald and Erzsebet Bukodi, I decided to use a formula commonly used in research on social policy to adjust the inflationary weights to ‘relative weights’.

The ‘relative weights’ reduced the number of weighted cases to the actual size of the sample by dividing the sum of the inflationary weights by the sum of the unweighted sample. This procedure for calculating relative weights ensures that the relative distribution of cases are in the same proportion as that of the inflationary weights, despite the fact that the overall size of the sample had been reduced to its original size (Aday, Cornelius 2006). The relative weights should therefore produce similar results to those of the inflationary weights without providing false readings on significance tests<sup>31</sup>.

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<sup>31</sup> These weights produced similar results to those of the other adjusted weight, in which the inflationary weight was divided by 1,000,000. However, the ‘relative weights’ may provide more accurate results as the proportion assigned to the earlier ‘inflationary weights’ is maintained.

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#### 4.C.III *Data Collection Procedures*

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The NFHS-III used three types of questionnaires: the Household Questionnaire<sup>32</sup>, the Women's Questionnaire and the Men's Questionnaire (IIPS, Macro International 2007, DHS 2008). ORC Macro determined the content of the questionnaires through a series of workshops in 2005-6 with the Ministry of Health and Family Welfare, representatives from international agencies and experts on HIV/AIDS. Interviews were conducted in every state in India under the stewardship of the Ministry of Health and Family Welfare in cooperation with the International Institute of Population Sciences, which acted as the nodal agency. Local organisations conducted the interviews in their states in two phases. Afterwards the data was entered into statistical computer programmes and edited. The data was frequently assessed in order to ensure its quality. This method of data collection generated a large sample of more than 230,000 participants, which provided accurate information on a large number of topics ranging from domestic violence to sexual behaviour.

The Women's Questionnaire was used to interview all female participants. It examined the respondents' background characteristics (e.g. age), reproductive behaviour, use of contraception, health behaviours, history of domestic violence and awareness of HIV and other sexually transmitted diseases (STDs). The data from this questionnaire was used in this thesis to assess the effects of gendered discrimination on Indian women's propensity towards HIV infection.

The NFHS-III has previously been established by Smith, Pellisery et al. (2007) to be one of the most reliable and valid demographic datasets in India. Rigorous procedures were established to ensure that the quality of data was high throughout the field collection stage: interviewers were trained through workshops, each research team in the field contained a Field Editor to check the interview data for completeness and accuracy of information.

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<sup>32</sup> The Household Questionnaire was used to list all the residents in each household, their relationship to each other, their level of education and health status. The NFHS-III also collected information on standard of living by recording the source of drinking water, access to basic facilities and ownership of a Below Poverty Line card. Health status was examined through using biomarker measurements recording the height and weight of participants and conducting blood tests to assess their HIV-status and haemoglobin levels. This data was used fruitfully to assess how respondents' health-status affected their utilisation of healthcare facilities.

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#### 4.C.IV *Representativeness of NFHS-III data*

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The NFHS-III conducted interviews with a total of 109,041 households in all 29 states in India. The household response rate was 98% for the whole of India and it barely differed between urban and rural areas. Within these households 124,385 women and 74,369 men were interviewed. The individual response rate for these interviews was 95% for India as a whole. Response rates for women differed by state. Despite these variations in response rates, coverage of the survey was uniformly high with some states, such as Madhya Pradesh, having 99% of eligible women undertaking the interview<sup>33</sup>.

Coverage for HIV testing was also high with 85% of 61,525 female and 58,759 eligible male participants agreeing to take the test. These high response rates to HIV testing during the NFHS-III were similar to that of other developing countries, in which coverage of surveys is often far higher than that of developed nations. According to Mishra, Vaessen et al. (2006) response rates for Demographic and Health Surveys in which respondents were tested for HIV varied between 70% in Kenya and 92% in Burkina Faso.

Respondents in the NFHS-III who were not tested for HIV had either refused to participate (6%) or were not present for the interview (1%). Participants' response rates were further tested against demographic characteristics in order to determine whether participation in this component of the survey was biased by respondents' social background or belief systems (Fenton, Johnson et al. 2001). Response rates for HIV testing of female participants varied little by age<sup>34</sup> and marital status, but coverage of HIV testing did differ by level of education, wealth, area of residence, state<sup>35</sup> and religion<sup>36</sup>.

There is always a possibility that the minority of participants who are most at risk of having HIV/AIDS may have refused to take the test as they either fear or know that they are HIV-positive. IIPS and Macro International (2007) tested response rates against variables

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<sup>33</sup> Information on response rates for the survey are in the NFHS-III report (IIPS, Macro International 2007).

<sup>34</sup> Please see Appendix 9 for a table on coverage of HIV testing for female participants by age, marital status, wealth, area of residence and educational status.

<sup>35</sup> Please see Appendix 10 for a table on coverage of HIV testing for female participants by state.

<sup>36</sup> Please see Appendix 11 for a table on coverage of HIV testing for female participants by religion.

which measured participants' sexual behaviour for the NFHS-III report. There was very little variation in response rates between participants who had either partaken in sexual risk activities or been tested for HIV and those who had not. Slightly fewer female respondents who had not been tested for HIV prior to the survey declined to provide blood (6%) than those who had (7%). This illustrated that NFHS-III results regarding participants' sero-status should be reliable, as they were not biased towards those who considered themselves unlikely to be HIV-positive.

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#### 4.C.V *Ethical Procedures*

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Organisations which collected data for the NFHS-III followed a strict set of procedures regarding participants' confidentiality and anonymity. Interviewers were required to sign a section of the questionnaire indicating that they had followed ethical procedures. Moreover, data was anonymised so that it was not possible to identify participants. These procedures should guarantee that interviewers treated participants appropriately and that the survey did not incur harm for respondents. However, as the survey was on such a large scale, it can never be possible to be completely sure that every interviewer correctly followed all ethical procedures.

Interviewers followed an additional set of ethical procedures to ensure that they did not know about any respondents' HIV-status. Respondents who consented to the HIV test provided blood drops from a finger stick that was collected on filter paper. Dried blood samples were attached to a bar code and sent to a laboratory, meaning that it was not possible for interviewers or other field staff to identify participants who had taken the test. Furthermore, no respondents received their test results back, and they were not questioned about their sero-status during the interview. This meant that it was not possible to ascertain if female HIV-positive respondents knowingly used healthcare facilities for their condition.

It was pertinent to identify which factors could have influenced female (or male) sero-positive participants' propensity to be tested for HIV as their awareness of their sero-status is

an important component of their later use of healthcare services. Most quantitative analysis of access to healthcare in this thesis concentrated on sero-positive women's use of HIV testing services, which was recorded in the survey.

Some procedures undertaken to ensure participants' anonymity when taking an HIV test could have a detrimental impact on the overall ethics of the survey. Experts in the field of HIV/AIDS have emphasised that PLWHA's awareness of their sero-status is important for increasing access to healthcare services and reducing the rate of transmission. Recent research has highlighted that PLWHA who know of their sero-status are less likely to engage in sexual risk behaviours in comparison to those unaware of their condition (Marks, Crepaz et al. 2006, Marks, Crepaz et al. 2005). Nonetheless, it is possible that many respondents would not have been willing to undergo an HIV test if they believed that there was a prospect of members of their community learning of their sero-status. In Nagaland there was such opposition to the HIV test that this element of the NFHS-III was cancelled in that state, leading to the state being excluded from subsequent analysis. The following section explores procedures employed in the qualitative stage of research.

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## 4.D Stage 2: Qualitative Research

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### 4.D.I *Setting*

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During the qualitative stage of research I collected interview data from multiple sites in Andhra Pradesh. Research was conducted with the collaboration of an NGO known as Vasavya Mahila Mandali (VMM)<sup>37</sup>. This NGO has set up programmes to implement home and community based HIV/AIDS care and support for patients living around Vijayawada, which is in Guntur district, an area with a HIV-prevalence much higher than the rest of the state 1.72% (Dandona, Lakshmi et al. 2006)<sup>38</sup>.

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<sup>37</sup> VMM is an NGO in Andhra Pradesh that mobilises the Community Action for Care and Support of HIV-positive patients' programme in partnership with the International HIV/AIDS Alliance.

<sup>38</sup> Vijayawada is characterised by trade of agricultural commodities, e.g. rice, and being part of a fast developing region with small-scale industries in automobile body building, garment making, iron and cement production attracting economic migrants searching for gainful employment (Rao, Rao 1991).

The remaining sites were located in the east coastal districts of Krishna and West Godavari. These areas were chosen because they were identified by NACO as having had a prevalence of over 1% for more than 5 years (NACO 2007). I collected data from three other NGOs and three local Positive Networks (PN). The three other NGOs (AIRTDS<sup>39</sup>, LEPR<sup>40</sup> and Department of Social Work in Dantuluri Narayana Raju College) have previously conducted community and care programmes for HIV-affected families. Additionally, the PNs, including CHES-plus<sup>41</sup>, SHIP-Network<sup>42</sup> and APPLE<sup>43</sup>, have organised social interventions designed to reduce HIV-related stigma in local communities, and therefore these sites provided the ideal setting for recruiting HIV-positive women who fitted the eligibility profile of this study.

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#### 4.D.II *Sampling Technique*

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I fitted the sampling technique into the work of each organisation, resulting in interviews being adjusted to participants' lifestyles. In collaboration with staff in the NGOs and PNs, who acted as gatekeepers' to data, I selected participants according to Patton's (2002) criteria of 'convenience sampling', whereby respondents were chosen from those willing to undertake interviews. Unfortunately, it was not possible to use a more targeted sampling technique for selection of female HIV-positive participants due to regulations on medical confidentiality, which meant that patients' details were concealed from the general public (NACO 2008b).

I sampled forty-three HIV-positive women from a population of patients who were clients of services provided by the NGOs and PNs. They were approached by staff from these organisations during outreach work for social interventions. The number of participants was based on previous qualitative studies on HIV-infected patients' experiences of using

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<sup>39</sup> Action for Integrated Rural and Tribal Development Social service organisation (AIRTDS 2011)

<sup>40</sup> Leprosy Relief Association (LEPRA 2011)

<sup>41</sup> Cheytha HIV Infected People Empowerment Society

<sup>42</sup> Society for Welfare of HIV Infected People (SHIP-network 2011)

<sup>43</sup> Association for Positive People Living Excellence (APPLE 2011)

healthcare services in India (Kumarasamy, Safren et al. 2005, Kumarasamy, Venkatesh et al. 2007, Tarakeshwar, Krishnan et al. 2006, Kalasagar, Sivapathasundharam et al. 2006).

As in Pierret's (2001) study, interviews were used in conjunction with organisations' programmes to observe patients' reactions to services they were receiving (Pierret 2003, Carricaburu, Pierret 1995). This approach was particularly appropriate to the Indian context because it ensured that patients' identities were not revealed to others in their community.

Ten of the interviewees were also peer providers, which meant that they were PLWHA who provided healthcare and social services to others with the same condition. These respondents offered a unique perspective as both a patient and provider of services. They were in contact with a wide range of clients and may have had a broader understanding of the issues other female HIV-positive patients face than other participants who were primarily service users.

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#### 4.D.III *Data collection*

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The purposes of these in-depth qualitative interviews were to examine respondents 'susceptibility' to HIV infection, participants' experiences of accessing facilities, to analyse the processes they undergo in choosing healthcare providers and further explore findings from the previous stage of research. The design of the topic guide was based on Wengraf's (2001) model of a heavily structured 'Biographic-Narrative' interview design in which questions are grouped according to their ability to generate theories and hypotheses through their capacity to answer central research questions. This type of qualitative interview design was best suited to this thesis because it was intended to develop narrative information and simultaneously create and test concepts.

The topic guide followed a narrative structure which started with respondents' lifestyles prior to diagnosis and ended with their assessment of their current health status (e.g.

ongoing symptoms) and ability to access the necessary treatment facilities in the future<sup>44</sup>. The interview schedule began with the purpose of the research being explained to the participants, after which they were asked ‘general descriptive’ questions (Burgess 1985, Farr 1982), regarding for example their occupation<sup>45</sup>. Answers to these questions were later used during analysis to explore the influence of participants’ socio-demographic characteristics on their ‘susceptibility’ and ‘vulnerability’ to the impact of HIV. Table 4.1 displays the structure of the interview schedule.

**Table 4.1:** Structure of interview schedule

Topic	Areas Covered
General Descriptive Questions (Demographics)	Age Marital status Occupation Income Caste
Participants narratives on the processes associated with HIV-related risk	Relationship with family Relationship with husband Socio-economic status prior to diagnosis HIV awareness
Illness Narrative	Diagnosis Pathways through healthcare Use of NGO services Experiences of using treatment
Outcomes	Current health status Symptom management ‘Continual’ access

Participants were encouraged to provide narrative with as little input as possible from myself or the translator, through questions such as ‘Can you please tell me about your experiences using treatment starting from when you were diagnosed?’. If respondents experienced difficulties in answering these questions they were gently guided into providing a narrative through a set of questions, firstly; on their lives prior to diagnosis, and; secondly, on their experiences of using healthcare services. The first set of questions was designed to

<sup>44</sup> Please see Appendix 1 for Demographics Sheet, in which participants and providers details were noted (e.g. age). Appendix 2 contains the Telegu version of the Demographics Sheet. Appendix 3 contains the service user’s topic guide.

<sup>45</sup> Pole and Lampard (2002) comment that topic guides need to be well paced, starting gentle before beginning to delve into complex questions.

encourage participants to speak on social structural processes that led to their infection, while the second set of questions dealt specifically with access. Peer providers were asked questions about the social characteristics of other WLHA they had been in contact with and about their clients' patterns of healthcare utilisation<sup>46</sup>.

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#### 4.D.IV *Translation Procedures*

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I did not have enough time or resources to learn how to speak Telugu<sup>47</sup> fluently, and therefore; I conducted qualitative interviews with the aid of an interpreter who was fluent in both English and Telugu. To minimize bias and increase validity, I employed a translator from outside the NGOs and PNs with the agreement of these organisations, in order to ensure that the contents of the interview were kept confidential from staff in these organisations<sup>48</sup>. This may have resulted in some participants feeling freer to disclose detailed information about their use of different types of health services<sup>49</sup> than they would have otherwise. Moreover, these procedures could have minimized difficulties for staff in NGOs and PNs as the interviews interfered less in their daily activities.

Interview data was interpreted according to Brislin's (1970) model of translation, originally developed to minimise errors. Brislin advises that firstly a transcript of the interview should be produced in the source language, which should then be translated into the target language. Secondly, the researcher should check the target version of the script for spelling and grammatical errors to make it comprehensible. Finally, the target script is translated back into the source language and compared to the original script in order to check that the translation is as reliable as possible (McDermott, Palchanes 1994).

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<sup>46</sup> Please see Appendix 4 for the Peer Provider's topic guide in English and Appendix 5 for the Telegu version of it.

<sup>47</sup> This language is commonly spoken in A.P. (Krishnamurti 2003).

<sup>48</sup> I hired a female translator who was of similar age to the respondents so that she would not appear intimidating to them.

<sup>49</sup> Previous research into people's use of healthcare services in India have shown that some participants would adapt their answers to please those conducting the interviews. This becomes a greater issue if the interpreter belongs to the institution (Bradby 2002)

Because of high associated costs, it was not possible to conduct all of the procedures underlined by Brislin (1970) to ensure the validity of translation. Audio-digital data was therefore transcribed by research assistants employed from the local university, and interpreters checked these transcripts for errors. Then other members of the team who were fluent in both Telegu and English translated it. Finally, the translator again evaluated the target script. I conducted my own assessments of the English interview transcripts by comparing them to my own notes on participants' responses to questions during the interview.

Other researchers advised that parts of qualitative interviews should be translated in real time, so that the researcher can effectively guide the direction of the narrative and adapt questions to participant's responses (Esposito 2001). Hence, I attended each interview to ensure that the responses were being guided according to the research questions. Furthermore in order to ensure reliability of the interviews, the interpreter was trained by VMM staff to communicate effectively with interviewees and quickly summarise participants' responses to the researcher without interrupting the flow of narrative. Most training was conducted during the pilot stage of the qualitative research phase, so that both the interpreter and I learnt together how to conduct interviews in an appropriate manner.

It is important to acknowledge that despite procedures put in place to increase validity of translations it remains possible that there was a large margin for error. Previous studies have illustrated that there are many ways in which one language may be translated into another (Temple 1997, Twinn 1997, Overing 1987). McDermott and Palchanes (1994) argue that it is particularly difficult to translate one language into another if the grammatical structure is different. This could be particularly problematic for research in this thesis as languages of Dravidian origin adopt very different grammatical and sentence structures to English (Krishnamurti 2003). In order to increase validity, words with multiple meanings were noted in the process of translation. However, when interpreting the data later it was

necessary to bear in mind that ‘no translation is ever innocent’ (Manguel 1996, cited Bradby 2002:852).

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#### 4.D.V *Procedures to validate the data*

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A set of procedures were implemented during the qualitative phase of research to ensure the validity of data<sup>50</sup>. Firstly, I kept an ‘audit trail’ of meticulous records of each stage of data collection and analysis through a field diary and memos (Silverman 2000). This guaranteed that analysis was as reflective as possible, as this technique of data validation allows us to acknowledge the effect that research and setting has on the methods.

Secondly, I sought out the translator’s viewpoint on interviews to check that the analysis was ‘credible’ (Creswell 2000). By employing a translator local to the setting I was reducing research bias which could result from being alien to social norms in A.P. and, thus not understanding unspoken cultural forms of communication or culturally dependent concepts (Overing 1987). This type of validation has been used by other researchers, like Silverman (2000) who would make his research assistant take notes during transcription and then discuss her interpretation. In my case, the interpreter assisted in the validation of documentation, as she contextualised interview data by providing a cultural perspective through the translation of the participants’ responses<sup>51</sup>.

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#### 4.D.VI *Ethical Procedures*

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The British Sociological Association’s ethical guidelines (2002) were followed in each interview. They stipulate that researchers must explain to the respondent that they have the right to anonymity, to withdraw at any time and to choose whether their answers are tape recorded or not. Additionally, I abided by the Economic and Social Research Council's ethical guidelines (2010), which specify that codes of ethics in the host country of the

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<sup>50</sup> Although there is no uniform way to analyse qualitative data, Tesch (cited in Sarantakos 1998) lists 27 strategies for qualitative research which makes it possible through rigorous examination to make sure that the data is valid.

<sup>51</sup> Hatim and Mason (1997) argue that translation of text is dependent on context as the meaning of words is reliant on the situation, who said them and in relation to what.

research should be observed, ‘informed consent’ obtained from the participants, the interests of respondents protected and confidentiality of records maintained<sup>52</sup>.

I ensured that interviews were conducted in an ethical manner by firstly informing participants about the purposes of the research, why they had been selected for the study and that they would be only required to attend a qualitative in-depth interview not lasting more than two hours. Then participants were told about the risks of partaking in such an interview, such as incurring emotional damage through the recovery of past memories. They were notified about the benefits of partaking in the research, such as that it might lead to programmes that improve the access to services of other female HIV-positive patients. Finally, they were informed that they had the right to refuse to answer certain questions or to withdraw from the interview at any time, their anonymity was guaranteed, and their answers would be kept confidential between myself, my supervisor and the research team.

All respondents were handed a certificate of consent<sup>53</sup> translated into Telugu, which further explained what was discussed earlier and contained a section for them to sign including my contact details<sup>54</sup>. In order to ensure participants’ anonymity and confidentiality, each respondent was assigned an individual code that indicated whether they were a beneficiary of services or a peer provider. The assignation of PF denoted that the participant was a female beneficiary of services rendered by the PN or NGO sampled, while PP was shorthand for peer provider.

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<sup>52</sup> These ethical considerations were strictly followed, as participants belonged to a highly marginalised and stigmatised group. NACO ensures that there are laws that protect the right of PLWHAs to informed consent, confidentiality and to prevent discrimination. They argue that ‘there can be no valid or effective response to HIV/AIDS without respect for the human rights, fundamental freedom and the dignity of human beings’ (NACO 2008c, NACO 2008b, NACO 2007a). Ethical clearance to interview HIV-positive patients was obtained through the Social Work Department in Dantuluri Narayana Raju College, in Andhra Pradesh, and Oxford University’s Ethical Committee.

<sup>53</sup> This certificate of consent is modelled on the WHO’s (World Health Organisation) ethical consent form, which is composed of two sections. The first explains the purpose of research and the ethical procedures which will be followed, and the second has a section for participants to sign for consent to partake in the research, which includes contact details for the researchers. Please see Appendix 6 for the English version of the ethical consent form and Appendix 7 for the Telegu version.

<sup>54</sup> I supplied the contact details of VMM staff in case any of the respondents experienced any psychological issues during the interview which they would like to resolve with the help of a professional. Participants who were illiterate or had difficulty fully reading the certificate had the consent form read out to them by the translator, who also explained to respondents any details that they at first found difficult to comprehend.

Despite these measures, there remain factors that could reveal participants' identity, e.g. the location of their village, their occupation or number of family members. The British Sociological Association's Guidelines (2002) note that it is sometimes impossible for research to be truly confidential, and that the researcher must therefore inform the participant of this, which I did in every interview. Furthermore, the interviewee was informed that it is possible that some material could be published later, but that it was very unlikely to reach members of their community or that their identity would be recognised<sup>55</sup>.

The most worrying feature of anonymity is that it depersonalises issues, which may lead to possible inequalities in the relationship between the researcher and respondent. The researcher is expected to take personal information from the participant without contributing to their relationship<sup>56</sup>. This could be a traumatic experience for female HIV-infected patients who confess their personal lives to a foreign researcher, with no guarantee of control over what is written<sup>57</sup>. Some researchers include respondents in the analysis of their results by encouraging them to read the subsequent article (Oakley 1981). Towards the end of fieldwork, a meeting was set up for respondents in which they were informed of the preliminary results of the qualitative phase of analysis. They were also encouraged to offer feedback on findings. Many respondents were interested in discussing HIV-related stigma and poverty. It was an equally informative session for the participants, as they were put in contact with staff from NGOs and PNs who could offer them psycho-social assistance.

The following section describes the integration of quantitative and qualitative methods during analysis.

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<sup>55</sup> Data from the interviews was encrypted and stored on a separate hard drive which only I had access to. This guaranteed that it was not possible for any member of their community to discover their HIV-status.

<sup>56</sup> In some circumstances, interviews could be a positive experience for participants who belong to marginalised groups that have previously been unable to voice their experiences. In Swain and French's (2004) study of people with learning difficulties, one participant who had suffered abuse in the past wanted to recount her experiences to prevent others with the same condition from being ill-treated.

<sup>57</sup> An adverse events form was created in order to record details of participants who reported that they were feeling suicidal. These participants were asked by the translator if they wanted to be put into contact with NGO services. Please see Appendix 8 for the Adverse Events Form.

## 4.E Integration of Analysis

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### 4.E.I *Quantitative analysis*

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Statistical analysis involved three phases of tests to establish relationships or correlations between different dimensions of ‘susceptibility’ and ‘vulnerability’, as described in the multivariate modelling techniques of Hosmer and Lemeshow (1989). First, descriptive statistics were generated on variables to test their frequency and distribution. Then bivariate forms of analysis tested associations between independent and dependent variables. Finally, multivariate analysis was used to account for the effects of many independent variables (such as age) on the dependent variable (e.g. female respondents’ sero-status).

Selection of independent and dependent variables to measure women’s ‘susceptibility’ and ‘vulnerability’ to the impact of HIV was informed by the theoretical frameworks guiding the research for this thesis. Statistical analysis of indicators of ‘susceptibility’ was informed by Barnett and Whiteside’s (2002) model for assessing the social structural factors of disease transmission. Meanwhile, the selection of indicators of ‘vulnerability’ was shaped by Andersen and Aday’s (1981) model of access. The selection of these variables will be further discussed in chapters including quantitative research findings (chapters 5, 8 and 9).

One of the most complex issues to examine statistically in this thesis was the identification of the social structural predictors affected transmission of HIV among women in India, which is explored in chapter 5. This is because some experts on HIV/AIDS in India argue that women’s ‘susceptibility’ to HIV infection can be affected by the sexual risk behaviour of their partner or spouse (Solomon, Mehta et al. 2010, Thomas, Chandra et al. 2009, Mlay, Lugina et al. 2008). As women’s propensity to contract HIV infection does not exist in a social vacuum, the male dataset was used to fully analyse aspects of disease transmission outside women’s control.

Furthermore, the NFHS-III provided a dataset containing data on both married partners, including their sero-status. It was possible to examine how far the sero-status of each partner within a married couple was determined by social structural factors or sexual risk behaviour. This dataset was complex as each case consisted of one married partnership. Data was analysed according to the sero-status of each married partnership within that dataset. There were four types of partnerships, namely: a) sero-concordant negative, in which each partner is HIV-negative; b) sero-discordant with a primary male partner, meaning that the woman within this relationship is sero-negative whilst the man is sero-positive; c) sero-discordant with a primary female partner, in which the woman within the partnership is HIV-positive while the man is HIV-negative; and, finally d) sero-concordant positive, meaning that both partners are sero-positive.

The findings from the quantitative stage of analysis on women's 'susceptibility' and 'vulnerability' to HIV guided the direction of the qualitative phase of research. The second qualitative phase of research analysed in-depth processes behind trends found in the quantitative stage of analysis. In addition, I investigated how temporal processes may have affected HIV-infected women's access to facilities. The following section will describe procedures used to analyse the qualitative data.

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#### 4.E.II *Qualitative analysis*

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Transcripts and audio recordings of interviews were stored digitally and analysed through a qualitative computer program called Nvivo, which allows the researcher to code the data, link concepts, examine similarities and differences within each interview, and review patterns and themes in the data (Nvivo 2011). Moreover, the program contains the applications necessary to allow the investigator to keep a field diary and memos linked to the raw data.

It is common in qualitative research to use 'grounded theory' to systematically analyse components of the text and infer theories from it (Glaser, Strauss 1968). This method

of analysis was not suitable to examine the data as it breaks down respondents' texts according to the coding framework, resulting in sections of participants' interviews being isolated from the rest of their overall narrative.

'Collocation analysis' was used to analyse the data, whereby the researcher locates the position of the respondent in relation to their narrative through multiple methods (Mello 2002). Firstly, narratives were identified within respondents' interview text by distinguishing themes and patterns and comparing these narratives with other interview transcripts. The text was also coded according to dimensions of the theoretical framework on 'susceptibility' and 'vulnerability'. These narratives were then coded according to the structure of the story (as identified by Labov and Waletzky 1967). Mathieson and Barrie (1998) effectively used this method of analysis to examine the illness narratives of cancer patients by coding sections of their transcript according to the overarching themes of patients' narratives and points of divergence from these themes.

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#### 4.E.III *Phase of Integration*

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According to Creswell, Fetters et al. (2004) 'integration refers to the point in the process of research procedures at which the investigator mixes or integrates the quantitative and qualitative data collection and analysis' (p.10). As mentioned earlier, both forms of data were drawn on during the analysis involved in this thesis. Data was combined at this phase rather than at an earlier point in time because of the fact that the quantitative phase of research involved the use of a secondary source of data.

The integration of data loosely drew on elements of Onwuegbuzie and Teddlie's (2003) conceptualisation for analysing mixed methods data. Firstly, a process of 'data reduction' was undertaken, in which the multidimensional nature of both types of data was reduced through the coding of text and the generation of descriptive statistics. Then some data was transformed, with the quantitative data being given a qualitative structure and vice versa. For instance, during the qualitative phase of research I collected demographic data,

which was then converted into numerical values. This allowed the representation of some findings of the qualitative data in statistical form (e.g. a graph) which could in turn be compared to the quantitative results.

Thirdly, I analysed both datasets through an iterative process in which the two sets of findings were compared and correlated. For instance, if the quantitative results indicated that female HIV-positive participants had a preference for private healthcare then I would explore qualitative texts for points where respondents referred to processes they undertook in choosing providers.

Finally, data was consolidated, and both forms of data were combined in order to create new units of analysis which made possible the comparative evaluation of findings. For example, participants' narratives were coded according to variables in the NFHS-III used to assess female respondents' experiences of physical and emotional violence. Through this process I was able to illustrate similarities and differences between the qualitative and quantitative findings.

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#### 4.E.IV *Limitations*

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One of the main weaknesses of the NFHS-III was that it was difficult to assess certain dimensions of 'vulnerability' due to ethical and logistical constraints which occurred during data collection. As noted earlier, a set of ethical procedures was initiated to ensure the anonymity of participants who undertook an HIV test as part of the survey. During the interview respondents were *not* questioned on their sero-status. One of the advantages of adhering to these ethical procedures was that the NFHS-III was able to sample HIV-infected women who may not yet have been aware of their sero-status and thus were not necessarily receiving any treatment for their condition. This meant that individual level indicators of 'susceptibility' (e.g. sexual behaviour) were not necessarily influenced by respondents' prior knowledge of their condition.

A further constraint of the NFHS-III was that it was not possible to adequately measure the temporal dimensions of women's 'susceptibility' and 'vulnerability' to HIV/AIDS using data from the NFHS-III. This is because the NFHS-III was the only round in which participants' blood was tested for HIV and it was a cross-sectional survey. The issue of temporality was further exacerbated by the fact that the survey was conducted prior to the enactment of NACO's third phase of policy, in which public healthcare facilities were established to provide sero-positive patients with free HIV-related care. It was therefore difficult to assess the impact of recent changes in policy on female HIV-positive participants' use of healthcare facilities.

An additional constraint was that the achieved sample size of HIV-positive women in the NFHS-III was only 191 cases. This was due to the fact that sero-prevalence in India is relatively low at 0.36% (0.27%-0.47%). This small number of female sero-positive respondents meant that it was difficult to conduct highly complex statistical analyses that would produce significant or meaningful results, such as structural equation modelling. However, it was possible to use other less complex forms of modelling to illustrate correlations between multiple variables.

Other sources of data on the rate of HIV infection among risk groups were supplied by the Bill and Melinda Gates Foundation and NACO, which offered detailed estimates on regional and district prevalence within states (Chandrasekaran, Dallabetta et al. 2008). However, these surveys did not provide as reliable data on HIV prevalence as the NFHS-III did, as data was only collected from populations with a history of high risk behaviour (e.g. IDUs). Moreover, they provide little reliable information on HIV-positive women's access to healthcare facilities as most data collected by NACO is on patients receiving ART treatment in public hospitals, while the majority of patients in India use private healthcare services. Data from the NFHS-III not only fulfils the requirements of validity for quantitative research but is also the most reliable survey for the purposes of this thesis as no other sources of data have produced such a wide range of information on the female HIV-infected population.

The limitations imposed by the nature of the NFHS-III were partially compensated through sampling a small minority of HIV-positive women who were not only aware of their sero-status but who had also been making continual use of healthcare services. These participants provided insights into the dynamic between ‘susceptibility’ and ‘vulnerability’ to HIV/AIDS by recording how their personal experiences of their condition had shaped their understanding of susceptibility and later their ability to reach services.

Nevertheless, it is important to note that the sampling technique employed for the qualitative phase of research could be biased. This is because participants were sampled from clients and peer providers of NGOs and PNs. The reason for using this sampling technique is that sero-prevalence in India is relatively low, meaning that it would be very difficult to find female HIV-positive participants by any other means. Unfortunately, it was not possible to find participants who solely used private healthcare services or who were unaware of their HIV-status. Using NFHS-III data ameliorated these weaknesses in the qualitative data.

I therefore employed both methods with the purpose of minimizing the weaknesses of each by drawing on the strengths that both approaches can offer. As Onwuegbuzie and Johnson (2006) stated:

*‘The greater the extent that the weakness from one approach is compensated by the strengths from the other approach, the more likely that combining a weak inference with a strong inference will lead to a superior or high quality meta-inference’.* (p.58)

# PART II



## **Chapter 5      WOMEN'S 'SUSCEPTIBILITY' TO HIV IN INDIA ACCORDING TO DATA FROM THE NFHS-III**

### **5.A Introduction**

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The second part of this thesis, comprising chapters 5, 6 and 7, addresses social structural predictors of HIV-status among women in India according to Barnett and Whiteside's (2002) model of 'susceptibility'. The HIV epidemic in India is complex to analyse due to the vast size of the population and geographical area (Wilson, Claeson 2009). Recent research suggests that prevalence is concentrated in certain geographical areas and among populations displaying high-risk behaviours, such as IDUs (Gajendra, Jagadish et al. 2011). Currently, the estimated prevalence of HIV is higher amongst men (0.36%) than women (0.22%) with a female to male ratio of 0.61 (NACO 2010, UNAIDS, WHO 2007).

Literature on HIV transmission among women highlights that there are two groups within the Indian population who are particularly susceptible to infection. The first is fairly simple to identify as they belong to marginalised sections of the population which often partake in sexual risk behaviour, e.g. CSWs or drug injecting users (Nagelkerke, Jha et al. 2002), while the second comprises women married to men belonging to high risk groups, such as migrant labourers (Newmann, Sarin et al. 2000, Venkataramana, Sarada 2001). These women are difficult to identify as few themselves partake in risk activities (Break Through 2003).

The biomedical concept of 'risk' is inadequate for investigating transmission dynamics among the second group of women as it largely predicates risk of transmission based on the individuals' behaviour. This concept fails to take into account the fact that the majority of women married to men belonging to high risk groups may not have partaken in sexual risk activity, e.g. extra-marital sexual relationships. In these cases, it is more fruitful to investigate social structural dynamics leading to infection within this group of women, and

hence this chapter undertakes a quantitative examination of the social structural predictors of HIV-status among women in India. The following section describes how variables were selected to measure social structural factors influencing female participants' HIV-status in the NFHS-III.

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### 5.A.I *Selection of variables to measure 'susceptibility'*

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As chapter 5 aims to explore possible predictors of HIV infection among women in India according to Barnett and Whiteside's (2002) model of 'susceptibility', the dependent variable used in all bivariate and multivariate analyses was the participants' sero-status. Independent variables were ranked according to their distance from risk and structural components. For instance, variables deemed to be reflective of economic and political context were assigned to the 'macro-environmental' dimension of 'susceptibility'.

The 'macro-environmental' dimension of 'susceptibility' encompassed: a) *socio-demographic characteristics* including age, state and area of residence; b) *socioeconomic status* comprising level of education, wealth and occupation; and c) *social status* including religion, caste identity<sup>58</sup> and marital status. These variables were chosen because recent research illustrated that in developing countries a woman's level of education, economic position (Gillespie 2008, Ghosh, Wadhwa et al. 2009, Ulin 1992, Booyesen, Summerton 2011) and occupation (Pradhan, Sundar et al. 2006, Gupta, Trivedi 2009) can influence their ability to avoid HIV infection in developing countries. Table 5.1 displays how independent variables were allotted to measure Barnett and Whiteside's (2002) model of 'susceptibility', which I modified for the purposes of the thesis.

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<sup>58</sup> The NFHS-III, firstly, recorded if participants self-identified as belonging to a caste or tribe. Respondents who did not self-identify as either category were allotted as having no caste/tribe status or as not knowing which group they belong to. Then it further documented participants' caste status by utilising Indian governmental measures of caste which compress heterogeneous categories of caste into five broad groups (Ministry of Home Affairs, Government of India 2001), which were scheduled castes, scheduled tribes, other backwards classes (OBC) or 'none of them'.

**Table 5.1:** The assignment of variables to measure dimensions of Barnett and Whiteside (2002) model of ‘susceptibility’

Distal → Proximal

Macro-Environmental determinants	Micro-social determinants	Behavioural Determinants
<u>Socio-demographic Factors</u>	<u>Gendered Discrimination</u>	<u>Sexual Behaviour</u>
Age	Attitudes to Domestic Violence	Total lifetime number of sexual partners
Marital status	Controlling behaviour	Recent sexual activity
State	Emotional violence	Last intercourse used condom
Area of residence	Experience of physical violence from spouse	
	Experience of sexual violence	
<u>Social status</u>	<u>Awareness and Attitudes to HIV</u>	
Religion	Ever heard of AIDS	
Caste	Knows of transmission routes of HIV	
Marital status	Misconception on HIV	
<u>Socio-economic Factors</u>	Stigmatising attitudes towards HIV	
Level of education	<u>Mobility</u>	
Income /wealth	Years lived in place of residence	
Occupation	Husband lives in house	

Secondly, variables proven through research to act as an aggregated proxy indicator of risk, e.g. experience of sexual violence, were assigned to the ‘micro-social’ dimension of ‘susceptibility’ (Rehle, Shisana et al. 2007, Pettifor, O'Brien et al. 2009, Pettifor, Hudgens et al. 2007, Pettifor, Rees et al. 2005). This dimension encompassed: a) *gendered discrimination* which incorporated variables measuring inter-relationship dynamics and female respondents’ history of domestic and sexual violence; b) *geographical mobility* that included variables assessing all participants’ previous type of residence, how many years they had been living in their current household and male respondents’ patterns of migration; and c) *attitudes to HIV* which incorporated measurements of participants’ knowledge of routes of transmission and stigmatising assumptions they held towards PLWHA. Measurements of respondents’ awareness of HIV included their understanding of methods to prevent sexual transmission<sup>59</sup>,

<sup>59</sup> Participants in the NFHS-III who had heard of HIV/AIDS were asked if it was possible to prevent transmission of HIV by abstaining from sexual intercourse, being faithful to one partner and condom use. These respondents were also asked to list other ways to avoid HIV.

their knowledge of treatment required for HIV<sup>60</sup> and misconceptions they held regarding the illness<sup>61</sup>. In addition, a set of variables was used to gauge participants' stigmatising attitudes to HIV, such as their willingness to care for relatives afflicted with AIDS.

Finally, 'behavioural determinants' were investigated. The NFHS-III included measures of *sexual behaviour* which recorded respondents' recent and lifetime history of sexual behaviour. These variables documented: the number of sexual partners they had during their lifetime, their recent sexual activity and information on their last few sexual partners 12 months preceding the survey<sup>62</sup>. One of the weaknesses of the NFHS-III data was that it was difficult to comprehensively analyse participants' sexual behaviour as few reported having more than one lifetime partner. Hence, some measurements of sexual behaviours used in the survey were not applied in this thesis, such as the length of time respondents knew their previous second concurrent sexual partner. However, a strength of the NFHS-III dataset was that it captured data on WLHA who may not be perceived as belonging to 'risk groups', such as wives of HIV-positive men.

Statistical tests were conducted in three stages. Firstly, a series of bivariate analyses were conducted on variables within each dimension of 'susceptibility'. These analyses were then further elaborated through examination of the male and married partners' dataset. Analysis of respondents' characteristics and behaviour in the married dataset could indicate the possible sequence of events leading to HIV infection. For instance, if there was a higher prevalence of HIV among respondents within sero-discordant married partnerships with a primary male partner then it is possible that the general trend in the population could be for husbands to contract HIV before their wives. Lastly, a three step logistical regression model was conducted in order to control for confounding factors affecting results from the bivariate

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<sup>60</sup> Participants were asked if they knew that HIV could be vertically transmitted from mother-to-child during and after birth, whether this could be prevented through drugs given to the mother, and whether they had heard of 'special antiretroviral' drugs to prolong HIV-infected patients' lives.

<sup>61</sup> Participants in the NFHS-III were asked if they believed that a healthy-looking person could have HIV and if it could be transmitted through hugging others, mosquito bites and sharing food with PLWHA.

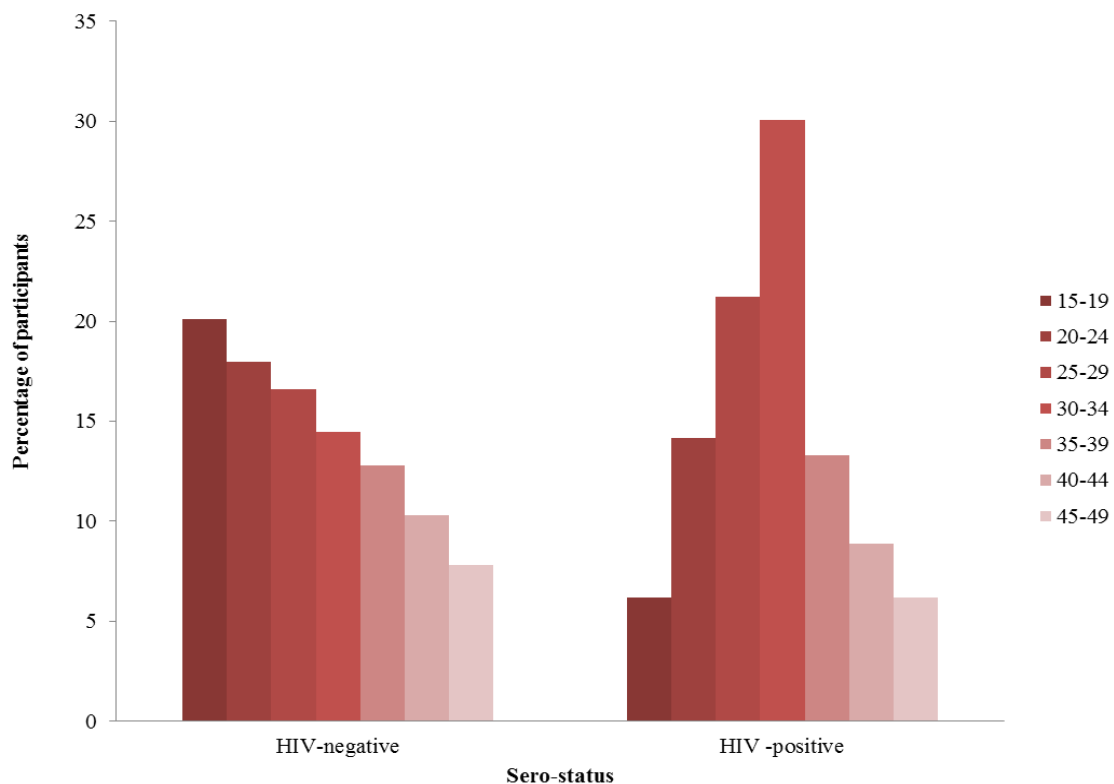
<sup>62</sup> They were asked to identify their relationship with their previous sexual partner, duration of their relationship and use of condoms during this time.

phase of analysis. These models also identified which dimensions acted as the strongest predictors of HIV-status amongst female participants.

## 5.B Macro-environmental predictors of HIV-status

### 5.B.I *Socio-demographic characteristics*

A set of bivariate analyses was conducted to examine the relationship between age and HIV-status. It was found that female HIV-infected respondents in the NFHS-III tended to be on average slightly older ( $M= 30.73$ ,  $SD=7.5$ ) than the general population ( $M= 29.03$ ,  $SD= 9.5$ ),  $t(114)=2.4$ ,  $p<.02$ ,  $r=0.22$ ). This is a product of the age distribution of female HIV-positive participants being roughly bell-shaped, with a sharp peak between the ages of 30-34. In contrast, the age distribution of HIV-negative women was heavily skewed towards the youngest age groups. Figure 5.1 illustrates the distribution of ages by HIV-status for women.



**Figure 5.1:** Distribution of ages by HIV-status of female respondents (weighted)

Additionally, there was a highly significant relationship ( $<.01$ ) between female participants' HIV-status and their area of residence, with higher rates of HIV-prevalence among women living in urban (0.29%) than rural areas (0.18%). Table 5.2 displays female participants' sero-status according to their area of residence.

**Table 5.2:** Female participants' sero-status and HIV prevalence by area of residence (weighted)

Area of residence	Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
Rural	<b>0.18</b>	35470	67	50	43
Urban	<b>0.29</b>	17269	33	65	57
Total	<b>0.22</b>	52739	100	115	100

Further bivariate analysis of area of residence and married couple's sero-status suggested that the distribution of HIV infection could be located in certain geographical areas. Among married couples, a higher percentage of sero-negative respondents with a sero-positive husband (0.4%) or wife (0.1%) lived in urban areas in comparison to relationships in which both partners are HIV-positive (0.08%). In contrast, a larger proportion of sero-concordant HIV-positive couples resided in rural areas (0.12%) than sero-discordant couples.

These findings concurred with that of other studies which indicated that HIV-prevalence was higher in urban than rural areas (Munro, Pradeep et al. 2008, Perkins, Khan et al. 2009). It has been argued that the reason for these findings are that certain types of risk-taking behaviours, e.g. drug injecting use and sexual contact with CSWs, are more common in urban than rural residences (Mahanta, Medhi et al. 2008, Saidel, Adhikary et al. 2008, Kumar, Virk et al. 2008, Gajendra, Jagadish et al. 2011, Gupta, Vaidehi et al. 2010, Verma, Saggurti et al. 2010)<sup>63</sup>.

The clustered nature of HIV-prevalence in India was further investigated by performing a chi-squared test on female participants' HIV-status and state of residence. There was a highly significant ( $<.001$ ) relationship between state and women's HIV prevalence.

<sup>63</sup> Please see Appendix 12 for a table showing married couple's sero-status and their area of residence.

The majority of states in India have an HIV-prevalence amongst women of below 0.3% apart from Maharashtra (0.48%)<sup>64</sup>, Manipur (0.86%), A.P. (0.75%) and Karnataka (0.55%). Moreover, the bulk of female HIV-positive participants were living in southern states (53%).

The primary mode of transmission in southern states is through heterosexual sexual risk activity (Jayanna, Washington et al. 2010, Rocca, Rathod et al. 2009, Solomon, Subbaraman et al. 2009, Thomas, Chandra et al. 2009). This may explain why results were fairly similar for male participants in the NFHS-III with Karnataka (0.8%), Maharashtra (0.8%), A.P. (1.2%) and Manipur (1.9%) also displaying higher rates of HIV-prevalence than the rest of the country<sup>65</sup>.

I examined the pattern by which HIV-infection was distributed among married couples by state<sup>66</sup>. Across all regions, partnerships affected by HIV were most frequently observed among sero-discordant couples in which the male partner was HIV-positive<sup>67</sup>. Some of the states with a high rate among these couples had a history of high sero-prevalence according to NACO (2010). These were: Maharashtra (0.6%), A.P. (0.8%) and Karnataka (0.8%). Moreover, there were other states identified by NACO (2010) as having districts which recently emerged as having an HIV-prevalence of over 1%, meaning they potentially have ‘pockets’ of high prevalence. These states were: Jammu and Kashmir (0.5%), Himachal Pradesh (0.7%), Madhya Pradesh (0.4%), Punjab (0.6%) and West Bengal (0.6%).

The second largest group of HIV affected partnerships were among married couples in which both members were sero-positive. These couples were mostly situated in A.P. (0.4%), Assam (0.4%) and Jammu and Kashmir (0.5%). These states also had a relatively high percentage of sero-discordant couples with a primary male partner. Andhra Pradesh and Assam have been affected by HIV for a longer period of time than most states in India

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<sup>64</sup> Please see Appendix 13 for a table showing female HIV-prevalence by state.

<sup>65</sup> Please see Appendix 14 for a table showing male HIV-prevalence by state.

<sup>66</sup> Appendix 15 displays couple’s sero-status by state.

<sup>67</sup> Please note that there are four types of partnerships according to sero-status within the married couples’ dataset. These types of partnerships are described in chapter 4 on p.93.

(NACO 2008), indicating that there may have been time for the virus to transmit from the male to female partner.

Finally, there was a uniformly low percentage of sero-discordant couples with a female partner who was HIV-positive. Only Himachal Pradesh (0.7%) and Delhi (0.7%) had a high portion of these partnerships. It is difficult to ascertain the reasons for higher percentages of married couples with a primary female partner in these states as so few respondents belonged to this type of partnership.

Results on the *socio-demographic characteristics* of respondents in the NFHS-III suggest that HIV prevalence could be clustered in certain geographical areas and according to the sexual behaviours of a minority of individuals. Findings on the distribution of HIV-positive sero-discordant and sero-concordant couples were particularly interesting, as they indicated that HIV could first enter communities through the sexual behaviours of the married male partner and then spread further as their wife acquires it. There are, however, other ‘macro-environmental’ determinants which could possibly impact women’s susceptibility, and therefore; the following section will explore how *socioeconomic status* may influence female participants’ sero-status.

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### 5.B.II *Socioeconomic factors*

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A set of bivariate analyses illustrated that female HIV-positive participants had lower levels of education in comparison to the general population. The majority of female HIV-infected respondents had either never attended school (49%) or had only a primary level of education (24%). Moreover, female HIV-positive respondents spent on average two years less in education ( $M=3.3$ ,  $SD=5.11$ ) than the rest of the population ( $M= 5.11$ ,  $SD= 5.02$ ),  $t(114)= 4.8$ ,  $p<.001$ ,  $r=0.41$ ). These low levels of education may have contributed to the majority of WLHA being illiterate (66%). Table 5.3 displays female participants’ sero-status according to their level of education.

**Table 5.3:** Female participants' sero-status and HIV-prevalence by level of education (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measures of education	HIV Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
<b><u>Highest Educational Level***</u></b>					
No education	<b>0.27</b>	20957	40	56	49
Primary	<b>0.35</b>	8018	15	28	24
Secondary	<b>0.15</b>	19891	38	29	25
Higher	<b>0.05</b>	3871	7	2	2
Total	<b>0.22</b>	52737	100	115	100
<b><u>Completed Educational Level***</u></b>					
No education	<b>0.27</b>	20957	40	56	49
Incomplete primary	<b>0.48</b>	4333	8	21	19
Complete primary	<b>0.16</b>	3685	7	6	5
Incomplete secondary	<b>0.15</b>	17409	33	26	23
Complete secondary	<b>0.08</b>	2482	5	2	2
Higher	<b>0.05</b>	3871	7	2	2
Total	<b>0.22</b>	52737	100	113	100
<b><u>Literacy***</u></b>					
Literate	<b>0.14</b>	26879	51	39	34
Illiterate	<b>0.29</b>	25605	49	75	66
Total	<b>0.22</b>	52484	100	114	100

Furthermore, the majority of female HIV-positive respondents were employed (59%), whereas many HIV-negative respondents were not working (63%). Employed female respondents had higher levels of HIV-prevalence (0.34%) than those who were unemployed (0.1%). Many employed female HIV-infected respondents were working in low skilled occupations<sup>68</sup> including 'agricultural employment' (23%) and 'services' (20%)<sup>69</sup>, indicating that these participants were hired for domestic work (e.g. as 'housekeepers') and customer service. Table 5.4 displays female participants' sero-status according to their work status and occupation.

<sup>68</sup> Respondents' level of occupation was recorded by grouping them into six categories which resemble Goldthorpe and Hope's (1974) conceptualisation of class in conjunction with the level of 'skill' involved in the occupation.

<sup>69</sup> Findings from the NFHS-III indicated that there was a higher level of HIV-prevalence among women working in services (1.4%) in comparison to other occupations. It is difficult to ascertain the possible causal mechanisms for these findings as there is little or no known research on risk factors affecting women working in service occupations in India.

**Table 5.4:** Female participants' sero-status and HIV-prevalence by work status, occupation and wealth (weighted)  
 (\*\*< .005, \*\*< .01 and \*< .05)

Multiple measures of socioeconomic status	HIV Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
<b>Work status***</b>					
Unemployed	<b>0.1</b>	33174	63	47	41
Employed	<b>0.34</b>	19500	37	67	59
<b>Total</b>	<b>0.2</b>	<b>52674</b>	<b>100</b>	<b>114</b>	<b>100</b>
<b>Occupation***</b>					
Not working	<b>0.2</b>	30059	57	47	41
Prof., Tech., Manag.	<b>0.07</b>	1478	3	11	0.9
Clerical	<b>0.4</b>	456	0.9	2	2
Sales	<b>0.5</b>	785	1.5	4	4
Agricultural employee	<b>0.2</b>	13108	25	26	23
Services	<b>1.4</b>	1631	3	23	20
Skilled & unskilled manual	<b>0.2</b>	5203	10	11	10
Don't know	<b>0</b>	1	100	0	0
<b>Total</b>	<b>0.22</b>	<b>52721</b>	<b>100</b>	<b>114</b>	<b>100</b>

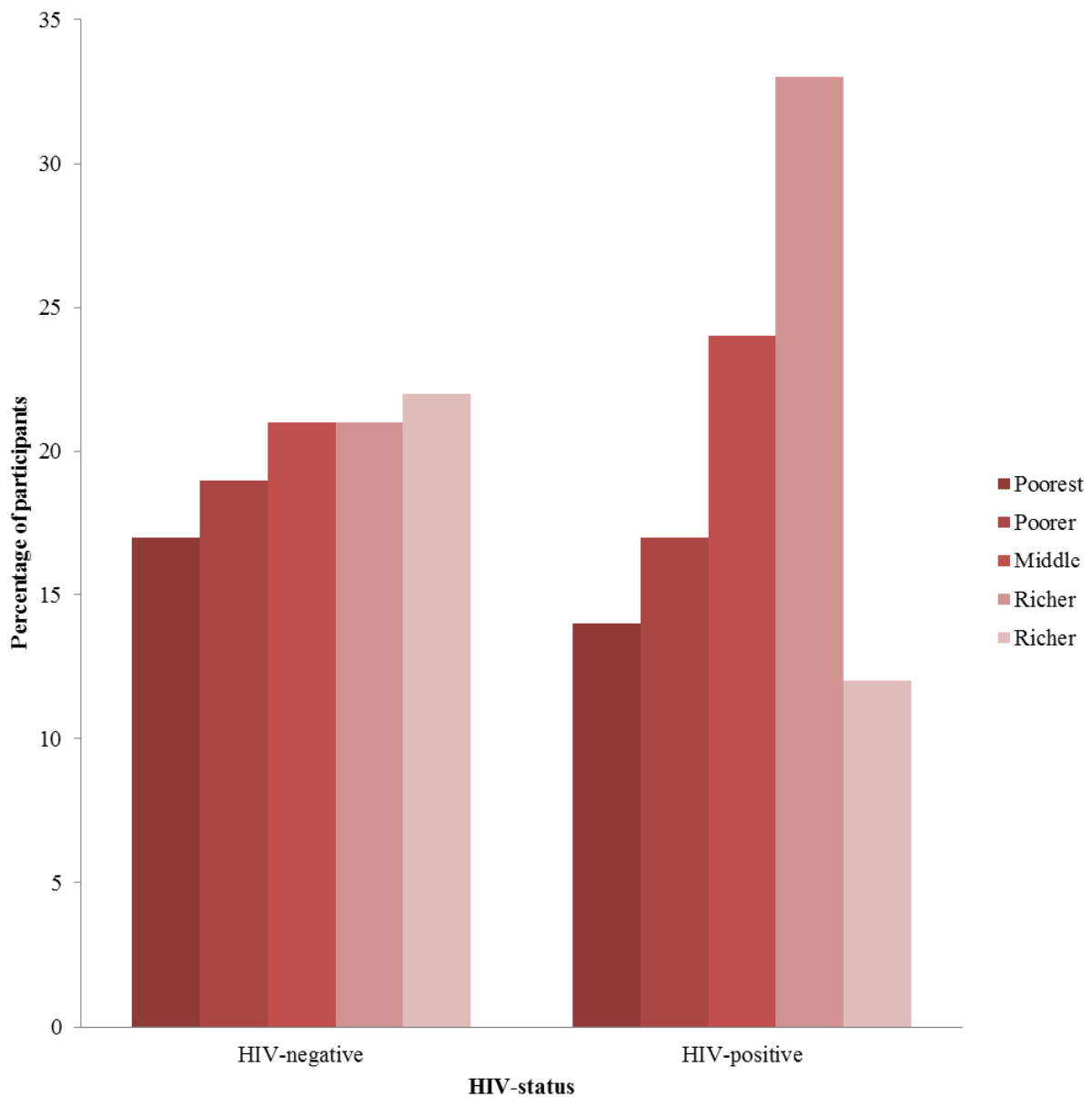
Other measurements of employment suggested that many WLHA could be working in the formal labour market<sup>70</sup>. For instance, almost a quarter of female HIV-negative participants had worked at home<sup>71</sup>. In contrast, over three quarters of female HIV-positive participants worked outside of their home. Furthermore, female HIV-infected participants were significantly (<.001) more likely to be paid in cash only (79%) or in cash and kind (16%) than those in the general population.

Findings on wealth suggested that WLHA in India tended to come from better off backgrounds. The NFHS-III defined participants' level of wealth in terms of their ownership of household items, which were assigned weighted scores based on factor analysis procedures and then divided into quintiles (IIPS, Macro International 2007, IIPS 2008). As the NFHS-III measures wealth in terms of ownership of household items, some employed WLHA could

<sup>70</sup> The NFHS-III employed multiple measures of agricultural work that ascertained female participants' employment status in the formal and informal economy. It recorded what type of land respondents worked on, their type of earnings and whether they were employed all year or seasonally.

<sup>71</sup> Please see Appendix 16 for a table on multiple measurements of agricultural work and female participants' sero-status.

have greater purchasing power after entering the ‘cash economy’. Being part of the formal market could offer these WLHA the economic means and opportunity to interact with wider groups and potentially sustain multiple sexual partnerships. Wealth distribution for sero-positive women was skewed towards the middle and richer wealth quintiles, with over half of these respondents belonging to these categories (56%). In contrast, wealth distribution for female HIV-negative participants was evenly spread. Figure 5.2 shows female participants’ sero-status according to their level of wealth.



**Figure 5.2:** Female participants’ sero-status according to their level of wealth (weighted)

These results could be indicative of wider social structural dynamics related to the trajectory of the HIV epidemic in India<sup>72</sup>. In the early phases of the HIV epidemic in Sub-Saharan Africa sero-prevalence was high among women from better off backgrounds (Ziegler, Newton et al. 1997, Cleland, Ali et al. 1999, Kirunga, Ntozi 1997, Hargreaves, Morison et al. 2002). A survey conducted on pregnant women attending an antenatal clinic between 1989 and 1990 in Malawi demonstrated that having a relatively affluent socioeconomic status was a ‘risk-factor’ (Dallabetta, Miotti et al. 1993). Findings on HIV-status and wealth among women in the NFHS-III will be further investigated through multivariate analysis to test whether ‘wealth’ still influences women’s propensity to contract HIV when confounding factors are taken into account. The following section will examine the impact of respondents’ *social status* on their sero-status, starting with their religion.

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### 5.B.III *Social Status*

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A chi-squared test was performed to examine the relationship between female respondents’ religion and their HIV-status. Hindu respondents had a significantly ( $p < .005$ ) higher rate of HIV-prevalence (0.25%) in comparison to their non-Hindu counterparts (0.1%). On the other hand, caste did not appear to have a significant association with women’s sero-status. The highest rates of HIV-prevalence for women were among those who did not know their caste status (0.77%) or belonged to the category of Other Backward Classes (OBC) (0.24%). It was difficult to ascertain the social status of participants who did not know their caste status, as it could act as an indicator of both social mobility and deprivation. For example, people from Sikh religious backgrounds purposefully do not ascribe a caste status (McLeod 2000). However, some participants might choose not to identify their caste background as they felt stigmatised by it. Table 5.5 displays female participants’ sero-status according to their religion, caste or tribal identity and type of caste.

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<sup>72</sup> It is important to note that wealth distribution in India is wider than many countries, due to the fact that many people living in rural areas do not form part of the formal economy. This means that someone belonging to the middle and richer wealth quintiles would not be considered as well off by standards in developed countries.

**Table 5.5:** Female participants' sero-status and HIV-prevalence by religion, caste or tribe identity, type of caste (weighted) (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measures of social status	HIV Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
<b><u>Religion</u>***</b>					
Hindu	<b>0.25</b>	42338	80	104	91
Non-Hindu	<b>0.1</b>	10337	20	10	9
<b>Total</b>	<b>0.22</b>	<b>52675</b>	<b>100</b>	<b>114</b>	<b>100</b>
<b><u>Caste or tribe identity</u></b>					
Caste	<b>0.23</b>	47153	89	107	94
Tribe	<b>0.11</b>	3634	7	4	4
No caste/tribe	<b>0</b>	1258	2	0	0
Don't know	<b>0.44</b>	682	1	3	3
<b>Total</b>	<b>0.22</b>	<b>52727</b>	<b>100</b>	<b>114</b>	<b>100</b>
<b><u>Type of caste</u></b>					
Scheduled caste	<b>0.23</b>	9869	19	23	21
Scheduled tribe	<b>0.12</b>	4188	8	5	4
OBC	<b>0.24</b>	20804	41	51	46
None of them	<b>0.19</b>	16142	31	31	28
DK	<b>0.77</b>	259	1	2	2
<b>Total</b>	<b>0.22</b>	<b>51262</b>	<b>100</b>	<b>112</b>	<b>100</b>

A large proportion of female HIV-infected participants (46%) belonged to the category of OBC. The categorisation of OBC has been previously used by governmental programmes to allot certain types of social or monetary services, such as the provision of food rations, to impoverished sections of the population (Jaffrelot 2006, Perkins, Khan et al. 2009). These findings suggest that some WLHA could belong to socioeconomically deprived backgrounds (Ministry of Home Affairs, Government of India 2001).

There was, however, a highly significant (<.001) relationship between women's marital status and their sero-status. The majority of HIV-positive respondents were currently married (66%), while a larger proportion of female HIV-positive participants were widowed (23%), divorced (2%) or living separately from their partner (6%) in comparison to the rest of the population. Moreover, there was a high prevalence of HIV within these marital categories. Table 5.6 displays female participants' sero-status according to their marital status.

**Table 5.6:** Female participants' sero-status and HIV-prevalence by marital status (weighted)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Marital status	HIV Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
<b>Marital status***</b>					
Never married	<b>0.04</b>	10743	20	4	4
Married	<b>0.19</b>	39468	75	75	66
Widowed	<b>1.5</b>	1709	3	26	23
Divorced	<b>1.27</b>	156	0.3	2	2
Not living together	<b>1.04</b>	663	1	7	6
<b>Total</b>	<b>0.22</b>	<b>52739</b>	<b>100</b>	<b>114</b>	<b>100</b>

There were similar results on HIV-status and marital-status within the male population<sup>73</sup>. The highest rates of prevalence were among those who were living separately from their partner (2%) or were divorced (1%). However, in contrast to their female HIV-infected counterparts, a larger proportion of HIV-positive men were married (80%) in comparison to that of the rest of the population (65%). These findings could be a product of men contracting HIV earlier than their female counterparts (Das, Mukhopadhyay et al. 2006, Das, Mukhopadhyay et al. 2009).

These findings were further supported by results on married female participants' reported duration of their partnership and their HIV-status<sup>74</sup>. There was a significantly (<.001) higher rate of sero-prevalence among women who had been married for 10-14 (0.4%) and 15-19 years (0.4%) in comparison to those who had a marital duration of 0-4 (0.2%) and 5-9 years (0.2%). These findings suggest that there is a possibility that some women married to sero-positive men may have acquired HIV through repeated sexual contact with their husband (LeGoff, Weiss et al. 2007, Schensul, Mekki-Berrada et al. 2006, Granich, Crowley et al. 2010).

<sup>73</sup> Please see Appendix 17 for a table displaying men's marital status according to their HIV-status.

<sup>74</sup> Please see Appendix 18 for a table displaying the duration of female respondents' marriage and their sero-status.

The possible direction of causation of female participants HIV-status was further investigated through analysis of the couples' dataset. Nearly 1% of the married NFHS-III sample contained couples in which either one or both partners were sero-positive. Table 5.7 shows the sero-status of each partner in the married sample.

**Table 5.7:** Couples' sero-status (weighted, n= 26230)

Sero-status of adults in marriages	Count	%
Concordant negative	26030	99.2
Concordant positive	54	0.2
Discordant: male positive	121	0.46
Discordant: female positive	25	0.1

Sero-status among married couples significantly ( $<.001$ ) varied between HIV-positive sero-concordant and sero-discordant couples. The smallest proportion of married couples affected by HIV were those in which the female partner alone was HIV-positive (0.1%), followed by HIV-infected sero-concordant couples (0.2%). HIV-positive sero-concordant couples also had the highest proportion of female HIV-infected respondents (61%). The largest percentage of married couples affected by HIV were among sero-discordant couples with a primary male partner (0.5%). As the majority of married HIV-infected men (75%) belonged to these partnerships, there is a strong possibility that HIV infection among the married female population could be driven by their spouse's risk-taking behaviours<sup>75</sup>.

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#### 5.B.IV *Multivariate analysis of 'macro-environmental' predictors of HIV-status*

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Bivariate analyses of female respondents' *socio-demographic characteristics*, *socioeconomic factors* and *social status* provided a complex profile of the 'macro-environmental' predictors affecting WLHA in India. According to findings within the *socio-demographic characteristics* component of 'macro-environmental' predictors, female HIV-positive respondents were older and lived in states with a history of high sero-prevalence

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<sup>75</sup> Pradhan, Sundar et al's (2006) household survey displayed very similar results, in which 6% of the HIV-infected sample lived in a household wherein only the wife was sero-positive.

(NACO 2010). These states were located in north eastern and southern regions of India. These rates of sero-prevalence by state were also reflected within couples, indicating there was a probability that certain types of risk behaviours could be located within a small geographical area which would result in pockets or hubs of HIV-prevalence.

The objective of the multivariate analysis was to identify significant ‘macro-environmental’ predictors of HIV-status within the female sample, controlling for the effect of confounding factors. The first forced model (Step 1) included *socio-demographic factors* (age, area of residence and state) with the dependent variable being the HIV-status of female respondents. As there were over 30 states, they were divided by the level of HIV prevalence according to estimates generated by NACO (2010). These analyses were conducted in order to test the earlier hypothesis generated from bivariate findings that living in environments with high rates of prevalence may increase the odds of female respondents being HIV-positive.

This hypothesis seemed to be substantiated as the only variable which had a significant ( $<.001$ ) impact on female respondents’ HIV-status was the level of sero-prevalence in their state. In comparison to those living in a region with low HIV prevalence, women residing in high prevalence states displayed increased odds of being sero-positive (OR=4.28, CI=2.75-6.67).

The second forced model (Step 2) included variables which had been previously used in bivariate analysis to measure *socio-economic factors*. These included: level of education, wealth, employment status and occupation. Age and wealth did not have a significant association with HIV-status. On the other hand, female participants’ level of education and employment status had a highly significant ( $p<.001$ ) relationship with their sero-status. Employed women displayed higher odds of being sero-positive than their unemployed counterparts (OR=2.68, CI=1.44-4.99). Additionally, female participants who were

uneducated or who only had a primary level of education were 2.99 times<sup>76</sup> as likely to be sero-positive in comparison to those who were better educated (OR=3.01, CI=1.85-4.91). Table 5.8 presents the intercept, with Step 1 including variables measuring *socio-demographic characteristics*; Step 2 comprising variables evaluating *socioeconomic status*, and Step 3 incorporating measurements of *social status*.

**Table 5.8:** ‘Macro-Environmental’ predictors of HIV-status among female participants in the NFHS-III (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

	Step 1	Step 2	Step 3
<b>Intercept</b>	***.00	***.00	***.00
<b>Socio-demographic characteristics</b>			
<b>Age</b>	1.02 (0.99-1.04)	0.997 (0.98-1.02)	*0.98 (0.95-1.00)
<b>Area of residence (Rural)</b>			
Urban	1.403 (0.97-2.03)	**1.75 (1.13-2.70)	*1.63 (1.06-2.23)
<b>States (Low prevalence)</b>			
High prevalence	***4.28 (2.75-6.67)	***4.14 (2.66-6.45)	***4.01 (2.57-6.25)
<b>Socio-economic factors</b>			
<b>Level of education (Secondary/higher)</b>			
No education/Primary		***3.01 (1.85-4.91)	***2.94 (1.80-3.78)
<b>Wealth (Poor/poorer)</b>			
Middle/richer		1.46 (0.92-2.32)	*1.63 (1.02-4.72)
<b>Employment (Unemployed)</b>			
Employed		***2.68 (1.44-4.99)	*2.05 (1.11-3.78)
<b>Occupation (Skilled)</b>			
Unskilled		0.77 (0.39-1.47)	0.76 (0.41-1.43)
<b>Social Status</b>			
<b>Religion (Non-Hindu)</b>			
Hindu			**2.47 (1.29-4.72)
<b>Marital status (Never married/currently married)</b>			
Formerly married			***7.78 (4.99-12.14)
Nagelkerke R2	0.037	0.062	0.11

The final model (Step 3) included variables assigned to *social status*. Female participants’ religion and marital status had a significant (<.01) association with HIV-status. Female participants’ marital status had the strongest association with HIV-status. Formerly

<sup>76</sup> The ‘relative risk’ of an event occurring was calculated using a formula suggested by Osborne (2006), which was  $OR / [(1-P0) + (P0 \times OR)]$ . According to Osborne (2006) in this formula, ‘RR=relative risk, OR= calculated odds ratio, and P0 = the proportion of non-exposed individuals that experience the outcome in question’ (p.3).

married participants, meaning that they were divorced, widowed or separated, were 7.1 times as likely to be sero-positive than those who were either never or currently married (OR=7.78, CI=4.99-12.14). These findings suggested that Indian women's marital status could increase their odds of being sero-positive.

Ramesh, Moses et al. (2008) illustrated that women in these marital categories were more likely in some areas of India to partake in casual sex work, perhaps through lack of available employment. Nevertheless, it was difficult to ascertain the direction of causation as it is just as possible that these respondents' or their partners' HIV-status may have caused difficulties in their marriage, or led to them being widowed (Das, Mukhopadhyay et al. 2009).

In addition, level of education, employment status and rate of sero-prevalence within states retained significance ( $<.05$ ) when controlled for variables measuring *social status*. In accordance with the previous multivariate models, female respondents who were uneducated, employed and lived in states with a higher rate of sero-prevalence displayed higher odds of being HIV-positive in comparison to their counterparts. These findings suggested that their low levels of education could have acted as a contributing risk factor as these respondents may have little or no awareness of HIV<sup>77</sup> (Rahbar, Garg et al. 2007, Shrotri, Shankar et al. 2003, Kalasagar, Sivapathasundharam et al. 2006), which could negatively affect their sexual risk behaviour (Firth, Jeyaseelan et al. 2010, Godbole, Mehendale 2005).

Strikingly, some variables measuring *socio-demographic characteristics* and *socio-economic factors* seemed to gain significance ( $<.05$ ) after variables evaluating *social status* were incorporated into the final model (Step 3). These variables were wealth, area of residence and age. Results related to area of residence indicated that female respondents living in urban areas displayed higher odds (OR=1.63, CI=1.02-4.72) of being HIV-positive than those residing in rural areas. These findings seemed to further substantiate multivariate

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<sup>77</sup> Statistical analysis performed on the NHFS-II indicated that awareness of HIV/AIDS was low for illiterate women (IIPS, ORC Macro 2000).

results on states, which illustrated that women living in states with higher levels of sero-prevalence were almost 4 times as likely to be HIV-positive (OR=4.01, CI=2.57-6.25). This may be because recent research has demonstrated that hubs of high sero-prevalence were often located in urban areas where populations displaying sexual risk behaviours (e.g. CSWs) may reside (UNAIDS, WHO 2009, UNAIDS, WHO 2007a, Pandey, Reddy et al. 2009).

Nonetheless, findings on wealth and age seemed to contrast with other results on female participants' *socio-demographic characteristics* and *socioeconomic factors*, which suggested that HIV-positive respondents could belong to economically deprived communities as they were less educated than those in the general population. Female respondents who belonged to the middle/richer wealth categories displayed higher odds of being HIV-positive (OR=1.63, CI=1.02-4.72) than those who were poor/poorer. Moreover, older respondents displayed marginally increased odds (OR=0.98, CI=0.95-1.00) of being sero-positive. As these odds were close to one, it is possible that age has little or no impact on participants' sero-status. Age is, therefore, excluded from the final model in this chapter, despite having a significant (<.05) association with HIV-status.

On the other hand, most of these variables operate on such a distal level that there is a possibility that they also act as indicators for other proximal determinants. For instance, the fact that Hindu respondents display a higher odds ratio of being sero-positive (OR=2.47, CI=1.29-4.72) in comparison to their non-Hindu counterparts could be indicative of 'behavioural' predictors. As a large proportion of the religious minority in India is Muslim (Srinivas 1952, Bojko, Schensul et al. 2010), there is a possibility that many non-Hindu men are circumcised, which has been illustrated by epidemiological research to be a protective factor against the transmission of HIV (Bailey, Moses et al. 2007, Gray, Kigozi et al. 2007). The following section will therefore examine the impact of 'micro-social' predictors on respondents' sero-status, starting with their experience of *gendered discrimination*.

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## 5.B Micro-social predictors of HIV-status

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### 5.B.I *Gendered Discrimination*

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Recent research has demonstrated that women who experienced Interpersonal Violence (IPV) in developing countries displayed an elevated risk of contracting HIV (Kambou, Magar et al. 2007, Buseh, Glass et al. 2002, Panchanadeswaran, Johnson et al. 2008). In Tanzania, Maman, Mbwambo et al. (2002) found that young HIV-positive women had a 10-fold increased odds of reporting physical violence compared to their HIV-negative counterparts. The NFHS-III created a set of variables to measure comprehensively inter-relationship dynamics, participants' attitudes to IPV<sup>78</sup> and female respondents' history of domestic and sexual violence comprehensively. Inter-relationship dynamics were examined through variables that assessed female participants' experience of 'controlling behaviour'<sup>79</sup> and 'emotional violence'.

Female HIV-positive respondents were significantly (<.05) more likely to experience different types of 'controlling behaviour' on the part of their spouses in comparison to those in the general population. This behaviour included: a) being accused of unfaithfulness (22%)<sup>80</sup>; b) their husband limiting contact with their family (18%); and c) their spouse insisting on knowing where they were (20%). These results indicated that the forms of 'controlling behaviour' that HIV-positive women may encounter interacted with control of their sexual behaviour and movement in the public sphere.

In order to establish a possible explanation for why HIV-positive women might be experiencing these controlling behaviours, these variables were tested against married

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<sup>78</sup> These attitudes were gauged by asking participants whether it was justified for a husband to beat his wife if she left the house without telling him, neglected her children, argues with him, refuses to have sex with him or burnt their food.

<sup>79</sup> These variables gauged whether married participants experienced the following types of behaviour from their spouse: jealousy if they spoke to other men, accusations of infidelity, being prohibited from speaking to relatives or friends and lack of trust in relation to money.

<sup>80</sup> Please see Appendix 19 for a table displaying multiple measures of controlling behaviours involving female participants and their sero-status.

couples' sero-status<sup>81</sup>. These tests were conducted in order to ascertain whether HIV-related stigma or inequality in the relationship could be the source of the behaviour. Married women in HIV-positive sero-discordant relationships with a primary male partner were more likely to experience controlling behaviour than those in other couples. For example, 19% of these respondents' spouses had accused them of being unfaithful; whereas, only 11% of participants in an HIV-positive sero-concordant relationship had experienced this behaviour.

The second component of inter-relationship dynamics, 'emotional violence', recorded married female participants experience of being humiliated, threatened with harm and insulted by their husband. Female HIV-positive respondents in the NFHS-III were significantly ( $<.05$ ) more likely to have ever experienced 'emotional violence' (24%) than the general population (16%). This could be a product of a significantly ( $<.05$ ) higher proportion of female HIV-infected participants reporting that they were humiliated (21%) and insulted (18%) in comparison to their HIV-negative counterparts. Table 5.9 displays multiple measures of female participants' experience of emotional violence on the part of their husband and their sero-status.

**Table 5.9:** Female participants' experience of emotional violence according to their sero-status (weighted) (\*\* $<.005$ , \*\* $<.01$  and \* $<.05$ )

Multiple measures on emotional violence	Female participants' sero-status		Total number
	HIV-negative	HIV-positive	
	%	%	
<b><u>Ever experienced any emotional violence*</u></b>			
Yes	16	24	
No	84	76	
<b>Total</b>	<b>100</b>	<b>100</b>	<b>30900</b>
<b><u>Types of emotional violence</u></b>			
Spouse ever humiliated her*	13	21	30901
Spouse ever threatened her with harm	5	12	30901
Spouse ever insult or make feel bad**	9	18	30900

<sup>81</sup> Please see Appendix 20 for a table displaying multiple measures of experience of controlling behaviour involving married female participants' and their HIV-status within their partnership.

In addition, respondents' attitudes to IPV were used to gauge WLHA's acceptance of gendered norms as experts on IPV have posited that it is culturally sanctioned in the Indian context (Mahajan 1990a). The majority of female participants rejected most of the justifications for wife beating. Nevertheless, in comparison to their HIV-negative counterparts, WLHA were significantly ( $<.05$ ) more likely to agree that it was justified for a wife to be beaten if she neglected her children (51%)<sup>82</sup>, burned food (31%), was disrespectful towards her in-laws (54%) or had extra-marital sexual relationships (36%).

Married couple's attitudes to domestic violence were also examined. Men<sup>83</sup> and women<sup>84</sup> belonging to HIV-positive sero-concordant partnerships seemed to hold more traditional views on domestic violence in comparison to their counterparts. Married female and male respondents within this type of partnership were significantly ( $<.05$ ) more likely to agree that it was justified for a husband to beat his wife if she went outside without telling him, neglected her children, was disrespectful towards her in-laws or had extra-marital sexual relationships<sup>85</sup>.

These findings might be suggestive of social structural dynamics which leave some women at greater risk of contracting HIV. Female sero-positive respondents in the NFHS-III were also significantly ( $<.001$ ) more likely to have experienced severe violence (26%) than the general population (13%)<sup>86</sup>. These findings could be a product of HIV-positive participants being significantly ( $<.001$ ) more likely to have experienced many different forms of physical violence on the part of their spouse, including being: pushed (23%), kicked (25%), strangled (8%), punched (26%), threatened with a weapon (9%) or having their arm

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<sup>82</sup> Please see Appendix 21 for multiple measures of attitudes to domestic violence and female respondents' sero-status.

<sup>83</sup> Please see Appendix 22 for a table displaying multiple measures of attitudes to domestic violence of married male participants' and their HIV-status within their partnership.

<sup>84</sup> Please see Appendix 23 for a table displaying multiple measures of attitudes to domestic violence of married female participants' and their HIV-status within their partnership.

<sup>85</sup> It is possible that a few sero-positive men and women may endorse traditional gendered norms similar to those displayed in Hindu religious texts which authorised husbands to retain absolute control of their wives' bodies and mind through the use of 'physical corrective methods' (Mahajan 1990b: 120).

<sup>86</sup> Please see Appendix 24 for a table on severity of violence experienced from spouse according to sero-status of female respondents.

twisted (30%)<sup>87</sup>. Table 5.10 illustrates types of violence that married female participants experienced and their HIV-status within their partnership.

**Table 5.10:** Types of violence that married female participants experienced and their HIV-status within their partnership (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Types of violence incurred by husband	Female participants' sero-status		Total number
	HIV-negative	HIV-positive	
	%	%	
Pushed, shook or threw something**	14	23	30891
Slapped	35	43	30893
Punched with fist or something harmful***	12	26	30889
Ever kicked or dragged***	12	25	30890
Strangled or burned***	2	8	30889
Twisted her arm or pulled her hair***	16	30	30885
Threatened or attacked with knife/gun or other weapon***	1	9	30802

It is possible that physical abuse could act as a risk factor in HIV infection, as women in violent relationships could have little power to negotiate safe sex practices (Solomon, Subbaraman et al. 2009, Gupta, Wyatt et al. 2008, Stephenson 2007). For instance, Schensul, Mekki-Berrada et al's (2006) study of married couples in Mumbai found that men's extramarital sex was significantly associated with their wives' experience of domestic violence. Nevertheless, these studies failed to differentiate between behaviours which may have led to HIV infection and those that were a product of HIV-related stigma.

I also explored the possibility that certain social structural dynamics related to *gendered discrimination* could negatively affect women's ability to prevent transmission of HIV by testing when domestic abuse started against female participants' sero-status. HIV-positive respondents seemed to experience physical abuse significantly (<.01) earlier in the marriage than those in the general population<sup>88</sup>. Many of these participants first encountered IPV during the first year of marriage (26%). In contrast, physical abuse started for most HIV-

<sup>87</sup> Results from the NFHS-III illustrated that female HIV-positive respondents were significantly (<.001) more likely to have suffered injuries from domestic violence (26%) than the general population (15%). The most common injuries for these participants were bruises (48%), followed by broken bones (19%) and sprains (17%). Please see Appendix 25 for a table displaying multiple measurements of injuries incurred by IPV and female participants' sero-status.

<sup>88</sup> Please see Appendix 26 for a table displaying when IPV started and female respondents' sero-status.

negative respondents in 1-4 years of marriage (64%). These results suggested that there is a possibility that some female sero-positive participants may have experienced IPV prior to contracting HIV.

Indicators of IPV were then tested against couples' sero-status<sup>89</sup>. Findings on couples' propensity towards IPV suggested that sero-status could have an impact on their behaviour. It was difficult to garner definitive results on this issue, though, as there was a relatively small sample of married couples with a sero-positive member, and this was divided between four types of couples. Nevertheless, female participants in HIV-positive sero-concordant couples did not seem to be any more likely to have experienced severe violence (14%) than those in the general population (11%). Conversely, women in sero-discordant relationships with a primary male partner were the most likely of all the couples to have experienced less severe (51%) and severe violence (21%).

Finally, individual HIV-positive female participants were significantly ( $<.001$ ) more likely to have experienced sexual violence at some point in their lifetime than the general population<sup>90</sup>. Almost a quarter of HIV-positive women had been sexually abused in comparison to ten percent of their HIV-negative counterparts<sup>91</sup>. Moreover, female HIV-positive respondents were significantly ( $<.001$ ) more likely than the general population to have been physically forced to have sex by their spouse. These respondents were two times more likely to have been raped by their partner during the last 12 months (21%) in comparison to HIV-negative women (10%).

The previous findings indicate that many WLHA may have been unable to avoid sexual transmission of HIV as their husband was physically and sexually abusive (Solomon, Batavia et al. 2009, Stephenson 2007). Bergen and Bukovec (2006) illustrated that women

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<sup>89</sup> Please see Appendix 27 for a table on severity of violence experienced from spouse according to married female participants' sero-status.

<sup>90</sup> The NFHS-III created a set of measures which recorded female participants' experiences of sexual abuse. They were asked if anyone had ever forced them to perform sexual acts, whether their spouse has ever forced them to have sex and the age at which they were first sexually abused and who did this to them. Only the first two variables were analysed as there were too few participants to answer the latter two questions.

<sup>91</sup> Please see Appendix 28 for a table presenting female participant's history of sexual violence according to their sero-status.

experiencing domestic violence are often sexually abused by their partners, who consider sex to be their spouses 'wifely duty'. I tested indicators of 'sexual violence' against couples' sero-status in the NFHS-III in order to establish the impact that abusive dynamics between married partners might have on women's sero-status in India. Results illustrated that women belonging to HIV-positive sero-concordant (19%) and sero-discordant couples with a primary male partner (19%) were significantly ( $<.001$ ) more likely to have been raped by their spouse than the general population (9%)<sup>92</sup>.

Findings for *gendered discrimination* provided a multidimensional picture of WLHA, showing that these women were more likely to have experienced IPV and sexual violence in the past than their sero-negative counterparts. These gendered risk factors might have been exacerbated by their traditional beliefs on IPV, indicating that they were more likely to condone the use of domestic violence to control women's behaviour. These results were further examined through analysis of the couples' dataset, in order to ascertain whether these women were in relationships with men who held patriarchal notions of their role as a husband. In many cases, sero-negative women married to HIV-infected men were more likely to report that they had experienced IPV and sexual abuse from their spouse than their peers who were in relationships with HIV-negative men. Although it is not possible to ascertain the exact time sequence of these events, these results indicated that many WLHA may have experienced physical and sexual violence prior to being infected or before they were aware that they were HIV-positive.

However, it is important to note that domestic violence is fairly common in India, 45% of all female participants in the NFHS-III having experienced some form of physical abuse from their spouse prior to the survey. As sero-prevalence is fairly low, these findings suggest that domestic violence does not by itself directly lead to HIV but acts in concert with other social structural determinants. The following section will examine the impact of female respondents' *attitudes towards HIV* on their sero-status.

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<sup>92</sup> Please see Appendix 29 for a table on history of sexual violence according to couples' sero-status.

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### 5.B.II *Attitudes to HIV*

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This section explores the impact that female participants' knowledge and attitudes to HIV may have on their sero-status. One of the advantages of the NFHS-III was that respondents were tested for HIV as part of the survey. This meant that it was possible to examine the behaviour and attitudes of female HIV-infected participants who may not as yet be aware of their sero-status. The association between female participants' awareness of HIV and their sero-status was first examined. A significantly ( $<.001$ ) higher proportion of female HIV-positive respondents (79%) were aware of the existence of HIV than those in the general population (62%)<sup>93</sup>.

Female participants who were aware of the existence of HIV displayed an inconsistent level of knowledge on routes of transmission. On one hand, the majority of both HIV-positive and negative female participants knew that limiting sexual partners (73%), abstaining from sexual intercourse (66%) and condom use (60%) were possible means of avoiding HIV infection<sup>94</sup>. On the other hand, very few female participants could recall any forms of transmission related to contact with HIV-infected blood. This is a crucial gap in knowledge as HIV is transmitted through direct contact with blood and other bodily fluids (Shah 2006, Avert 2009). Hence, many female participants were unsure of other means of preventing transmission of HIV, with a large proportion of respondents believing that it was possible to avoid HIV by not kissing others (67%) and using blood only from relatives (64%)<sup>95</sup>.

This may explain why many female participants held misconceptions on routes of HIV transmission. The two most commonly held misconceptions among female participants were that a healthy-looking person cannot be HIV-positive (22%) and that it is possible to acquire HIV by sharing food (18%). Moreover, a significantly ( $<.005$ ) higher proportion of

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<sup>93</sup> Please see Appendix 30 for a table presenting female participants awareness of the existence of HIV and their sero-status.

<sup>94</sup> Please see Appendix 31 for a table displaying female participants' sero-status and their knowledge of the Abstaining from sexual intercourse, Being faithful to one partner and Condom use (ABC) method of HIV prevention.

<sup>95</sup> Please see Appendix 32 for a table listing answers by female participants on ways to avoid HIV and their sero-status.

female HIV-positive respondents were not sure whether mosquito bites transmitted HIV (32%) in comparison to the general population (18%). Table 5.11 displays female participants' sero-status and their commonly held misconceptions about HIV.

**Table 5.11:** Female participants' commonly held misconceptions about HIV according to their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Commonly held misconceptions about HIV	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<u>A person who appears healthy can be HIV-positive</u>				
Yes	20049	61	53	59
No	7290	22	17	19
Don't know	5272	16	20	22
Total	32611	100	90	100
<u>Can acquire HIV by sharing food with person who has AIDS</u>				
Yes	5935	18	18	20
No	22380	69	57	63
Don't know	4295	13	16	18
Total	32610	100	91	100
<u>Can acquire HIV by hugging who has AIDS</u>				
Yes	4917	15	13	14
No	23084	71	60	66
Don't know	4601	14	18	20
Total	32602	100	91	100
<u>Can acquire HIV through mosquito bites***</u>				
Yes	6465	20	17	19
No	20229	62	42	46
Don't know	5915	18	32	35
Total	32609	100	91	100

Additionally, a low proportion of participants knew of treatment available for HIV. Three quarters of female respondents in the general population knew that HIV could be transmitted from mother-to-child during pregnancy but less than half knew that there were drugs available to prevent such an occurrence. HIV-infected women displayed very similar levels of knowledge on these subjects, with the majority not knowing of ART (85%). This low level of knowledge could impede WLHA's access to healthcare services as they may be more likely to seek services from 'quacks' promising a cure for AIDS (Nag 1996, Moshabela,

Pronyk et al. 2010). Table 5.12 displays female participants' knowledge of ART and mother-to-child transmission according to their sero-status.

**Table 5.12:** Female participants' knowledge of ART and mother-to-child transmission according to their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Knowledge of ART and mother to child transmission	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<u>AIDS transmit. during pregnancy</u>				
Yes	24946	76	72	79
No/Don't Know	7670	24	19	21
Total	32616	100	91	100
<u>Drugs to avoid AIDS transmission to baby during pregnancy</u>				
Yes	9959	40	34	47
No/Don't Know	14970	60	38	53
Total	24929	100	72	100
<u>Heard of drugs to help infected people to live longer</u>				
Yes	4682	14	14	15
No	27928	86	77	85
Total	32610	100	91	100

Finally, many female HIV-infected respondents seemed to hold stigmatising views towards PLWHA. Female HIV-positive participants in the NFHS-III were significantly (<.05) more likely to report that if they had a sero-positive relative then they would conceal their sero-status from others in their community (44%) than those in the general population (32%). Moreover, over half of female HIV-infected participants stated that they would not buy vegetables from a sero-positive trader (52%). It could be argued that these measures of stigma are unreliable as someone could be willing to care for an HIV-infected relative but also keen to conceal their sero-status to others in the community in order to protect their interests. A few respondents in the qualitative phase of research mentioned that they had been evicted after their landlord learnt of their sero-status.

On the other hand, female sero-negative participants in the NFHS-III seemed to be slightly more likely to express positive attitudes to PLWHA. The majority of female HIV-negative respondents were willing to care for HIV-infected family members (75%), buy vegetables from an HIV-positive vendor (60%) and have their children taught by a sero-positive teacher (74%). Table 5.13 demonstrates female participants stigmatising attitudes to HIV according to their sero-status.

**Table 5.13:** Female participants' stigmatising attitudes towards HIV according to their sero-status (weighted) (\*\*<math> < .005</math>, \*\*<math> < .01</math> and \*<math> < .05</math>)

Multiple measurements of HIV-related stigma	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<u>Allowed to keep AIDS infection secret*</u>				
Yes	10407	32	40	44
No	20994	64	45	50
Don't know	1205	4	5	6
Total	32606	100	90	100
<u>Willing to care for relative with AIDS</u>				
Yes	24482	75	61	67
No	6392	20	22	24
Don't know	1731	5	8	9
Total	32605	100	91	100
<u>Female teacher with AIDS allowed to continue teaching</u>				
Yes	24079	74	69	77
No	6744	21	17	19
Don't know	1781	5	4	4
Total	32604	100	90	100
<u>Would buy vegetables from vendor with AIDS*</u>				
Yes	19631	60	47	52
No	11589	36	42	46
Don't know	1391	4	2	2
Total	32611	100	91	100

Findings on female participants' *attitudes to HIV* illustrated that although the majority of female HIV-infected participants in the NFHS-III were aware of the existence of HIV (19%), their knowledge of routes of transmission were limited to factors related to sexual risk behaviour (e.g. condom use). This could be the product of governmental and NGO

programmes which promote these methods of HIV prevention within the local population (Chhabra, Anand 2010, Dean, Fenton 2010, Dandona, Kumar et al. 2009).

Limited knowledge of HIV may have led to some female sero-positive respondents who may not yet be aware of their own sero-status holding stigmatising assumptions towards other PLWHA. These findings align with those from the qualitative phase of research, where participants reported that stigmatising attitudes to HIV deepened among community members as it spread to others they knew. The following section will examine the impact of respondents' *geographical mobility* on their sero-status.

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### 5.B.III *Geographical Mobility*

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Previous studies of the transmission of HIV in India have illustrated that mobile labour could be a contributing factor to men's sexual risk behaviour (Gupta, Vaidehi et al. 2010, Verma, Saggurti et al. 2010 and Saggurti, Schensul et al. 2009). This is because they are more likely to have sexual contact with CSWs when working away from home. Therefore, analysis was conducted on variables which measured participants' migratory behaviour to ascertain whether this had an impact on their HIV-status.

I examined whether HIV-infected respondents were any more likely to have moved household in their lifetime than the general population. HIV-positive women were not any more likely to have moved household (62%) in comparison to their HIV-negative counterparts (67%). In contrast, male HIV-positive participants (38%) were significantly (<.001) more likely to have changed residence in their lifetime than the rest of the sample (25%). These preliminary results indicate that HIV-positive men could be more mobile than the general population and HIV-infected women. Table 5.14 illustrates female and male participants' history of mobility and their sero-status.

**Table 5.14:** Percent distribution of male and female participants aged 15-49 in the NFHS-III according to their history of mobility and their sero-status (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Ever moved residence	Women			Men		
	HIV-neg (%)	HIV-pos (%)	Count	HIV-neg (%)	HIV-pos (%)	Count
Always lived in the same residence	33	38	17688	75***	62****	36904
Moved	67	62	35125	25***	38***	12198
<b>Total</b>	<b>100</b>	<b>100</b>	<b>52813</b>	<b>100</b>	<b>100</b>	<b>49102</b>

I further examined the migratory patterns of married couples. Women belonging to HIV-positive sero-concordant (34%) partnerships were significantly (<.05) more likely to have always lived in their home than the general population (14%)<sup>96</sup>. In comparison, their male partners seemed to be more mobile, with men belonging to HIV-positive sero-concordant couples were less likely to have always stayed where they lived (63%) than those in a couple where both partners were HIV-negative (74%)<sup>97</sup>. These findings illustrate that HIV-positive women could have partners who are more mobile than themselves, and that this predisposed them to HIV infection as their spouse may have been engaging in sexual risk behaviours when working away from home.

Researchers have argued that it is not economic migration in itself that encourages sexual risk behaviour but a host of other factors associated with it, e.g. having a wife living separately (Gupta, Vaidehi et al. 2010, Verma, Saggurti et al. 2010, Greenfield, Nayak et al. 2010, Saggurti, Verma et al. 2008, Nayak, Korcha et al. 2010). Gupta, Vaidehi et al's (2010) study of spatial mobility and sexual health among male participants in the NFHS-III found that men who stayed away from their home for more than a month prior to the survey were more likely to have had many sexual partners during their lifetime than non-migrant men. Bivariate analysis of labour related migration among male participants in the NFHS-III revealed that their current migratory behaviours may not have a predictive impact on their

<sup>96</sup> Please see Appendix 33 for a table on multiple measures of mobility of married female participants and their sero-status within their partnership.

<sup>97</sup> Please see Appendix 34 for a table on multiple measures of mobility of married male participants and their sero-status within their partnership.

sero-status. HIV-infected male respondents were significantly ( $p < .05$ ) more likely to have not spent any time away from their home over the 12 months prior to the survey (40%) than those in the general population (31%). Moreover, HIV-positive male participants were no more likely to have stayed away from their home 10 times or more during the period of a year (19%) in comparison to their HIV-negative counterparts (18%). Table 5.15 illustrates how many times male participants have stayed away from home for their work according to their sero-status.

**Table 5.15:** How many times male participants stay away from home for their work according to their sero-status (weighted)

Times away from home	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
0-4	32678	66	122	69
5-9	8301	17	22	12
10 or more	8796	17	33	19
Total	49775	100	177	100

These findings were similar to that of Gupta, Vaidehi et al's (2010) study in which migration did not seem to have a significant relationship with HIV prevalence among men, although mobile labour did seem to play an important role in male participants sexual risk behaviour. This study found that other behavioural predictors, such as alcohol use and lifetime sexual behaviour, displayed a significant association with male participants' sero-status.

It is difficult to ascertain why *geographical mobility* of men does not act as a strong predictor of their HIV-status. There is a possibility that some HIV-infected men experience debilitating symptoms which already curtails their ability to engage in mobile labour<sup>98</sup>. On the other hand, results from the qualitative phase of research indicate that HIV may have

<sup>98</sup> This underlines the inherent problem of proving causality in data from a cross-sectional survey. As data is collected from participants at a single point in time, it is sometimes difficult to demonstrate that the independent variable directly impacted the dependent variable.

entered a few small communities through mobile labour and then spread to other members through sexual risk behaviour. This suggests the role of economic migration in transmission of HIV should perhaps be reassessed. Hence, the following section will use multivariate analysis to examine the impact that *geographical mobility* has when tested with other macro-environmental determinants.

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#### 5.B.IV *Multivariate analysis of 'micro-social' predictors of HIV-status*

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Bivariate analyses of female respondents' *attitudes to HIV*, *gendered discrimination* and *geographical mobility* illustrated which 'micro-social' predictors may impact their HIV-status. Results on *gendered discrimination* indicated that there could be factors within marital relationships which could affect women's HIV-status. Female HIV-positive respondents were significantly ( $<.05$ ) more likely to have experienced psychological and physical abuse than the general population. For example, a larger proportion of female HIV-infected participants reported that their husband had humiliated (21%) and insulted them (18%) prior to the survey in comparison to their HIV-negative counterparts.

The original purpose of the first forced multivariate model (Step 1) was to identify which indicator of *gendered discrimination* within marital relationships had the most impact on women's status when controlled for other 'micro-social' predictors. Unfortunately, it was not possible to utilise all measures of *gendered discrimination* due to logistical constraints. Only a small subset of participants from the married female sample was questioned on their experience of psychological and physical abuse (IIPS, Macro International 2007); and thus, inclusion of these measurements within the model reduced the dataset to a quarter of its original size. Therefore, the only measurement of *gendered discrimination* included was their attitudes to IPV as every female participant was asked these questions.

Female respondents who agreed with any justification of IPV displayed a higher odds ratio (OR=1.59, CI=1.08-2.34) of being HIV-positive in comparison to those who did not.

These findings suggest that some WLHA may condone domestic violence, believing that it could be used to control wives' behaviour. In Jejeebhoy's (1998) paper on women's attitude towards their autonomy in U.P. and T.N., participants believed that it was justified for a man to physically abuse his wife if she acted in a disobedient manner towards him by failing to perform her household duties.

The second model (Step 2) incorporated measurements of female respondents' *attitudes to HIV*. Measurements of stigma, knowledge of routes of transmission and misconceptions about HIV were not included in this model as it was found that there was a degree of multicollinearity between these variables. This meant that it was difficult to generate reliable results when all these measurements of attitudes to HIV were included in the model. Consequently, only one variable measuring participants' awareness of the existence of HIV was included in the second model. This variable was chosen because it is difficult for an individual to hold any positive or negative attitudes towards HIV unless they know of its existence. Table 5.16 presents the intercept, with Step 1 including variables measuring *gendered discrimination*; Step 2 comprising variables measuring *attitudes towards HIV* and Step 3 including measurements of *geographical mobility*.

**Table 5.16:** 'Micro-social' predictors of HIV-status among female participants in the NFHS-III (weighted) (\*\*\*) <.005, \*\*<.01 and \*<.05)

	Step 1	Step 2	Step 3
<b>Intercept</b>	***.002	***.000	***.001
<b>Gendered discrimination</b>			
<b>Agreed with any justification for domestic violence (No)</b>			
Yes	**1.59 (1.08-2.34)	**1.70 (1.15-2.50)	**1.70 (1.15-2.50)
<b>Attitudes towards HIV</b>			
<b>Ever heard of HIV (No)</b>			
Yes		***2.49 (1.57-3.90)	***2.45 (1.54-3.87)
<b>Geographical mobility</b>			
<b>Ever moved residence (No)</b>			
Yes			.909 (.621-1.33)
Nagelkerke R2	0.004	0.015	0.015

It was found that female participants who knew of the existence of HIV/AIDS were 2.49 times as likely to be sero-positive as those who had never heard of the illness (OR=2.49, CI=1.57-3.90). One could erroneously argue that these findings indicate that awareness of the existence of HIV could predispose one to contract the virus. However, findings from the qualitative phase of research indicated that there was a possibility that knowledge of HIV could be a product of social structural dynamics of HIV transmission in the community. Qualitative interviewees commented that they learnt of the existence of HIV after witnessing other members of their community dying from HIV-related illnesses, e.g. TB. These findings will be further discussed in the following chapter.

The final model (Step 3) included measurements of female participants' history of *geographical mobility*. Variables measuring *gendered discrimination* and *attitudes towards HIV* retained their significance (<.05) even when controlled for the effect of *geographical mobility*. Female respondents who agreed with any justification for domestic violence (OR=1.70, CI=1.15-2.50) and knew of the existence of HIV/AIDS (OR=2.45, CI=1.54-3.87) displayed higher odds of being HIV-infected than their counterparts.

On the other hand, female respondents who had changed residence in their lifetime seemed to be no more likely to be HIV-positive than those who had never moved home (OR=0.91, CI=0.62-1.33). This finding aligned with that of the bivariate results which indicated that most HIV-positive women were not geographically mobile. It is possible that findings in the NFHS-III on women's *geographical mobility* could be indicative of other structural determinants associated with cultural practices of marriage. In southern areas of India it is fairly common for Hindu and Muslim women to marry cousins belonging to the same community, meaning that they are rarely expected to move far from the area where they were born (Basu 1999, Moily 2011, Nagamani, Sharma 2011, Kalpagam 2008).

The multivariate analysis of 'micro-social' predictors displayed some interesting results which indicated that *gendered determinants* and *attitudes towards HIV* could perhaps have an impact on female respondents' sero-status. Nevertheless, it is important to note that

the final model (Step 3) had very little explanatory power as it covered only 1.5% of variance within the female sample. This could possibly be a product of there being so few variables within the model. The previous model measuring macro-environmental predictors of HIV-status covered more variance in the female sample (11%), suggesting that these variables could better explain transmission dynamics among WLHA than the current model. However, the previous model still covered little prevalence, indicating that there could be other extraneous factors not yet accounted for. Hence, the following section will examine ‘behavioural’ predictors of HIV-status, including participants’ sexual behaviour.

## 5.C Behavioural predictors of HIV-status

### 5.C.I *Sexual Behaviour*

Studies in sub-Saharan Africa have identified premarital sex as a potential risk factor for HIV transmission as many unmarried women could be forced through poverty and hardship to partake in transactional sexual relationships (Booyesen, Summerton 2011, Gregson, Todd et al. 2009, King, Lifshay et al. 2009). Contrary to findings in these studies, the majority of HIV-positive male (61%) and female (87%) participants in the NFHS-III first had intercourse when they were married. These results suggest that there is a possibility that cultural practices related to arranged partnerships, such as separation of sexes under the purdah system prior to marriage (Olsen, Mehta 2006), could mediate people’s sexual behaviour in the Indian context. Table 5.17 illustrates female participants’ previous sexual history and their HIV-status in the NFHS-III.

**Table 5.17:** Female participants’ previous sexual history and their HIV-status (weighted)

Sexual History	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Never had intercourse	10712	20	4	3
Had sexual intercourse at first union	5629	69	11	87
Had intercourse prior to marriage	36390	11	100	10
<b>Total</b>	<b>52731</b>	<b>100</b>	<b>115</b>	<b>100</b>

Furthermore, male and female respondents in the NFHS-III reported low levels of sexual behaviour prior to the survey with over three quarters claiming that they had one lifetime sexual partner. On the other hand, female HIV-infected respondents displayed slightly higher levels of sexual risk activity than those in the general population. For instance, a significantly ( $<.001$ ) higher proportion of WLHA had two or more sexual partners in their lifetime (8%) in comparison to their HIV-negative counterparts (2%). Table 5.18 displays female and male respondents' recent and lifetime number of sexual partners and their HIV-status.

**Table 5.18:** Multiple sexual partners and high risk sexual intercourse during participant's lifetime, including respondents who never had sex, in the last 12 months and their sero-status: Women and Men (weighted) (\*\*\*)  $<.005$ , \*\* $<.01$  and \* $<.05$ )

Multiple measures of sexual behaviour	Women			Men		
	HIV-neg %	HIV-pos %	Count	HIV-neg %	HIV-pos %	Count
<u>Number of lifetime sexual partners***</u>						
1	98	92	41281	81	71	28486
2 or more	2	8	735	19	29	6819
<b>Total</b>	<b>100</b>	<b>100</b>	<b>42016</b>	<b>100</b>	<b>100</b>	<b>35305</b>
<u>Number of sexual partners in the last 12 months***</u>						
0	28.2	29.8	14895	35	22	17420
1	71.8	69.3	37894	64	75	31880
2 or more	0.04	0.9	21	1	3	668
<b>Total</b>	<b>100</b>	<b>100</b>	<b>52810</b>	<b>100</b>	<b>100</b>	<b>49968</b>

Male HIV-infected respondents reported having more sexual partners than the rest of the male sample and female sero-positive participants<sup>99</sup>. Almost 30% of HIV-infected male participants reported having two or more sexual partners in their lifetime. In contrast, less than 20% of sero-negative men reported this figure. These findings indicate that up to a third of male sero-positive participants may have contracted HIV through their sexual risk activity, though, it is difficult to prove this to be the case due to lack of data.

<sup>99</sup> Please see Appendix 35 for a table on male participants' sexual history and their sero-status.

Additionally, a chi-squared test was performed to further analyse the sexual behaviour of married couples. Married women reported low levels of sexual risk-taking behaviour, with over 90% claiming that they had only one sexual partner<sup>100</sup> in their lifetime. In contrast, married HIV-positive men were significantly ( $<.005$ ) more likely to have had two or more sexual partners in their lifetime than the general population. Almost half of men in HIV-positive sero-concordant partnerships had two or more sexual partners in their lifetime. In contrast, less than a quarter of men in sero-discordant relationships in which they were the primary partner had this many lifetime sexual partners<sup>101</sup>.

It is important, however, to note that HIV-positive women were significantly ( $<.001$ ) more likely to have had a sexual relationship with someone other than their husband (5%) in comparison to the general population (0.2%)<sup>102</sup>. These findings suggest that a minority of HIV-infected women could be partaking in pre or extra-marital relationships. HIV-infected men displayed very different results from those of their female counterparts. Male HIV-positive participants were no more likely to have engaged in a sexual relationship with someone other than their spouse (4%) than their HIV-negative counterparts (3%).

Respondents' recent sexual activity was also examined. WLHA were significantly ( $<.001$ ) more likely not to have been sexually active (45%) in the four weeks prior to the survey than those who were HIV-negative (22%)<sup>103</sup>. In contrast, a significantly ( $<.001$ ) larger proportion of male HIV-infected participants had recently been sexually active (64%) in comparison to the general population (52%)<sup>104</sup>. This indicates that most of the HIV-positive female respondents may not have acquired the virus through engaging in high risk sexual behaviour. It was not possible to analyse whether these findings could be affected by

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<sup>100</sup> Please see Appendix 36 for a table displaying the number of lifetime sexual partners that married women had and their sero-status.

<sup>101</sup> Please see Appendix 37 for a table displaying the number of lifetime sexual partners that married men had and their sero-status.

<sup>102</sup> Please see Appendix 38 for a table on male and female participants' relationship to their last sexual partner and their sero-status.

<sup>103</sup> Please see Appendix 39 for a table displaying female participants' recent sexual behaviour and their sero-status.

<sup>104</sup> Please see Appendix 40 for a table display male participants' recent sexual behaviour and their sero-status.

respondents' awareness of their sero-status as the latter were not asked this question during the survey to ensure that the interviewer did not know participants' HIV-status.

Finally, participants' use of condoms during last sexual intercourse was analysed. The vast majority of men (91%)<sup>105</sup> and women (94%) had not used a condom during their last act of sexual intercourse. HIV-positive women and men did not seem to be any more likely than those in the general population to have used a condom indicating that they may not perceive themselves as being at risk of contracting HIV.

Variables within the 'behavioural' component of 'susceptibility' add another dimension to the ever-increasingly complex and nuanced depiction of dynamics affecting the sero-status of women in India. Although it is possible that many participants may not have truthfully disclosed their sexual behaviour prior to the NFHS-III, the findings indicated that most respondents engaged in little sexual behaviour with many having their first sexual experience of intercourse when they married. This suggests that at this stage of the HIV epidemic in India, the transmission of HIV within the heterosexual population occurs through a minority of individuals engaging in sexual risk-taking behaviour. Some PLWHA may unknowingly transmit HIV to their sexual partners who may abide by traditional socio-cultural practices forbidding sex outside marriage. The following section will further investigate dynamics of HIV transmission through multivariate analysis of the 'behavioural' predictors.

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### 5.C.II *Multivariate analysis of behavioural predictors of HIV-status*

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The objective of multivariate analysis was to identify significant individual-level variables that were associated with HIV-status within the female sample, controlling for the effect of other variables. There were few variables to analyse as most female participants displayed few sexual risk behaviours. Consequently, a two step forced logistical regression

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<sup>105</sup> Please see Appendix 41 for a table on female and male participants' use of a condom in their last act of sexual intercourse and their sero-status.

model was used<sup>106</sup>. The first forced model tested when participants reported their sexual debut and this model yielded no significant results. Findings in the second step of the model were contradictory and unexpected. On the one hand, female participants who reported having recently had sex experienced lower odds of being HIV-positive (OR<1, CI=0.31-0.65) in comparison to those who had no sexual activity<sup>107</sup>. On the other hand, female participants who stated that they had two or more partners had an increased odds ratio (OR=4.71, CI=2.34-9.50) of being HIV-infected than those who had only one sexual partner during their lifetime. Table 5.19 presents the intercept, Step 1 that includes a variable measuring when respondents first had intercourse, and Step 2, which comprises of variables measuring recent and lifetime sexual behaviour.

**Table 5.19:** Correlates of 'behavioural' predictors of HIV-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

	Step 1	Step 2
Intercept	***0.00	***0.00
<b>Sexual behaviour</b>		
<b>When respondents first had intercourse (First union)</b>		
Had intercourse prior to marriage	0.69 (0.37-1.1)	0.65(0.35-1.23)
<b>Recent sexual activity (No sexual activity)</b>		
Recently had sex		***0.44 (0.31-0.65)
<b>Lifetime sexual partners (1)</b>		
2 or more		***4.71 (2.34-9.50)
Nagelkerke R2	0.001	0.02

One possible explanation for these findings could be that this model had very little explanatory power as it covered only 2% of variance within the female sample, indicating that there could be extraneous factors which may explain these results. This hypothesis will be further explored in the following section of this chapter, which will describe the overarching model in which all social structural predictors of HIV-status were tested.

<sup>106</sup> Respondents who reported that they never had sexual intercourse were excluded from this model

<sup>107</sup> It is, however, important to take into account the fact that some HIV-positive respondents may have curtailed their sexual activity in response to being diagnosed with HIV.

## 5.D Multivariate analysis of macro-environmental, micro-social and behavioural predictors of HIV-status

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An overarching multivariate logistic model was created with the purpose of identifying which proximal and distal social structural predictors of ‘susceptibility’ could in combination possibly impact female respondents HIV-status. This forced model was conducted in three steps, which tested variables within each dimension of ‘susceptibility’ that had a significant ( $p < .05$ ) association with female participants sero-status in previous bivariate and multivariate analyses in this chapter.

The first model (Step 1) tested ‘macro-environmental’ predictors, which included: area of residence, rate of prevalence in states, level of education, wealth, employment status, religion and marital status. All variables tested, apart from wealth, had a significant ( $< .05$ ) association with female respondents’ HIV-status. Female participants who lived in urban areas (OR=1.58, CI=1.02-2.46) and in states with high levels of sero-prevalence (OR=4.06, CI=2.58-6.38) displayed increased odds of being sero-positive in comparison to their counterparts.

The second forced model (Step 2) tested variables that measured ‘micro-social’ predictors of HIV transmission, which included respondents’ attitudes to domestic violence and their awareness of the existence of HIV. Most variables incorporated into the previous model retained their significance, indicating that the ‘macro-environmental’ component of ‘susceptibility’ has an ability to predict the HIV-status of female participants. For instance, formerly married participants were 5.6 times as likely to be sero-positive as those who had either never been or were currently married (OR=6.05, CI=3.97-9.21)<sup>108</sup>.

On the other hand, variables assigned to the ‘micro-social’ component of ‘susceptibility’ had less of an impact on female participants’ sero-status in comparison to ‘macro-environmental’ predictors. Adding variables allotted to ‘micro-social’ predictors to

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<sup>108</sup> As the survey is cross-sectional, it is difficult to decipher the direction of causation. It is possible that some female HIV-positive participants were widowed after their spouse died from HIV-related illnesses.

the second model (Step 2) marginally increased the amount of variance explained in the female sample from 9.7% to 11%. Furthermore, the only variable within the ‘micro-social’ component of susceptibility which had a significant impact on female respondents’ sero-status was their awareness of the existence of HIV/AIDS. Female participants who knew that HIV existed displayed increased odds of being HIV-infected (OR=2.82, CI=1.71-4.65) in comparison to those who have never heard of the virus.

The third forced model (Step 3) tested variables which measured ‘behavioural’ predictors of female participants’ sero-status. These variables were female participants reporting of recent sexual activity and the number of sexual partners they have had during their lifetime. As in the previous model measuring only ‘behavioural’ predictors (displayed on p.138), women who had two or more lifetime sexual partners were 4.21 times as likely to be HIV-positive in comparison to those who had only one lifetime partner (OR=4.38, CI=2.11-9.10). These findings indicate that there is a possibility that there are some women who may have contracted HIV through their own sexual risk behaviour, rather than that of their partner.

The most illuminating findings, however, were within the ‘macro-environmental’ and ‘micro-social’ components of susceptibility. These results indicated that distal social structural factors related to educational opportunities and social status may have mediated female participants’ propensity to be HIV-positive. It was found that female respondents who were formerly married (OR=5.27, CI=3.07-9.04), Hindu (OR=2.35, CI=1.22-4.54) and employed (OR=1.45, CI=0.96-2.18) showed significantly ( $<.05$ ) increased odds of being sero-positive than their counterparts. Moreover, female participants who had a low level of education were 2.26 times as likely to be HIV-infected in comparison to those who had attended secondary or higher educational institutions (OR=2.27, CI=1.40-3.68). Table 5.20 presents the intercept, with Step 1 including variables measuring ‘micro-social’ predictors; Step 2 comprising variables evaluating ‘macro-environmental’ predictors; and Step 3 including measurements of ‘individual behavioural’ predictors.

**Table 5.20:** Correlates of all predictors of HIV transmission (weighted)

(\*\*\*) &lt;.005, \*\*&lt;.01 and \*&lt;.05)

	Step 1	Step 2	Step 3
<b>Intercept</b>	***.00	***.00	***.00
<b>Macro-environmental predictors</b>			
<b>Area of residence (Rural)</b>			
Urban	*1.58 (1.02-2.46)	1.44(0.93-2.22)	1.42(0.92-2.19)
<b>States (Low prevalence)</b>			
High prevalence	***4.06 (2.58-6.38)	***3.35(2.11-5.32)	***3.48(2.19-5.54)
<b>Level of education (Secondary/higher)</b>			
No education/Primary	**1.92(1.19-3.08)	***2.35(1.45-3.79)	***2.27(1.40-3.68)
<b>Wealth (Poor/poorer/middle)</b>			
Richer/richest	1.54 (0.97-2.44)	1.32(0.84-2.08)	1.35(0.85-2.13)
<b>Employment (Unemployed)</b>			
Employed	*1.55(1.03-2.32)	1.47(0.98-2.21)	*1.45(0.96-2.18)
<b>Religion (Non-Hindu)</b>			
Hindu	*2.25(1.17-4.35)	**2.20(1.20-4.47)	**2.35(1.22-4.54)
<b>Marital status (Never married/currently married)</b>			
Formerly married	***6.15(4.04-9.35)	***6.05(3.97-9.21)	***5.27(3.07-9.04)
<b>Micro-social predictors</b>			
<b>Agreed with any justification for domestic violence (No)</b>			
Yes		1.28(0.85-1.92)	1.28(0.85-1.92)
<b>Ever heard of HIV (No)</b>			
Yes		***2.82(1.71-4.65)	***2.87(1.74-4.75)
<b>Behavioural predictors</b>			
<b>Recent sexual activity (No sexual activity)</b>			
Recently had sex			0.91(0.55-1.46)
<b>Lifetime sexual partners (1)</b>			
2 or more			***4.38(2.11-9.10)
Nagelkerke R2	0.97	0.11	0.12

These multivariate results on *socioeconomic status* indicate that many female HIV-positive respondents could belong to disadvantaged groups which deprived them of educational opportunities. Other studies have illustrated that women with low levels of education displayed a heightened risk of contracting HIV (Rajesh, Sanjay et al. 2011, Van Rompay, Madhivanan et al. 2008, Samuel, Sriyayanth et al. 2007). Silverman, Decker et al. (2008) noted that a lower proportion of female participants with a secondary level of education were sero-positive, in comparison to those who had only attended primary school.

Finally, female participants who were living in states with a high prevalence of HIV (OR=3.48, CI=2.19-5.54) and were aware of the existence of HIV/AIDS (OR=2.87, CI=1.74-4.75) displayed increased odds of being HIV-infected. These findings may corroborate

previous bivariate and multivariate results which suggest that living in areas with high levels of sero-prevalence can increase one's susceptibility to HIV infection.

## 5.E Discussion

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The results for this chapter offer a complex and multi-layered profile of female HIV-positive participants. Bivariate results for 'macro-environmental' predictors of 'susceptibility' reveal that WLHA were more likely to be older, employed in poorly paid occupations and have low levels of education in comparison to women in the general population. Furthermore, many WLHA lived in states with higher levels of sero-prevalence and in urban areas of residence.

These findings could be indicative of wider social trends in the Indian population related to economic development, such as the possibility that many participants could belong to communities in transition which are vulnerable to various types of environmental and social shocks (Agarwal 1990, Anyangwe, Mtonga et al. 2006, Devine, Wood 2010, Gota, de Corta et al. 2011). These social environments could heighten women's 'susceptibility' to the impact of HIV/AIDS by curtailing their opportunities for education or more lucrative and stable employment.

Further bivariate analysis of 'macro-environmental' predictors reveals that female respondents' *social status* could have played a mediating role in the transmission of HIV within these social environments. There was a significantly ( $<.001$ ) larger proportion of female HIV-positive participants who were widowed (23%), divorced (2%) and living separately from their partner (6%) in comparison to the general population. Although some female participants could have been widowed as a consequence of their spouse dying of HIV-related illnesses, these findings suggest that there was a possibility that some WLHA may have contracted HIV from their spouse. I further examined this hypothesis through analysis of the married couples' dataset, where it was found that the highest rate of HIV-prevalence was among sero-discordant couples with a primary male partner (0.5%).

Findings within the ‘micro-social’ component of ‘susceptibility’ indicated that there were certain inter-relationship dynamics within WLHA’s marital partnerships which could have previously negatively affected their ability to avoid HIV infection. Female HIV-infected respondents were more likely to have experienced on a frequent basis controlling behaviour, emotional and physical violence on the part of their partner than the general population. These HIV-positive respondents also held more ‘traditional views’ towards domestic violence with some believing that a husband was justified in beating his wife if she refused to have sex with him. Hence, rather than belonging to vulnerable sections of the population, as might be believed of those who engage in sexual risk behaviours, most female HIV-positive participants seemed to come from ‘traditional’ backgrounds.

In contrast, ‘behavioural’ predictors had little impact on female respondents’ propensity to contract HIV. Statistical analysis was constrained by the fact that few respondents reported partaking in sexual risk behaviours, such as having concurrent sexual partners. These findings did, nevertheless, provide illuminating results indicating that many female HIV-infected respondents reported that they first had sexual intercourse when they were married. These findings indicated that ‘distal’ and ‘macro-environmental’ structural components of ‘susceptibility’ had a stronger impact on Indian women’s HIV-status than their own sexual risk behaviour.

Multivariate analysis of variables within each dimension of ‘susceptibility’ further substantiated findings from bivariate analysis. Findings within the ‘macro-environmental’ component of ‘susceptibility’ indicated that female participants’ level of education, employment status, awareness of HIV and the region of India where they lived had a significant ( $<.05$ ) impact on their propensity to contract HIV. When the effect of confounding factors were controlled for; it was found that predictors associated with residing in social environments with high levels of HIV-prevalence had the strongest impact on female respondents’ sero-status. For instance, participants living in high prevalence states (OR=3.48, CI=2.19-5.54) and those who were aware of the existence of HIV/AIDS (OR=2.87, CI=1.74-

4.75) had increased odds of being HIV-infected. These results illustrate that for many women in India, it could be the environments and communities they live in, rather than their specific behaviour which leaves them at greater risk of contracting HIV.

## 5.F Conclusion

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Findings from the NFHS-III indicated that there are concentrations of HIV infection among women in certain areas of India. Over half of WLHA lived in southern high prevalence states, such as A.P. and Karnataka. Moreover, there was a significantly ( $<.01$ ) higher rate of HIV-prevalence among women living in urban (0.29%) than in rural areas (0.18%). These findings were similar to those of other studies conducted in Asia, which have highlighted high-risk sexual networks clustered around areas of economic development. For instance, Doherty (2011) illustrated through network analysis that in areas of China and Russia with networks of IDUs, HIV has spread into the general population via heterosexual transmission.

This indicates that there is a temporal and communal dynamic to the transmission of HIV in these areas, perhaps as a product of the epidemic being concentrated. Ruxrungtham, Brown et al. (2004) posited that the trajectory of HIV transmission in any given area in Asia was influenced by: a) 'variations in behavioural factors', such as the predominant risk behaviour in that particular population; b) 'geographic and population differences in biological factors', like male circumcision; and c) 'the timing of HIV introduction into populations with high behavioural risk'.

A few of these factors may have influenced the course of the HIV epidemic in India, which is geographically diverse. For instance, areas in which the virus was introduced in the early nineties have higher rates of HIV infection (e.g. Tamil Nadu) in comparison to regions that have recently experienced an increase in HIV prevalence. These findings suggest that with sufficient time HIV may propagate throughout a community and become increasingly prevalent (Nag 1996). These results will be further investigated in the following chapter,

which examines findings from the qualitative phase of research that converges with results on ‘susceptibility’ in the NFHS-III.

## Chapter 6 COMPARATIVE ANALYSIS OF DATA FROM THE QUANTITATIVE AND QUALITATIVE PHASE OF RESEARCH

### 6.A Introduction

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Results from the previous chapter illustrated that Indian women's propensity to HIV infection was not necessarily influenced by their own sexual risk behaviour. For example, over 90% of female HIV-infected participants had only one sexual partner in their lifetime. 'Micro-social' and 'macro-environmental' components of 'susceptibility' seemed to have a stronger impact on female participants' predisposition towards HIV infection. Findings related to these components of 'susceptibility' indicated that female HIV-infected respondents were older, employed in low status occupations (e.g. agricultural labour) and were more likely to have experienced domestic violence than the general population.

These results contrasted with findings from other studies conducted in India which indicated that women who were most at risk of contracting HIV belonged to socially marginalised groups who resorted to sex work or transactional relationships in order to survive (Fung, Guinness et al. 2007, Thappa, Singh et al. 2007)<sup>109</sup>. In contrast, a large proportion of female HIV-positive participants in the NFHS-III belonged to 'traditional' backgrounds, such as housewives.

The previous chapter demonstrated *which* social structural predictors is overall affecting the sero-status of women in India. The objective of chapter 6 is to investigate possible social structural processes which may affect results in the last chapter using data from the qualitative phase of research. This phase of research involved over forty interviews that were conducted with sero-positive beneficiaries and peer providers<sup>110</sup> of NGOs and PNs in the districts of Guntur, Rangareddi, Krishna and West Godavari in Andhra Pradesh. These

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<sup>109</sup> It is important to note that although the NFHS-III is a reliable source of data, it is unknown how well it detects the sexual risk behaviours of certain groups, owing to the fact that very few men or women may admit to having multiple partners. This type of caveat could also be applied to other surveys charting risk behaviours.

<sup>110</sup> Peer providers were deliberately sampled because they offered a unique perspective both as a patient and a provider of healthcare and social services.

social structural processes are identified through analysis of data from the qualitative phase of research. Particular attention was paid to participants' narratives of their lives prior to being diagnosed as HIV-positive, in order to identify points at which their accounts converged with findings from the NFHS-III.

As mentioned in chapter 4, quantitative and qualitative sources of data were integrated according to Onwuegbuzie and Teddlie's (2003) conceptualisation for analysing mixed methods data. For the purposes of this chapter, data was transformed so that qualitative texts were given a quantitative structure. For example, I coded participants' accounts of domestic violence according to measurements of IPV used in the NFHS-III.

This chapter utilises the modified Barnett and Whiteside's (2002) model of 'susceptibility' used in the previous chapter. The purpose of using this model is to identify points of convergence and divergence between findings in the qualitative and quantitative phases of research. The first section of this chapter examines 'macro-environmental' determinants of susceptibility through examining the *socio-demographic characteristics*, *socio-economic factors* and *social status* of the participants in the qualitative stage of research, e.g. their age and occupation<sup>111</sup>.

This section also provides a comparison between qualitative and quantitative results on these determinants of 'susceptibility' in order to identify the characteristics of each sample. The qualitative sample is not representative of the wider population of HIV-positive women as I sampled participants who were users of NGO and Positive Network services<sup>112</sup>. It would have been difficult to sample WLHA in any other manner given both the exceptionally small percentage of the female population (0.3%) with sero-status and the stigma they may encounter. However, the qualitative sample could be reflective of a small section of WLHA who not only are aware of their sero-status but are also continually getting treatment for it,

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<sup>111</sup> This information provides a provisional profile of respondents, which offers a useful background information for subsequent chapters displaying qualitative findings.

<sup>112</sup> As noted in chapter 4, the purpose of qualitative research is often to generate theories rather than test theories on a representative sample from the wider population.

meaning that these participants would be able to reflect on factors which left them susceptible to HIV infection.

Then I examined other possible ‘macro-environmental’ determinants of HIV transmission within communities according to qualitative interview participants’ accounts. This type of analysis permitted me to decipher possible social structural processes that may have led to quantitative findings in the previous chapter. In particular, I examined which communal processes may have led to there being geographical hubs or ‘hotspots’ of HIV-prevalence in India.

The second section of this chapter covers ‘micro-social’ determinants of HIV transmission in the form of *gendered discrimination*. Qualitative interview participants’ accounts of their marital relationships prior to their diagnosis were examined. As in the previous chapter, I explore behaviours within marital relationships which could possibly have negatively affected these participants’ ability to protect themselves from infection. In order to establish linkages between the qualitative and quantitative data, close attention is paid to respondents’ attitudes towards IPV and experiences of controlling behaviour, domestic and emotional violence.

Finally, ‘behavioural’ determinants of HIV transmission are addressed. Particular attention is paid to qualitative interview participants’ accounts of sexual risk behaviour within their marital relationships. These narratives are used to uncover how certain social structural determinants may have affected participants or their spouses' risky sexual behaviour.

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## 6.B Macro-Environmental determinants

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### 6.B.I *Socio-demographic characteristics*

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Quantitative findings on *demographic characteristics* and *socioeconomic factors* diverged with results in the qualitative phase of research on religion and marital status. The vast majority of female HIV-positive respondents in the NFHS-III were Hindu (91%). This finding seemed to contrast markedly with results in the qualitative phase of research, in

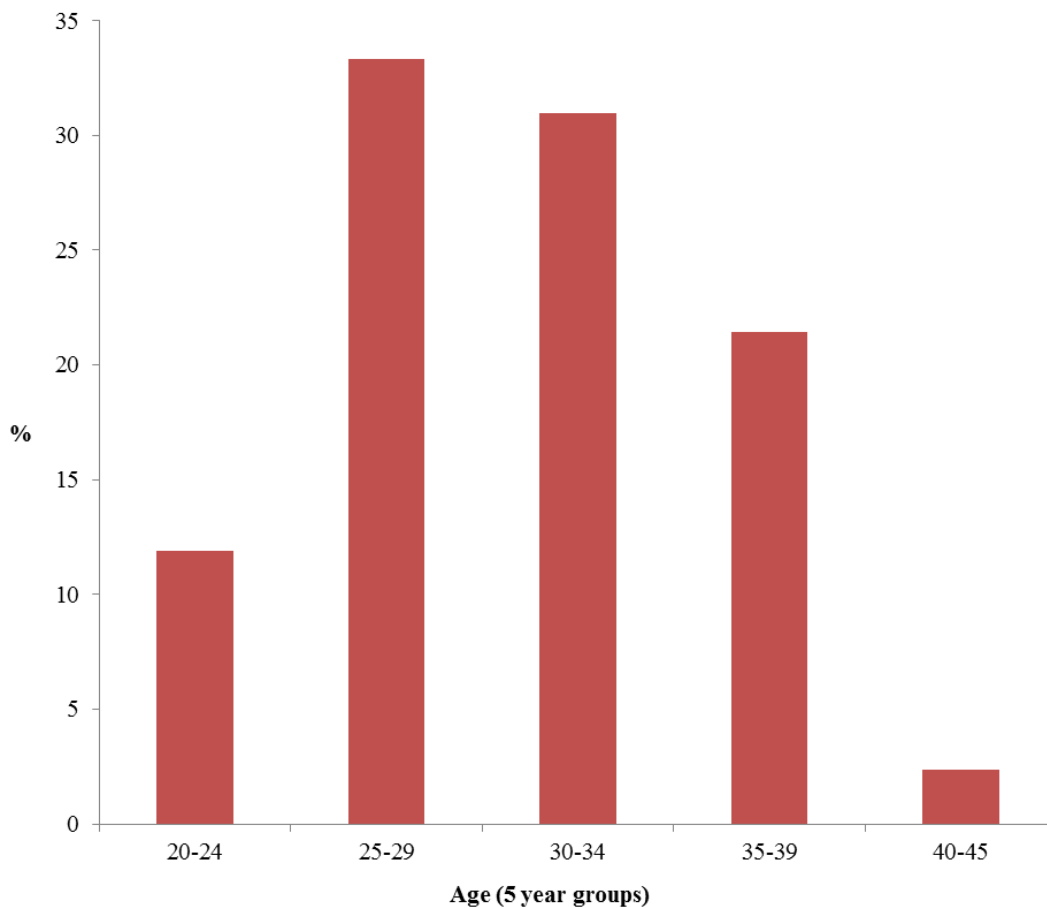
which almost half of all the participants were Christian. As these findings are so vastly different from the quantitative results, there is a possibility that this could be a product of how qualitative interviewees were sampled. Analysis of qualitative interviewees' narratives revealed that PNs and NGOs may have close associations with Christian faith based organisations (e.g. World Vision) and local churches. Some participants commented that local Christian groups would often refer HIV-positive members of their community to NGOs providing social services and healthcare to PLWHA.

There were some respondents who described themselves as 'converts' as they had recently been baptised. A few had decided to convert from Hinduism to Christianity after repeated contact with staff from Christian organisations. One such example was PF17, who was living in a convent with her mother and daughters. She claimed that as a Brahmin she felt heavily restricted in what she could eat, as many types of food were deemed to be polluting. After she had been diagnosed as HIV-positive, she was treated as an outcast or 'untouchable' by her husband's relatives who perceived her as being unclean. This indicated that they perceived her illness as a 'polluting product', hence a threat to their high caste status (Moffatt 1975). The only form of psycho-social and financial support she received at this time was from staff at her local convent. For instance, they provided her with employment in domestic service with employees who were accepting of her sero-status. As a consequence, she wanted her children to be baptised as Christian in order to ensure that they received the same type of support as she did.

Furthermore, the vast majority of respondents from the qualitative stage of research were widowed (61%). These results contrasted to that of the NFHS-III whereby less than a quarter of female HIV-positive participants were widowed. The qualitative findings could be a product of the sampling framework, in which participants were selected from a small subset of the population of WLHA who were aware of their sero-status and using some form of HIV-related treatment. Hence, it is possible that some qualitative interviewees could be in the

later stages of their illness and treatment than many female HIV-positive respondents in the NFHS-III.

Quantitative and qualitative results did, however, converge on other *socio-demographic characteristics*. Female HIV-positive respondents in the NFHS-III seemed to be more likely to be uneducated, employed in low-status occupations and on average slightly older than their sero-negative peers. Qualitative interview participants displayed similar characteristics, with the age distribution of respondents being roughly bell-shaped sharply peaking between the ages of 25-29<sup>113</sup>. Figure 6.1 is a graph illustrating the age distribution of respondents from the qualitative stage of research.



**Figure 6.1:** Age distribution of female HIV-positive participants in the qualitative stage of analysis

<sup>113</sup> Qualitative interview participants were slightly younger than female HIV-positive respondents in the NFHS-III. This could be a product of many respondents being diagnosed at a young age through a routine HIV test as part of antenatal care when pregnant.

Participants in the qualitative phase of research displayed similarly low levels of education to the female HIV-infected respondents in the NFHS-III. Over half of qualitative interview participants either had no education (24%) or had only attended primary school (29%). Many of these respondents reported that they were illiterate or unable to read sentences fluently<sup>114</sup>.

Some qualitative interview respondents' narratives offered insight into social structural processes leading to their loss of education, which in turn contributed to their low awareness of the virus as HIV-related education is often provided at secondary school (McManus, Dhar 2008). A few commented that after attending school for a few years, they and their families lacked the motivation to continue their education. As PF33<sup>115</sup> stated:

*'I have studied only up to first class and after that my mother did not send me to school and neither was I interested in going'.*

Respondents' natal families may have possibly perceived education as an unnecessary expense as it is common in India for women to discontinue working after marriage (Caldwell, Reddy et al. 1983). These respondents decided to partake in more lucrative agricultural work or other types of self-employment (e.g. tailoring) as children. According to these respondents' accounts there was little or no skilled work available in their local labour market for those with a higher level of education. There were a few participants living in rural areas who still partook in agricultural manual labour despite having a secondary level of education as there was no other type of work available.

There were also some respondents who were unable to continue their education due to extreme poverty. One such example was PF9, whose father died when she was a young child. This unfortunate set of circumstances left her mother in a financially precarious position as

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<sup>114</sup> A larger proportion of respondents in the qualitative phase of research had a secondary (30%) and higher (11%) level of education in comparison to female HIV-infected participants in the NFHS-III. The foremost reason for these findings was that peer providers were also sampled. Peer providers often had a higher level of education as it was required for them to understand the intricacies of HIV-related medical treatment in order to provide the appropriate services to other PLWHA.

<sup>115</sup> All participants were assigned a code in order to ensure their anonymity. The assignation of PF denoted that the participant was a female beneficiary of services rendered by the PN or NGO sampled, whilst PP was shorthand for peer provider.

the sole carer for her six children. She said, 'Since my father died when I was very small, I have had no occasion to attend school but do work from a very little age'. Since there were so few economic resources within PF9's family, none of her other siblings received any education. Her mother ensured that her siblings were married as soon as possible in order to guarantee that they were financially catered for by other families.

It is possible that these accounts may also demonstrate the wider macro-environmental processes that led to the majority of participants being employed (82%). Many of these respondents worked in low status occupations as manual labourers (28%) or as domestic servants (14%). Participants involved in manual seasonal agricultural labour, e.g. planting chillies, survived on a 'daily wage' of around Rs. 100-200 (£1.29-2.58). The availability of such work fluctuated between seasons; hence, many did not work for a full five day week.

On the other hand, respondents employed in domestic work were paid a slightly higher income of Rs. 1000 (£12.90) on a monthly basis. This form of employment was more stable than manual labour as they had a consistent income. Nonetheless, these respondents had few employee rights as they were not offered sick leave and there was a provision of only three days of holiday on a monthly basis, although they were expected to work every weekend. PF11 reported that she was dismissed by her employees after being ill for a few weeks with Chikungunya, a viral disease spread by mosquitoes that occurs in Africa and Asia (WHO 2008a).

The most stable types of occupations were in administration/office work or peer provider work. Peer providers were employed in a variety of jobs related to the provision of services for HIV-positive women<sup>116</sup>. The two most common types of peer provider work were either as outreach workers (ORWs) who provided antenatal care for HIV-positive

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<sup>116</sup> Peer providers were employed in a variety of jobs related to the provision of services for HIV-positive women. The two most common types of peer provider work were either as outreach workers (ORWs) who would provide antenatal care for HIV-positive pregnant women or as in-house adherence counsellors in their local PN. These respondents were paid on average Rs. 2000 (£25.80) per a month.

pregnant women or as in-house adherence counsellors in their local PN. These respondents were paid on average Rs. 2000 (£25.80) per a month. They reported that they felt secure in their work as they could declare their sero-status to their employers without fear of dismissal.

Many qualitative interviewees seemed to deem education as the most important *socioeconomic characteristic* to affect the trajectory of their lives. They believed that they were excluded from higher paid and long term stable jobs as these occupations often required at least a functional level of literacy and numeracy. Jobs in agricultural labour and domestic work were often precarious, inconsistent in availability, labour intensive and barely covered their cost of living. These conditions constrained participants' level of economic agency. As PF10 stated:

*'We are not educated and the work we do is very heavy, not as if it would be as working in an office. This heavy work is only for 10 to 20 days a month. We have to pay our rent, eat, other problems may arise, like sickness... The day when I feel extremely exhausted and do not go to work, then we have to starve'.*

There were a few respondents who commented that these occupations not only curtailed their working rights but also left them vulnerable to sexual exploitation. PF32, who worked in construction, reported that many parents in her community were reluctant for their daughters to work as a manual construction worker as managers had a reputation for sexually exploiting or abusing their female employees<sup>117</sup>.

Qualitative findings on *socio-demographic characteristics* added depth to results from the NFHS-III, which illustrated that some WLHA could belong to economically deprived backgrounds. Respondents' narratives from the qualitative phase of research touched on social structural processes which led to their current socioeconomic position. They belonged to communities in which the local market offered little or no opportunities for those with a higher level of education. Consequently, they were forced to work from a young age in

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<sup>117</sup> Recent research highlighted that women in seasonal agricultural work often experienced sexual abuse and harassment from higher caste masons and contractors (Mosse, Gupta et al. 2005, Mishra, Swain et al. 2008, Garikipati 2008).

unstable occupations, which may have sometimes left them vulnerable to sexual exploitation. Nonetheless, it could be argued that many women belong to communities which offer few educational or occupational opportunities (Agarwal 2000, Agarwal 2003, Agarwal 1997, Agarwal 2001), yet they never contract HIV. Hence, the following section of this chapter will examine dynamics within qualitative interviewees' communities which could possibly lead to transmission of HIV. Table 6.1 displays participants in the qualitative stage of research *socio-demographic characteristics*, including area of residence, occupation, type of wage and income.

**Table 6.1:** Participants' characteristics in the qualitative stage of analysis

<b>Respondent code</b>	<b>Area of residen</b>	<b>Occupation</b>	<b>Type of wage</b>	<b>Income (Rs)</b>
PF1	Urban	Service	Monthly	2,000
PF2	Urban	Unemployed		
PF3	Urban	Unemployed		
PF4	Rural	Service	Monthly	800
PF5	Rural	Unemployed		
PF6	Rural	Unemployed		
PF7	Rural	Self-employed	Daily	40
PF8	Urban	Administration	Monthly	3,500
PF9	Urban	Unemployed		
PF10	Rural	Manual labour	Daily	80
PF11	Rural	Service	Monthly	DK
PF12	Rural	Administration	Monthly	2,000
PF13	Rural	Self-employed	Daily	300
PF14	Rural	Manual labour	Daily	100
PF15	Rural	Service	Monthly	900
PF16	Rural	Manual labour	Daily	50
PF17	Rural	Service	Monthly	300
PF18	Rural	Service	Monthly	800
PF19	Rural	Self-employed	Daily	40
PF20	Urban	Self-employed	Daily	41
PF21	Rural	Administration	Monthly	2,500
PF22	Rural	Manual labour	Daily	100
PF23	Rural	Manual labour	Daily	150
PF24	Urban	Manual labour	Daily	100
PF25	Urban	Service	Monthly	350
PF26	Urban	Service	Daily	50
PF27	Rural	Unemployed		
PF28	Rural	Manual labour	Daily	200
PF29	Rural	Unemployed		
PF30	Rural	Manual labour	Daily	100
PF31	Urban	Self-employed	Daily	30
PF32	Urban	Manual labour	Daily	120
PF33	Urban	Manual labour	Daily	150
PP1	Urban	Peer Provider	Monthly	2,500
PP2	Rural	Peer Provider	Monthly	2,500
PP3	Urban	Peer Provider	Monthly	4,800
PP4	Urban	Peer Provider	Monthly	3,000
PP5	Urban	Peer Provider	Monthly	1,500
PP6	Urban	Peer Provider	Monthly	2,500
PP7	Rural	Peer Provider	Monthly	5,000
PP8	Rural	Peer Provider	Monthly	2,080
PP9	Rural	Peer Provider	Monthly	2,500
PP10	Urban	Peer Provider	Monthly	10,000

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### 6.B.II *Communal trends of HIV transmission*

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Findings from the NFHS-III indicated that female participants living in states with a high sero-prevalence were at a heightened risk of contracting HIV. This result converged with findings in the qualitative phase of research, in which a recurring theme in participants' narratives were that they belonged to communities negatively affected by HIV. Many qualitative interview respondents mentioned that they knew of others in their community who were HIV-positive. For instance, PF31, PF32 and PF33 lived in the same village and they mentioned that there were many other PLWHA residing in the same area. These respondents' narratives suggested that there was a possibility that their area of residence had high levels of sero-prevalence, which may have later heightened their own risk of contracting it.

These pockets of high prevalence in India have been attributed by researchers to the trend of male members of rural communities temporarily migrating to urban areas in search of work (Bailey, Hutter 2008, Deering, Vickerman et al. 2008, Mishra, Swain et al. 2008). It is argued that male temporary economic migrants are more likely to engage in risk-taking behaviour, such as sexual contact with CSWs, in urban areas when spending prolonged periods of time away from their spouse and family. A few male migrants may possibly contract HIV whilst working in urban areas then transmit it to others in their natal communities after they return.

It is possible that HIV could have spread beyond the 'risk' and 'bridge' groups to the 'general' population within a few communities with a recent history of high HIV-prevalence and labour migration in India. Halli, Blanchard et al's (2007) study of risk behaviour and migration in rural Karnataka illustrated that HIV had spread beyond the male seasonal migrants to other members of the community. The qualitative findings in this thesis seemed to support this hypothesis. Many qualitative interview respondents mentioned that there were members of their communities who would have sexual relationships with multiple partners

over a short period of time. PF24 reported that her husband would leave her house every night to drink alcohol with women he was having sexual relationships with. She stated:

*'Every night he was with women drinking to the full and they also had connections with my husband. Even those women died without knowing that they are HIV-infected'.*

Some of the respondents in the qualitative stage of research reported that they had previously resided in areas which had a high concentration of individuals who partook in risky sexual behaviour. PF24's testimony of how her husband inadvertently transmitted HIV to multiple sexual partners attests to this dynamic of risk. In PF24's case, it was not her own sexual behaviour which resulted in her contracting HIV but that of others in her community.

These participants' narratives suggested that there might have been a destructive pattern of HIV transmission, whereby the virus entered these small communities via economic migration and then further infiltrated it through risk behaviours within certain sections of the population. It was also possible that HIV was further transmitted in these communities through iatrogenic infection or drug injecting use. However, it was difficult to ascertain the role of these routes of transmission within participants' communities as few respondents mentioned them.

These transmission dynamics might have been exacerbated through a low level of awareness<sup>118</sup> and misconceptions of HIV within these communities. Many qualitative interview respondents reported that they had very little knowledge of HIV before being diagnosed as sero-positive with some commenting that they 'had never heard of the name HIV'. PP4 was one such respondent, she associated HIV with other chronic illnesses like diabetes. She stated:

*'Actually, I did not know anything about this disease but I thought this disease is also similar to other diseases like diabetes, etc. I did not know that people would react indifferently and treat HIV patients from afar'.*

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<sup>118</sup> These findings were similar to results in the NFHS-III in which female sero-positive respondents had erratic levels of knowledge on routes of transmission, with some believing that it was possible to acquire the virus through sharing food with a PLWHA (18%).

This testimony indicated that PP4 implicitly understood the serious consequences that HIV can have on a person's lifestyle as she drew similarities with other life threatening conditions. Nevertheless, she was unaware of the stigmatised nature of the illness as she did not know that it could be sexually transmitted.

Other participants had a rudimentary knowledge of HIV, which meant that they were aware of its existence and in some cases knew of one route of transmission. These participants commented that they held stigmatising attitudes towards PLWHA prior to being diagnosed as sero-positive. These participants' narratives were crucial in highlighting how having a low level of awareness of HIV could later lead to holding stigmatising views of the condition.

At first, it seemed that qualitative interviewees' descriptions of their attitudes towards HIV prior to being diagnosed could explain social processes that led to some female sero-positive respondents in the NFHS-III holding stigmatising attitudes towards HIV, such as reporting that they would be unwilling to purchase vegetables from a HIV-positive vendor. Instead, analysis of the qualitative interviewees' narratives on HIV-related stigma revealed that the NFHS-III's measurements could be inadequate for gauging the complexity of an individual's attitudes towards HIV/AIDS. Many qualitative interviewees stigmatising attitudes towards HIV were influenced by their traditional views on sexuality, which stipulated that most sexual relationships should be conducted within the confines of marriage, and fear of contagion. They did not, however, seem to believe that just being HIV-positive was necessarily a 'character blemish' (Goffman 1968: 3). Contrary to the measurements of the NFHS-III, many qualitative interview respondents were willing to care for HIV-infected relatives, even if they believed that other members of their community had deserved to contract HIV through their own sexual risk behaviour.

Some participants in the qualitative stage of research seemed to identify most with the belief that HIV is 'associated with deviant behaviour, both as a product and as a producer of

deviant behaviour' (Alonzo, Reynolds 1995: 305)<sup>119</sup>. PP10 believed that she held this stigmatising attitude because prior to her diagnosis she only knew of sexual contact as a mode of transmission of HIV. She said,

*'We have seen ads on the TV about HIV but we were not able to understand it. Only thing we knew that if we went about having illegal relationships with others, we would get HIV'.*

This quote illustrated that PP10 associated HIV with deviant sexual behaviours outside marriage. Other respondent's described pre and extra-marital sexual relationships in very similar socially negative terms of having 'illegal contacts' or as 'roaming'. The concept of 'illegal contacts' was often used in participants' narratives to describe pre and extra-marital sexual relationships. The pejorative use of this term indicated that such partnerships were socially prohibited to the point of being 'illegal'. In addition, the use of the term 'roaming' denoted that the subject was seeking sexual relationships in the public sphere.

These terms indicated that some respondents may have held traditional attitudes towards female sexuality, which usually prohibits any type of sexual contact outside of the confines of marriage. These traditional attitudes may have resulted in some participants believing that those who 'roamed' or had 'illegal contacts' with others deserved to contract HIV as they were contravening social norms. PF12 described a female neighbour who had died of HIV, as having led 'a very bad life having illegal relationships with men'. This indicated that she may have perceived her neighbour's death as her karmic fate for having 'illegal relationships' with multiple partners. PF12's perception of her neighbour aligned with the attitude that HIV is 'tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable behaviour and therefore thought to represent a character blemish' (Alonzo, Reynolds 1995: 305). Since none of the respondents had partaken in such

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<sup>119</sup> These attitudes fitted into Alonzo and Reynolds (1995) typology of HIV-related stigma which took into consideration 'variations in the construction of stigma and strength of negative response'. This was achieved by merging dimensions and types of stigma as described by various theorists, e.g. Goffman (1968).

behaviour they viewed the risk of themselves contracting HIV before diagnosis as outside the realm of possibility.

These participants' narratives illustrated that their stigmatising attitudes towards HIV were driven by their lack of knowledge of routes of transmission and negative attitudes towards sex outside of marriage. Respondents' lack of awareness of HIV resulted in them believing that transmission was only associated with sex rather than through other types of contact with bodily fluids which are less stigmatised, e.g. transmission through infected blood<sup>120</sup>. These socially negative concepts were a reflection of a traditional Indian attitude towards sexuality, which stipulates that female sexual behaviour should be restricted within the confines of marriage. As Solomon, Mehta et al. (2010) stated, 'Women are raised from an early age to repress sexual desires and adopt the role of the obedient wife, whose primary responsibility is to reproduce' (p.2).

Furthermore, many participants who belonged to communities with a high prevalence of HIV commented that other members held stigmatising assumptions towards HIV. Participant narratives of members of their communities' reactions to HIV identified with the perception that HIV is 'associated with an undesirable and an un-aesthetic form of death' (Alonzo, Reynolds 1995: 305). PF12 mentioned that she learnt of HIV after a member of her community died from it. The act of witnessing this neighbour lose copious amounts of weight as her health degenerated convinced her that HIV was terminal. She stated:

*'I heard of the name when a neighbour of mine died with AIDS. I did not have any knowledge about it... I used to get frightened seeing AIDS patients because they would become so thin and ultimately die.'*

The final stigmatising attitude that respondents belonging to these communities identified in their narratives was the perception that HIV was 'contagious and threatening to the community' (Alonzo, Reynolds 1995: 305). PP5 commented that prior to diagnosis, she

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<sup>120</sup> Female respondents in the NFHS-III also knew very little on transmission of HIV via blood or other bodily fluids. For instance, 15% of all female participants knew that it was possible to contract HIV through a blood transfusion.

knew of 'AIDS but not HIV'. This meant that she understood HIV/AIDS in terms of it being a terminal 'disease' rather than being a controllable 'virus'. Other members of her community held similar stigmatising assumptions towards HIV. Hence, she was warned by her neighbours against allowing her children to interact with members of a family affected by HIV. She stated:

*'I was told by people that this is a contagious disease so do not allow your child to play with them. When, I heard this I felt very bad for the family'.*

Other respondents also reported that HIV-infected members of their community had been socially isolated out of fear that it could be transmitted to them. PP7 described a particularly tragic case of a woman who was locked in a room after her husband died of AIDS. She said:

*'People used to talk loudly about HIV patients those days. There was a case of a woman who got HIV and the husband too died with HIV, the village people put her away in a room with nobody to visit her. Neither her people came to see her. This incident was very bright in my mind'*

These participants' narratives illustrate how a community's negative response to PLWHA can result in increased transmission of HIV. The communal response to the epidemic is to stigmatise PLWHA out of fear of contracting HIV. As members of these communities have little or no knowledge of the routes of transmission, they tried to avoid any type of physical contact with PLWHA. It has been demonstrated by de Bruyn (1992) that such stigmatising behaviour often forces PLWHA to take extreme measures to conceal their condition. This type of behaviour in some circumstances may increase the rate of HIV-infection within these communities as PLWHA would be unwilling to disclose their sero-status to their sexual partner out of fear of social ostracisation.

Qualitative interview respondents' accounts of wider communal dynamics of HIV transmission offer some explanation to why some female HIV-infected respondents in the NFHS-III resided in areas of high sero-prevalence. Their narratives converged with quantitative findings through highlighting how low levels of awareness can eventually lead to

members of HIV-affected communities holding stigmatising assumptions towards PLWHA. However, there were other factors within their marital relationship which may have increased their propensity to contract HIV. Hence, the following section of this chapter will examine ‘micro-social’ determinants within marital relationships which mediate women’s risk of contracting HIV, starting with female participants’ attitudes towards domestic violence.

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## 6.C Micro-Social Determinants

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### 6.C.I *Gendered Discrimination*

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Many respondents, interviewed as part of the qualitative stage of research, commented that they had a fraught relationship with their partner even before they had been diagnosed as sero-positive. Themes in their narratives on domestic violence converged with findings in the NFHS-III, which indicated that female HIV-positive respondents were more likely to experience IPV than their HIV-negative peers.

Analysis of both datasets was integrated through coding qualitative interviewee’s narratives on interrelationship dynamics according to measurements employed by the NFHS-III to gauge female participants’ experience of domestic violence. In this manner I was able to identify points of convergence and divergence in the qualitative and quantitative dataset. The main themes within qualitative interview participants’ narratives on IPV were: a) participants’ attitudes towards domestic violence, b) their experience of their husbands’ ‘controlling behaviour’ towards them, and c) the occurrence of physical abuse within their marital relationship.

Qualitative interview participants’ accounts of their attitudes towards domestic violence suggested that a few respondents would attempt to normalise their spouse’s physically abusive behaviour. These respondents commented that it is common for couples to ‘fight’ on occasion. PF10, whose husband would purposely smash her glass bangles across her arms when angry, would downplay the abusive nature of their disputes. She repeatedly described violent arguments with her spouse as ‘little tiffs and quarrels’. PF31 held very

similar attitudes towards the abusive behaviour that she had experienced from her husband.

She stated:

*'He (PF31's husband) used to get irritated, beat me, I used to try to accommodate myself and adjust to his whims and fancies. Between husband and wife, there will always be some small litigants and misunderstanding but that is the way in life'*

This quote indicates that PF31 conceptualises the physical abuse that she endured as part of the evolution of her marital relationship with her husband. She comprehended that his motivation for beating her was irrational as she describes it as a product of him being 'irritated'. Nonetheless, she believed that it was her wifely duty to 'accommodate' and 'adjust' her behaviour according to his 'whims and fancies'. Similarly to the previous respondent, she downplayed her husband's violent behaviour by framing it within the wider context of her marriage and claiming that it is no different than 'small litigants' or 'misunderstandings'.

One similarity between PF10 and PF31 was that they had 'love' marriages. Rocca, Rathod et al. (2009) reported that women in 'love marriages'<sup>121</sup> had an increased likelihood of experiencing domestic violence. It is possible that these women experienced physical assault aggravated by familial tension. Qualitative interview participants' narratives on their relationship to their husband suggested that the type of marriage modulated how they coped with physical assault. These respondents believed that it was their 'wifely duty' to endure physical abuse as they had chosen their husband, thus cutting ties with their natal family and other members of their community. These participants' acceptance of gender roles within marriage could have diminished their ability to negotiate the terms of their sexual relationship (Gupta, Wyatt et al. 2008). As Panchanadeswaran, Johnson et al. (2008) stated, 'When women internalize and accept traditional and oppressive gender roles that impact behaviour, this further erodes women's power in intimate relationships, which in turn affects their capacities to resist abuse' (p. 162).

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<sup>121</sup> The term 'love marriage' is often used to describe a marital relationship arranged by both partners.

There were other respondents who did not attempt to normalise their husbands' physically and emotionally abusive behaviour towards them. These participants would repeat throughout their interview that their husband was a 'sadist'. Moreover, when asked what they believed triggered these violent attacks, these respondents would answer that their spouse would start their physical abuse based on the slightest justification. PF17 experienced violent behaviour from her husband on a daily basis. She claimed that he would hit her 'with his hands and also a stick', which would have been defined by measurements of IPV in the NFHS-III as 'severe violence'. In hindsight, she commented that her husband would for 'little reasons' physically attack her when drunk.

It is possible that these respondents consciously refused to offer an explanation for their husband's abusive behaviour as they believed that by doing so they would be justifying their spouses' violent tendencies. This could be an indication that a few of these participants have a more liberal outlook towards gender relations as they had been in contact with Positive Networks and Women's groups, which held meetings on issues related to domestic violence. These respondents consequently did not conceive that it was acceptable for their spouse to physically abuse them<sup>122</sup>.

Some qualitative interview respondents reported that their husband treated them in a domineering manner, fitting into the NFHS-III category of 'controlling behaviour'. This behaviour was defined by the NFHS-III as incidences reported by the respondent in which their spouse tried to control their finances or their interaction with the opposite sex<sup>123</sup>. These behaviours were recorded by the NFHS-III as experts on IPV argue that it could be predictive of violent behaviour (IIPS, Macro International 2007, IIPS 2006, Garcia-Moreno, Jansen et al. 2006).

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<sup>122</sup> Nonetheless, it is not possible to know if these respondents held these attitudes towards IPV when they were experiencing domestic violence. It is equally possible that some of these respondents may have felt more empowered to voice these opinions after their husband had passed away.

<sup>123</sup> Recent research in developed countries indicated that psychological abuse is not always predictive of domestic violence (Follingstad 2007).

According to some qualitative interviewees, their husbands' tendency to abuse them emotionally and physically was part of a continuum of 'controlling behaviour' rather than acting as a predictor of IPV. Many respondents mentioned that their spouses would accuse them of having 'illegal connections' with other men and would refuse to offer them any financial support. One such participant was PP9, who claimed that her husband would constantly monitor her behaviour with other men and refused to give her any money in order to run the household. She stated:

*'He was not such a nice man. He did not allow me to talk to outsiders. If I talked with men folk, he would blame me with some connection. He never allowed me to go out of the office and I was always inside the house. If I addressed anybody as brother, he would immediately attack me and say, 'There must be some relationship between you both'. If I said anything, he would raise his hand to beat me'.*

This quotation illustrated that PP9's husband was controlling of her movements in the public sphere. He accused her of having 'some connection' even with men she addressed as brother, which is a fairly common form of addressing male friends and acquaintances who belong to the same social strata in Andhra Pradesh. It is possible that these accusations of infidelity combined with threats of violence were used by her husband to control her social interactions with others in her community and her sexual behaviour within their marital relationship.

This type of 'controlling behaviour' ultimately resulted in PP9 separating from her spouse and returning to live with her mother<sup>124</sup>. There were some respondents who also reported that they would separate from their husband for short periods of time as they could not cope with their physically and emotionally abusive behaviour. These findings may explain interrelationship dynamics that may have led to some female HIV-positive respondents in the NFHS-III being more likely to be divorced or living separately from their spouse than their HIV-negative peers.

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<sup>124</sup> Straus (1990) illustrated that participants in married relationships experiencing a lot of psychological abuse tend to be more likely to divorce.

There were some respondents who believed their husband's violent behaviour was triggered by over-consumption of alcohol. These respondents commented that their spouses would arrive home and attack them when drunk. Over-consumption of alcohol has often been linked with domestic violence and sexual risk behaviour (Silverman, Decker et al. 2008, Saggurti, Schensul et al. 2009)<sup>125</sup>. Moreover, in some areas of India it could be perceived as a man's prerogative to drink alcohol, even if it is negatively affecting their household finances (Greenfield, Nayak et al. 2010, Nayak, Korcha et al. 2010). Women who question this type of behaviour may experience IPV, as they were perceived as acting in an insubordinate manner. PF24 reported:

*'I use to check him (PF24's husband) about his drinking... As a result, he turned round beating me and scolding me. This made him very weak and I started working to overcome our financial hazards'.*

Other qualitative interviewees reported that their husband would violently attack them if questioned on their extra-marital relationships. Recent research on IPV has demonstrated that men who are violent towards their wives are also more likely to engage in sexual risk behaviour, which could be a product of their misogynist attitudes towards women (Sivaram, Srikrishnan et al. 2005, Jain, Sanon et al. 2004). As Silverman, Decker et al. (2008) stated, 'As abusive men have been found to demonstrate both higher levels of sexual risk behaviour and, as an inherent aspect of their abuse, higher levels of control over sex and sexual protection, women experiencing IPV face "double jeopardy" regarding risk for HIV infection from male partners' (p.708).

Some qualitative interview participants' narratives indicated that violence was employed to force respondents to silently acquiesce to their husbands' sexual relationships with other women. PF21's narrative offered a detailed account of how violence is used within these relationships as a means of control. She stated:

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<sup>125</sup> In Verma, Saggurti et al's (2010) study on alcohol and sexual risk behaviour amongst CSWs and male migrants, most respondents consumed alcohol before sexual intercourse.

*'He (PF21's spouse) roamed outside well with girls/women and if I questioned him he used to hit me badly and so I used to just stare and sit silently. I used to stay silent because I could not bear the wounds and the beatings'*

This quotation illustrated that PF21's spouse used violence and intimidation to control her behaviour. She reported that his physical attacks were so vicious that she discontinued questioning him on his tendency to 'roam' with other 'girls/women'. This meant that as a result of domestic violence PF21 was unable to negotiate her husband's sexual behaviour, hence avoid transmission of HIV. Her narrative further demonstrated that IPV could be caused by deep seated gender inequalities within heterosexual relationships which later increases women's vulnerability to HIV infection (Garcia-Moreno, Jansen et al. 2006, Schensul, Mekki-Berrada et al. 2006).

Research on domestic violence and HIV transmission often failed to take into account the social structural processes within the family which could have potentially left these women vulnerable to repeated incidents of IPV in the first place. PF21 entered her relationship on very unequal terms as she had married with the intention of finding a husband who would support her endeavours to care for her other disabled relatives. Her spouse did not meet this criterion. Soon after they married, he forced her to place her disabled family members in an 'orphanage'. Then he proceeded to use violence as a means in which to control her and other relatives, to establish his dominance as the patriarchal head of that family.

During the interview, PF21 implied that her spouse was able to continually perpetuate violence as she was unable to seek any support from her natal family as they were either physically or mentally incapable of offering her a safe haven from the violence. Anthropological research in AP has illustrated that women who suffer from IPV utilise their natal family networks as a means of coping with their husbands' violent behaviour (Vindhya 2000). For instance, they may stay at their parent's home whilst elder members of their family discussed what procedures needed to be taken to ensure that the abuse does not continue. It has been argued that this system of negotiation is a product of traditions related to

marriage in the southern Indian context, whereby women still keep close ties with their natal family (Karve 1953, Caldwell, Reddy et al. 1983, Dumont 1957). In PF21's case, the only people who could attempt to intervene on her behalf were her husband's relatives. She described an incident in which her sister-in-law 'scolded' her husband after discovering that he had physically abused her. PF21 stated:

*'She (PF21's sister-in-law) scolded him indirectly for beating me and questioned him. 'Why did you do that to that poor girl? Is it because her sisters are mute? And, do you think that there is no one to question you hence you'll be paid all your deeds?' she scolded'.*

This incident demonstrated that both PF21's spouse and his sister were fully aware of the power differentials between PF21's family and her husband. Her sister-in-law understood that her husband could continually physically abuse PF21 without retribution. This was because she had no elder male members of her family who could potentially reprimand him on his abuse. Hence, in PF21's case, it was not just IPV which prevented her from being able to take the necessary precautions to protect herself but it was also a product of her not having the necessary familial resources to regulate her spouse's behaviour.

There were many points of convergence in findings on *gendered discrimination* in the quantitative and qualitative datasets. Results from both these datasets seemed to indicate that domestic violence could heighten women's susceptibility to HIV infection. However, the most crucial findings on *gendered discrimination* were actually related to how qualitative interviewees' narratives diverged from results in the NFHS-III. A recurring theme in many qualitative interview participants' narratives were that they believed their husband repeatedly deployed violence as a psychological mechanism to control their behaviour and force them to acquiesce to gendered inequalities in their relationship. This indicated that IPV was part of a spectrum of controlling behaviour. The following section will examine behavioural determinants of HIV according to qualitative interview participants' accounts of their own and their spouses' *sexual behaviour*.

## 6.D Behavioural Determinants

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### 6.D.I *Sexual behaviour*

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Themes within qualitative interview participants' narratives on *behavioural determinants* seemed to converge with results from the quantitative phase of analysis. Findings from the NFHS-III indicated that most female HIV-positive respondents had displayed low levels of risky sexual behaviour with the majority having one sexual partner during their lifetime. Most qualitative interviewees stated that they contracted HIV from their current spouse suggesting that the only *behavioural determinant* that left most of these women susceptible to HIV transmission seemed to be the sexual behaviour of their spouse.

Many respondents interviewed as part of the qualitative stage of research were aware of their husband's extra-marital relationships. They linked their spouses' sexual risk-taking behaviour to two factors, the first of which was mobile labour. They mentioned that their husband previously had a job which required them to travel long distances and spend long periods of time away from home<sup>126</sup>. PF14 commented that her husband 'used to travel about and spend days and days outside the home'. They believed that the mobile nature of their spouse's work offered them ample opportunity to maintain extra-marital sexual relationships without their knowledge. PF4 reported that her husband would traverse A.P. in search of menial service work in restaurants. She stated:

*'He (PF4's husband) worked in a sweet meat shop. Later, he quit the work and started working in a hotel, wayside eatery, at Guntur and other places. He used to return home once ten or twenty days. Once he did not visit home for eight months. He must have contracted the disease at that time.'*

As mentioned earlier, other participants reported that their husbands had sexual relationships with other women in their community. These narratives demonstrated how sexual risk behaviours within communities could cause further transmission of HIV after it

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<sup>126</sup> Early literature on HIV prevention in India identified mobile labour as a factor in transmission of the virus (Mishra, Swain et al. 2008, Solomon, Mehta et al. 2010, Agarwal 2002).

first entered the community through migratory labour. One such respondent was PF8, whose husband had an extra-marital relationship with a woman in their neighbourhood. Her husband's family arranged a match in order to avoid a scandal caused by his relationship to a woman of a lower caste. PF8's husband had wanted to marry this woman but her family had refused. After he married PF8 he continued his sexual relationship with the woman he had been unable to marry. PF8 reported that her husband's extramarital relationships were a source of tension:

*'In fact, for the first four years, I did not allow my husband to come anywhere near me... He would leave me all night alone, when I use to spend the time crying. When I got up in the morning, my eyes would be swollen because I was crying all night. He led such an illegal life that he got HIV and passed it on to me also'.*

Other participants reported that their husbands' extra-marital relationships with women in their community were a point of contention within their marriages. They would repeatedly have long arguments with their spouse over their sexual relationships with other women in their communities, which sometimes ended in violence. Many respondents demonstrated their disapproval of their husband's extra marital relationships with other women by reiterating throughout the interviews that they had contracted HIV through their spouse. The participants therefore absolved themselves of doing anything morally 'wrong' and the direction of blame was pointed towards their husband for the transmission of HIV<sup>127</sup>.

A few peer providers mentioned that their female clients had acquired HIV through their own sexual risk behaviour, rather than that of their husband. They reported that they had a few female clients whose husbands were HIV-negative whilst they were HIV-positive. These clients would at first claim that they did not know how they could have contracted HIV. Then they would inform the peer provider that they had acquired it through a contaminated blood transfusion<sup>128</sup>. Finally, they would divulge that they had contracted HIV

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<sup>127</sup> The NIMH Collaborative HIV/STD Prevention Trial Group (2007) found that gendered power dynamics in marital relationships were skewed towards men, resulting in extramarital sex being acceptable for men but proscribed for women.

<sup>128</sup> Halli, Blanchard et al's (2007) study of wives of migrant workers in Karnataka suggested that there could be a minority of married women in India partaking in risky sexual behaviour. Some participants admitted that

through ‘some illegal relationship’, meaning an extramarital sexual liaison. This meant that they had acquired HIV through unprotected heterosexual sexual intercourse with someone other than their husband before or after marriage. As PP10 reported:

*‘In some cases, when women are tested and found with HIV, they are very frightened where their husbands will come to know about it. They also test their husbands and if they do not have HIV and when they find that the men folk do not have HIV, they are scared where they will be shouted and harassed and what the in-laws and others will think of them. We try to ask such women how they have caught this disease but they never tell the truth. Finally after many attempts we come to know the truth as to how she has got this disease’.*

These peer providers’ narratives diverged from findings in the quantitative phase of analysis. Results in the NFHS-III suggested that few women contracted HIV outside of marriage as the lowest rate of HIV-prevalence within married couples were amongst sero-discordant couples with a primary female partner (0.1%). This indicated that some peer providers could be describing a relatively rare phenomenon.

None of the respondents in the qualitative stage of analysis reported that they had contracted HIV through extra-marital sexual relations. However, there were a few respondents who belonged to sero-discordant relationships in which they were the primary partner. One such respondent was PF9, who reported that she contracted HIV through her first husband who had an ‘illegal connection’ with another woman. They had a ‘big quarrel’ over his promiscuous behaviour and then decided to divorce. She also reported that her husband would act in a violent manner towards her. PF9 stated:

*My first husband did not look after me well. He never use to be in the house but always with that woman whom he had illegal connection. After leaving their house and coming to my mother’s place, I am eating well, attending to my work and I am happy.*

Subsequent to this set of events PF9’s mother decided to marry her to another man in her community to secure her welfare. PF9 stated, ‘So, she (her mother) thought that as nobody knows about my having HIV, she got me married for the second time’. During the interview PF9 confided that she had not yet disclosed her sero-status to her second husband.

She went to great lengths to conceal her sero-status from him, such as hiding her ART medication. As a consequence, she felt that she had no other choice but to acquiesce to his sexual demands in order to ensure that he did not learn of her sero-status.

PF9's narrative illustrates the complex structural processes which mediate transmission of HIV from the female to the male population in India. It is possible that there could be some women who are acquiring HIV through their own sexual risk behaviour as stipulated by many peer providers. On the other hand, it is also possible, as in PF9's case, that these women may have contracted HIV from a relationship with a previous spouse who had engaged in sexual risk behaviour. Due to economic and familial pressures these women may not be able to take the necessary precautions to prevent transmission of HIV to their next partner.

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## 6.E Discussion

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This chapter utilised data from the qualitative stage of research in order to uncover the chain of events which may have led to findings in the initial quantitative phase of analysis. Points of convergence between the two datasets were identified through examining qualitative interview participants' *socio-demographic characteristics*, such as their age and marital status. It was found that these respondents held similar demographic characteristics to female HIV-positive participants in the NFHS-III. Similarly to respondents in the NFHS-III, a large proportion of qualitative interview participants were uneducated, and employed in low status occupations such as that of an agricultural labourer.

Participants' narratives in the qualitative phase of research were pertinent in suggesting the potential sequence of events which might have led to some respondents in the quantitative phase of analysis belonging to economically deprived sections of the population prior to diagnosis. Although some of the qualitative interview respondents' accounts points to factors subsequent to their diagnosis as sero-positive (e.g. their conversion to Christianity),

their narratives illustrated that they belonged to environments which left them vulnerable to external social forces.

These findings could be related to the process of economic development in which some sections of the population accumulate wealth whilst other impoverished communities are more vulnerable to various types of environmental and social shocks (Agarwal 1990, Anyangwe, Mtonga et al. 2006, Devine, Wood 2010, Gota, de Corta et al. 2011), such as famine. People belonging to these communities often live within environments that curtail their ability to cope with any larger structural changes as there is little social security available. These types of unstable economic environments could have resulted in some respondents being unable to protect themselves from HIV infection as male members of their communities were compelled to seek work in other areas of India due to lack of all year round manual employment. Mobile labour offered them ample opportunity to partake in sexual risk behaviours outside of their social group.

These external forces related to economic development were most evident in qualitative interview respondents' accounts of factors leading to their loss of education. According to some qualitative interview participants' narratives, they lived in areas where the labour market had little demand for highly skilled or stable work. This resulted in these respondents having little motivation to continue their education as it was not lucrative to do so. Hence, very few respondents were aware that they were potentially at risk of contracting HIV as sex education is more often taught at secondary school (McManus, Dhar 2008). Moreover, it was possible that they were trapped in unstable occupations which offered little economic security, curtailed their workers' rights and left them vulnerable to sexual exploitation (Mosse, Gupta et al. 2005, Mishra, Swain et al. 2008, Garikipati 2008).

Respondents' narratives indicated that certain risk behaviours within their communities could have been driven by wider 'macro-environmental' processes. Some participants' accounts suggested that these risk behaviours may have resulted in further transmission of HIV after it entered their communities through labour migration. According

to respondents' narratives, they belonged to environments which put them at elevated risk of contracting HIV. For instance, some participants commented that there were many other PLWHA in their close-knit communities, indicating that they could be living in an area with a high prevalence of HIV. These findings could be a product of HIV-prevalence being localised in small areas of India rather than being generalised across the population as it would be in a Sub-Saharan African country with high levels of sero-prevalence, such as South Africa (Booyesen, Summerton 2011).

Other studies have illustrated that high risk sexual networks vary across regions and cultures in Asian countries. Yang, Wen et al. (2011) used GIS techniques to identify the spatial distribution of high risk populations, e.g. MSM, in Taiwan. They demonstrated that spatial patterns of these groups differed according to their type of risk behaviour. For instance, participants who had unprotected heterosexual sex clustered around urban areas. Qualitative interview respondents' narratives on wider *communal trends of HIV and sexual behaviour* suggest that there is a possibility that their spouses belonged to communities which were part of a sexual network displaying high risk behaviour.

Social structural determinants affecting qualitative interview participants' susceptibility to HIV infection once they entered a marital relationship were also examined. Participants' accounts provided illuminating results on transmission dynamics within their relationships, although as in any qualitative study on HIV, there is always the possibility that participants were either not entirely truthful or may have contracted HIV through unknown sources, e.g. blood transfusion. Findings from qualitative interviewees' narratives suggested that their 'susceptibility' was affected by a combination of 'micro-social' and 'behavioural' determinants, the most direct being their spouse's sexual risk behaviour as they were often aware of their husbands' extra-marital relationships with other women in their communities. These findings were similar to that of Solomon, Mehta et al.'s (2010) study on the impact of high risk behaviour of IDUs and MSM on their spouse. The overarching theme with both these groups of women was that the only factor which predisposed them to HIV infection was

their proximity to their husband, who was partaking in sexual and other types of risk behaviour.

*Gendered discrimination* in the form of emotional and physical abuse exacerbated the impact of respondents' husbands' sexual risk behaviour on their propensity to contract HIV. As in the profile compiled in chapter 5, some qualitative interviewees reported that they had experienced 'controlling behaviour' or domestic violence from their husband. These respondents commented that their spouse would physically attack them when questioned on their consumption of alcohol or their sexual relationships with other women. PF21 believed that her husband used violence as a means of controlling her behaviour and ensuring that he was able to continue to have extra-marital affairs without facing retribution. Consequently, these respondents were unable to directly confront their spouse on his sexual behaviour.

Recent research in developing countries has highlighted that married women experiencing IPV are at escalated risk of contracting HIV (Stephenson 2007, Decker, Seage et al. 2009, Chowdhary, Patel 2008). In Chandrasekaran, Krupp et al. (2007) study on the determinants of domestic violence amongst women in a voluntary testing and counselling centre in Bangalore, two thirds of the respondents had previously experienced some form of physical abuse from their spouse. Experts have posited that the reasons for these findings are that IPV limits a woman's 'ability to discuss marital infidelity, negotiate condom use, and refuse sexual intercourse' (Solomon, Subbaraman et al. 2009:754).

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## 6.F Conclusion

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The most illuminating findings in this chapter were related to 'macro-environmental' determinants of 'susceptibility'. Qualitative results on participants' *socio-demographic characteristics* and *communal trends in HIV transmission* suggested that social structural forces associated with economic development could create unstable environments for those living in marginalised communities, which have not reaped economic benefit from industrialisation. Individuals belonging to these communities are often compelled either to

migrate in search of work, which could provide ample opportunities to partake in risk activities (e.g. sexual contact with a CSW) (Kumar, Dandona et al. 2006), or are vulnerable to sexual exploitation (Mosse, Gupta et al. 2005, Mishra, Swain et al. 2008, Garikipati 2008).

Experts in the field of HIV prevention have long acknowledged that it is a developmental issue due to costs associated with treatment of PLWHA and loss of economic productivity of populations affected by HIV/AIDS (Cowley 2003, Harris 2003, Haacker 2009, Das, Mukhopadhyay et al. 2009). Nevertheless, there are few known studies which examine how social structural processes associated with economic development could encourage risk behaviours in certain sections of the population. These findings indicate there is a possibility that some qualitative interviewees' susceptibility to HIV infection may have predated them finding a sexual partner as they lived in an environment of high risk. Hence, the following chapter will examine findings emerging from the qualitative data on respondents pathways into relationships with partners who display high risk sexual behaviour.

## **Chapter 7 EMERGING FINDINGS ON ‘SUSCEPTIBILITY’ FROM THE QUALITATIVE PHASE OF ANALYSIS**

### **7.A INTRODUCTION**

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The previous chapter identified qualitative findings which converged with that of the quantitative phase of research. This iterative form of analysis was undertaken in order to uncover processes which may have led to results in the quantitative stage of analysis. For instance, results in the NFHS-III suggested that many WLHA lived in regions of high seroprevalence in India. Analysis of qualitative interviewees’ narratives indicated that they belonged to communities with close-knit sexual networks resulting in rapid spread of the infection. This indicated that many women’s susceptibility to contracting HIV may have started prior to finding a spouse.

Although many experts in the field of HIV prevention have identified women married to men partaking in high risk sexual behaviour as being susceptible to HIV infection (Kambou, Magar et al. 2007), there is no known research which uncovers processes which compel these women to seek such partnerships. This could be the product of most research on HIV transmission using the biomedical model of ‘risk’, which stipulates that HIV is spread only through individual risk-taking behaviours, e.g. unprotected sex (Fee, Krieger 1993).

Consequently, the objective of this chapter was to explore emerging findings from the qualitative phase of research that illustrated processes which may have impelled these women into partnerships with husbands who engaged in sexual risk behaviour. Qualitative interviewees’ narratives indicated that there were two pathways to finding a lifetime partner, which were categorised as: ‘familial’ and ‘individual’. Respondents in the former category allowed elder members of their family to select their husband. Participants in the latter category chose their own spouse. Within both pathways there were many factors outside their sphere of control (e.g. poverty and lack of education) which resulted in them having a narrow choice of potential partners.

This chapter first explores processes undertaken in the selection of partners within familial and individual pathways. Unfortunately, the NFHS-III did not collect any data on different types of marriages, meaning that it was not possible to gauge how these partnerships could influence respondents' 'susceptibility' to HIV infection in the wider Indian population. As it was not possible to assess *what* the impact was of these different types of marriages on women's susceptibility to HIV in India, I examine *how* these partnerships might have led to infection.

Finally, I combine qualitative findings from the previous chapter with results emerging within this chapter. This method of analysis provides a fuller depiction of the possible social structural processes involved in the transmission of HIV among qualitative interview participants.

## **7.B FACTORS WHICH CONSTRAIN A RESPONDENT'S CHOICE OF PARTNER**

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### *7.B.I Familial factors*

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In the Indian context 'arranged marriages' are the most common form of organising partnerships. According to Ghimire, Axinn et al. (2006) 'Marriages in Hindu areas of South Asia have a long history of being arranged by parents and the parental family, with no involvement of the husband and wife-to-be in the choice of the spouse' (p. 1184). The choice of spouse is based on the social class, caste and their perceived compatibility with the family (Nanda 1992). Customs associated with arranged marriages vary according to caste, religion and region (Engels 1884, Uberoi 1993, Maye 1960). In northern areas of India it is common for high caste Hindu women to be married to someone of the same caste who belongs to another community (Currie 1992). The bride's family will offer a dowry to the groom's relatives. In southern India, it is traditional for low caste Hindu women to marry uncles or cousins belonging to the matrilineal side of their family (Pfeffer 1983, Rudner 1990, Krishnamoorthy, Audinarayana 2001).

It has been argued that traditions related to marriage in Southern India are more gender equal than those in northern areas as the wife's family is not required to pay a dowry and she is allowed to keep close ties with her natal relatives. However with the advent of globalisation and upward social mobility, it is not unusual for people belonging to lower castes to adopt upper caste habits (Srinivas, Shah et al. 1996, Srinivas 1952). Hence, it is becoming increasingly common for women belonging to lower caste families in southern India to have arranged marriages with dowries to men outside their community.

All qualitative interview participants who had partaken in an arranged marriage stated that they had contracted HIV from their husband. These respondents' narratives of their lives prior to diagnosis illustrated that in some cases their susceptibility began when their family underwent the process of selecting a partner. According to these participants' accounts, their parents' or elders' ability to seek a suitable match was severely constrained by their poor socio-economic status within their community. They commented that as their familial financial resources were very low, their parents were forced to marry them in haste to someone belonging to a wealthier family. Two such examples of this dynamic were PF22 and PP7. PF22 was married at the age of 12 to a man who was over 10 years older than her. She stated:

*'His (PF22's husband) family is well known and has riches enough and hence my people got me married to him. In the beginning he came to seek my sister's hand in marriage. My sister is unfortunately dark and he was quite fair and so he decided not to marry her. Just then I had come of age and 12 years old. I was playing outside and they called me in, dressed me and showed me to him. He liked me and the elders decided to get me married to him.'*

It is often customary in arranged marriages for there to be a long process of negotiation. As PF22's family was in an impoverished state they had few economic resources to use as bargaining tools within this protracted period of negotiation. This created an asymmetric power dynamic between PF22 and her husband's families, leaving her relatives with little choice but to acquiesce to the demands of her in-laws. Her husband's elders were able to defy the common conventions of the arranged marriage system by choosing the

youngest and most malleable member of PF22's family. It is suggested in PF22's account that her parent-in-laws may have ensured through this process of negotiation that she occupied a low status within their family as the youngest and most impoverished member. This left her in a powerless position to protect her own interests within her husband's family, let alone prevent HIV infection.

On the other hand, PP7 argued that her family's ability to arrange a suitable match was greatly hindered by the dowry system. She reported:

*'Actually at that time... I did not know what was sex, marriage, etc. My father's financial state also was very bad and we were two daughters only for him. My husband's people were rich and had property, so my father gave me in marriage to them'.*

This quote indicated that PP7's parents were in a disadvantaged position to negotiate the terms of her partnership as her family unit consisted entirely of female siblings, meaning that her parents considered additional costs of later marrying her younger sister. She did not have any male siblings resulting in there being no economically productive members of her family who could contribute their income towards her dowry. This left her father with a narrow choice of potential partners for PP7 as he could not afford the high transactional costs of marriage. Therefore, her relatives hurriedly partnered her with a man who owned 'a lot of property' in order to ensure that she was financially secure.

It is well-documented that the dowry system of exchanging gifts leaves the woman's family in a disadvantageous position as they are expected to pay a vast sum towards their marriage with little long term financial return (Caldwell, Reddy et al. 1983, Banerjee 1999). Once the woman is married, she is expected to loosen ties with her own relatives and become part of her husband's family unit. This places many women in the uncomfortable position of being perceived as a 'temporary guest' and unnecessary burden on their natal family. In contrast, the husband's family is put in a considerably advantageous position as they are paid a dowry and keep their son as a financial contributor to the family.

Similarly to the cases of PF22 and PP7, many respondents believed that their parents' impoverished status placed them at an even more precarious position under the dowry system compared with other more affluent women. Their families were forced through poverty to select potential partners based on the narrow criteria of their economic status. This resulted in these respondents being assigned husbands who had a 'bad' reputation in their communities as they were rumoured to have had sexual relationships with many other women prior to marriage. Minturn (1993) revealed the social phenomenon of 'deviant marriages' in the context of a Rajput village in U.P (cited in Kaur 2004). These partnerships were arranged by families whose sons lost considerable bargaining power in the marriage market due to 'scandal' caused by pre-marital sexual relationships. Hence, these men's families would seek women from poor families who were willing to marry their daughters to someone for an affordable dowry.

A few participants were adamant that their husband had contracted HIV before they had married them based on two assumptions. Firstly, they had heard rumours from their communities that their partners had engaged in multiple sexual relationships with other women in their community. PF22's family made 'enquiries' in her community on her husband's character, in which she learnt that he was 'a drunkard, womanizer' and that 'because of this dirty nature of his I got HIV'.

Other participants believed that their husband's parents had arranged their marriage knowing that their son was HIV-positive. These respondents believed that their parents-in-law arranged their marriage to save their family's reputation through concealing their son's sero-status. PP7 learnt of a single event in which her husband contracted HIV after she had been diagnosed as sero-positive. She said:

*'Before marriage, he has had the habit of having illegal connections with people. He along with his 4 friends went to a woman who told them that she was an HIV patient. On hearing this, the friends left him back and went away. He had illegal relations with her and the disease passed on to him. This he informed his friends that he had got HIV. They ridiculed him and told him this is the reason why we all came back and you went with her and have now got this disease'.*

PP7's account of this incident pointed to many factors which may have resulted in her husband having a tainted reputation within his community, meaning that it was not possible for his family to find a match from someone within their own social strata. She implied that her husband and his friends regularly partook in sexual relationships with other women in their social network, who were perhaps CSWs, when she described it as a 'habit'. Moreover, her husband had sexual contact with a woman who forewarned him that she was HIV-infected. It was not clear in this account whether a condom was used during this sexual encounter. Nevertheless, others in his community attributed his sero-status to this particular encounter. Consequently, it is doubtful that other families within his community who knew of this incident would be willing to risk their daughter's health by arranging a partnership with him. It is possible that PP7's parents-in-law may have arranged the marriage in order to avoid further scandal falling on their family.

The second assumption was based on their observation of their spouses' health-status. PF22 commented that her husband had exhibited HIV-related symptoms, like 'boils', within the first few months of their marriage. Other participants reported that their husband had displayed HIV-related symptoms (e.g. 'fits' and weight-loss) within the first year of their partnership. These symptoms could be indicative of them being at the final stages of the infection (Kigozi, Dobkin et al. 2009), when PLWHA often have high viral loads (Kmietowicz 2010, Antiviral Briefs. 2010)<sup>129</sup>. Unfortunately, many participants may have started their sexual relationship with their husband during the most infectious stage of his illness, thus, increasing the odds of them later contracting HIV.

Another factor which limited participants' families' ability to seek a match was personal or familial disability. Around a quarter of respondents in the qualitative sample

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<sup>129</sup> Recent research has highlighted that transmission is most likely to occur when an HIV-positive individual has a high viral load (Quinn, Wawer et al. 2000). Hence, it has been argued that the most effective method of preventing transmission is to prolong the 'dormant' stage of the virus through providing PLWHA with anti-retroviral treatment (Das, Chu et al. 2010).

either had a disabled member of family or were themselves disabled<sup>130</sup>. Currently, there are very few governmental policies established to ensure financial security for families with disabled members in India (Indian Government 2010). These families suffer extreme poverty as there is little work available for physically disabled people, especially for those with little or no education (Parasuram 2006, Ghai 2002, Mitra, Sambamoorthi 2008). Hence, participants who were either disabled or had a disabled member in their family commented that their purchasing power within the arranged marriage system was diminished as they were either unable to afford a dowry or potential partners were unwilling to accept a disabled wife into their family.

A few peer providers mentioned that a sizeable proportion of female HIV-positive beneficiaries of their services were disabled. According to these peer providers' accounts of dealing with disabled sero-positive women, informal practises (such as chaperoning deaf beneficiaries to group counselling sessions) were well established to meet the demand of this client base. These peer providers believed that in many cases the disabilities had existed prior to the clients contracting HIV rather than being a product of their illness<sup>131</sup>. They were unable to offer an explanation as to why so many of their clients were disabled, yet their narratives indicated that there was a possibility that some disabled women in A.P. could experience a heightened risk of contracting HIV<sup>132</sup>.

PF18's narrative illustrated a set of processes which may have predisposed her to HIV infection as a disabled woman. She had a debilitating skin condition that severely restricted her physical mobility and ability to partake in heavy agricultural work. Her disability was a source of stigma prior to contracting HIV, which was a product of her belonging to a high caste background in which her disability was considered as a form of impurity. She

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<sup>130</sup> According to the WHO (2011) disability is a 'problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations' (p.1).

<sup>131</sup> Unfortunately, it was not possible to ascertain if individual or familial disability contributed to a woman's risk of contracting HIV on a statistical level as there were variables measuring this in the NFHS-III.

<sup>132</sup> Groce (2005) reported that disabled individuals in developing countries belong to the most marginalised sections of society, hence in some cases were more likely to partake in risk behaviours than their non-disabled counterparts.

commented, 'My family never treated me well as I had an allergy. They never even handed me a glass of water'.

It is possible that stigma associated with PF18's disability could have left her vulnerable to sexual abuse. Research in other countries has highlighted that women with disabilities are more likely to experience sexual exploitation and abuse than their non-disabled peers (Yousafzai, Dlamini et al. 2004). PF18 stated:

*'When I was young a guy who stayed in my neighbourhood called me to make tea. When I had gone there he closed all the doors and raped me.'*

The reaction of PF18's parents to this set of events was to treat her yet again as if she was a source of shame and impurity rather than taking an effort to ensure that her assailant was convicted of rape. She claimed that her parents persuaded her to undertake an abortion when it was apparent that she was pregnant. This was followed by an operation to render her infertile, indicating they might believe that the act of rape polluted her body to the extent that she was no longer deemed able to participate in the ordinary and natural life-course of having children (Roy, Ram et al. 2003). Then she was furtively married to another man of her caste in a small wedding ceremony, perhaps to avoid rumours spreading around her village concerning her virginal status prior to marriage as any form of pre-marital sex by female members of the family is often perceived as shameful to the whole family unit by others in a rural community (Caldwell, Reddy et al. 1983). Therefore, PF18's disability and her previous history of sexual abuse severely narrowed her choice of potential partners.

On the other hand, PF21's family's ability to choose a suitable partner was severely hindered by her parents' and siblings' level of impairment. She reported that her mother was 'mentally innocent', implying that she suffered from a cognitive disability, and two of her sisters were deaf and mute. As resources were tight, her father ensured that PF21 and her non-disabled sister received enough education so that they could both financially contribute to the household as nurses. She stated:

*'He (her father) used to work so hard. Since he was having a heart problem he used work on only one acre. I and my sister used to work at nursing to earn money and my mother used to stay with my two elder sisters at home'.*

Elder members of PF21's family insisted that a match should be arranged for her when her father was extremely ill from his 'heart condition'. PF21 reported:

*'This match was settled by my aunt. When I looked at my father, he suffered with ill health and my mother was innocent so I needed someone to assist and help me so I married'*

This quote illustrates that PF21 was forced by an unfortunate set of circumstances into an arranged marriage. She believed that it was necessary for her to marry as she needed a man to assist her in taking care of other disabled members of her family. As a consequence, her aunt had to hastily arrange a match for PF21 before her father died. Similarly to other respondents PF21's husband had a history of risky sexual behaviour which predated her marriage.

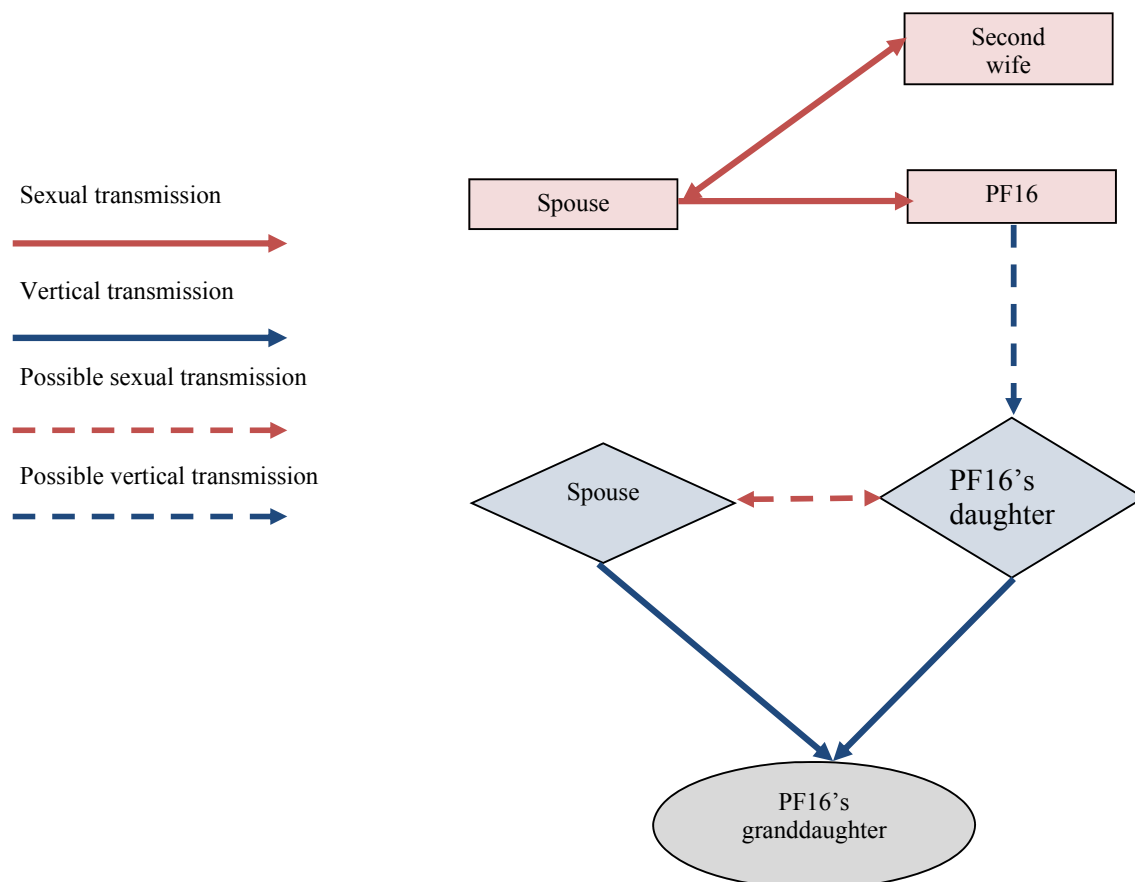
Finally, almost a quarter of all respondents reported that they had other relatives who were HIV-infected. Nine participants, four of whom were related, commented that either a parent or a sibling was sero-positive. PF33 stated, 'In my relations, there are people who have HIV. My sister, my brother and my younger sister all have HIV'. In these cases, HIV was not vertically transmitted from parent to child but was probably acquired through risky sexual behaviour. It is possible that dynamics of HIV transmission existent within the community, as described in the previous chapter, may have filtered down into the family unit.

A few peer providers acknowledged that they had to deal with families which had many members who were HIV-positive. PP4 reported that she had cared for a family in which three generations of its members had recently died of an AIDS-related illness. She commented that in this family the 'grandfather, grandmother, daughter, son-in-law and granddaughter all suffered with HIV and ultimately died'. According to PP4's account of this family, the first two generations may have acquired HIV through their own sexual risk behaviour. The virus was then vertically transmitted from parent to child in the youngest

generation. Unfortunately, PP4 was unable to offer an explanation to the question why this particular family was more susceptible to HIV infection than others that she had dealt with.

PF16's narrative of her family's experience of dealing with HIV may capture the social structural processes involved in inter-familial transmission. The first two generations of PF16's family were infected through sexual transmission. The virus may have initially entered the family through her husband, who was having a concurrent relationship with a second wife. Then she believed that her daughter may have contracted HIV from her own spouse. Finally, HIV was vertically transmitted from PF16's daughter to her granddaughter. Unfortunately, it is not possible to verify the exact times or means in which HIV was acquired as it is entirely dependent on PF16's account of interfamilial transmission<sup>133</sup>. Figure 7.1 illustrates the hypothesised transmission dynamics within PF16's family.

**Figure 7.1:** Transmission dynamics in PF16's family



<sup>133</sup> It was not possible to verify if this was the only mode of transmission as PF16's daughter had recently died. Hence, I cannot reject the possibility that PF16's daughter may have contracted HIV through vertical transmission.

The selection of PF16's and her daughter's partner was strongly affected by 'macro-environmental' determinants related to socio-cultural norms mediating practices of arranged marriages in southern India. In this region it is traditional for low caste Hindu women to be partnered with male relatives belonging to the matrilineal line of the family (Dumont 1957, Pfeffer 1983, Rudner 1990, Krishnamoorthy, Audinarayana 2001, Dube 1955). Hence, according to traditions in Andhra Pradesh, PF16 and her daughter were both married in their early teens to an older male relative. This may have heightened their susceptibility to HIV infection as they were married to someone with far more sexual experience than they had (Pettifor, O'Brien et al. 2009). Their ability to negotiate safe sexual practises would have been severely inhibited by their lack of awareness of HIV/AIDS and their relative inexperience in navigating sexual relationships<sup>134</sup> (Clark 2004).

Another 'macro-environmental' determinant which may have increased susceptibility was *geographical mobility*. PF16 reported that her husband moved for a short while to another district in A.P. and married a second wife, who may have transmitted HIV to him<sup>135</sup>. These risk behaviours could be attributed to wider social trends related to economic development that pushed these vulnerable communities into transition, heightening mobility of male members who worked elsewhere in order to survive. PF16 suggested that *geographical mobility* of male members of her family enabled them to maintain concurrent partnerships, she said:

*'I am the second wife to my husband. I am legally the first wife and he went around with a lady while in G- and I think due to his habits, I got HIV... My husband is my second cousin. My husband is my mother's maternal uncle's son. Both my brother and my husband married somebody else. My brother's wife had two children and then he died. My husband had a link with my brother's wife as well... Then, after a time, my husband returned saying that he wanted his wife and child.'*

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<sup>134</sup> PF16 believed that her daughter who was 'not so worldly but on the innocent side of life' was infected with HIV by her husband who was older and more educated.

<sup>135</sup> Findings in the NFHS-III illustrated that HIV-positive men were significantly (<.001) more likely to have two wives/partners (2.1%) than the general population (0.8%). These results illustrated that polygamy, though fairly uncommon in India, can put those who participate in it at greater risk of contracting HIV; perhaps as they have a higher tendency towards other risk activities. Please see Appendix 42 for table displaying the amount of wives male participants had according to their sero-status.

PF16 locates her husband and son-in-law's<sup>136</sup> sexual risk behaviour within the structure of their family by mentioning that both her spouse and brother had married second wives. Her spouse also had a sexual relationship with his sister-in-law after her husband died. PF16's narrative suggests that it may have been acceptable practice for male family members to maintain concurrent relationships with women belonging to their familial network. This sexual network was further expanded through male members initiating sexual relationships with women outside of their community. As these men already had a history of risky sexual behaviour, it was probable that PF16 was choosing from a pool of potential partners for her daughter who were already susceptible to HIV infection.

PF16's daughter later learnt that she was HIV-positive at the age of 15 after she undertook a routine HIV test as part of antenatal care when pregnant. She did not know that there were public healthcare facilities providing treatment to prevent vertical transmission from parent to child. Moreover, PF16 had heard 'rumours' in her community that staff at her local hospital were murdering PLWHA. This made her so apprehensive that she insisted that her daughter should give birth at home. She said:

*'We were told that such people with HIV were being treated badly and kerosene is poured over their bodies and they are burnt in hospital, so we did the delivery of my daughter at home only'.*

This portion of PF16's narrative illustrates how dynamics within the family can lead to intergenerational transmission of HIV. As the matriarch of the family, PF16 was responsible for most decisions on care of her daughter whilst pregnant as it is customary in A.P. for women to reside with their mothers for a period of a few months whilst pregnant with their first child. Unfortunately, PF16 was unable to make any rational or informed choices on her daughter's treatment as she had little knowledge of HIV. In addition, she was reluctant to visit any Western healthcare practitioners out of fear of stigma. This may have resulted in HIV being passed on from the second to the third generation of PF16's family.

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<sup>136</sup> She did not offer an explanation of how her son-in-law contracted HIV but it is implied throughout the interview that he may have partaken in sexual risk behaviour.

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### *7.B.II Individual factors*

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The system of the traditional arranged marriage has shown few signs of abating, with only a small minority partaking in 'love marriages' in India (Banerjee 1999, Bandyopadhyay 2003). Strikingly, almost half of the participants in the qualitative phase of research mentioned that they had a 'love marriage', often with someone from a different caste. These participants first met their spouses in their neighbourhoods or through work. In the past, these types of relationships may not have been possible as many south Indian villages were segregated on a caste framework whereby the highest and the purest castes, such as Brahmins, would live in the centre and the lowest castes would be relegated to hamlets outside the village (Moffatt 1975). These relationships in the modern contemporary context could be indicative of wider social change, whereby urbanisation and economic development have reduced the rigidity of class and caste boundaries (Thorat 2002, Jodhka, Shah 2010, Banerjee, Knight 1985).

These wider social changes whilst beneficial to some social groups that previously experienced oppression (e.g. Dalits are able to seek employment outside their caste occupations) may also increase transmission of HIV as individuals are provided with the opportunity to initiate sexual relationships with those outside their caste-based communities. Prior to these social developments many women may have been part of a restricted sexual network, consisting only of those within the same caste in their community. As these communities industrialise and urbanise, these women's sexual networks would widen to include people outside their immediate communities due to migration of labour and increased interaction with other social groups.

Participants' narratives indicated that they may have used increased interaction within the public sphere through their occupations to match themselves with partners of a higher social standing than their own. In the arranged marriage system, there would be a restricted level of hypergamy as their parents would seek a partner with high earning potential from their own caste. Respondents who chose their own husbands were able to contravene social

norms of the arranged marriage system to marry an individual occupying a higher caste or class, thus engaging in a heightened form of hypergamy.

Some participants who chose their spouse had a sexual relationship with their partner prior to marriage, suggesting that their susceptibility to HIV may have been linked to their own behaviour. Many of these respondents entered their relationships on unequal terms as their partners were older, more educated, from a higher caste background or had a better paid position in their work than they had. PF30 met her spouse (an owner of a flower shop) through her work arranging flowers into accessories usually worn in women's hair. Additionally, PF23 (PF22's sister) first encountered her husband through her work in a 'rice mill' factory. Similarly to PF30, she was in a junior position in her occupation as a 'coolie' or labourer in the factory, whilst her partner managed the machinery.

Respondents who first met their spouses in their neighbourhoods also entered marriages with an asymmetric power differential between themselves and their partner. One such respondent was PF10, who started her relationship when she was 12 years old. It was not clear in her account whether she and her partner had sexual contact before marriage. However, she implied that there could be a sexual element to their relationship when she kept on reiterating how 'in love' with him she was<sup>137</sup>.

Qualitative interviewees' narratives illustrated how the processes involved in negotiating these 'love marriages' could later influence these women's propensity to HIV infection. There could be many risks associated with a self-arranged partnership due to the relationships involving pre-marital sex; often leaving women in a vulnerable position should their relationship not evolve into marriage. These respondents may have felt 'social pressure' to formalise their relationship to their partner as any form of interaction with the opposite sex is prohibited under the purdah system (Rocca, Rathod et al. 2009).

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<sup>137</sup> As her spouse was over 10 years older than her and she would have been considered as under the age of consent in most states in India (Avert 2011), her relationship could be deemed as morally wrong or paedophilic by modern standards.

In addition, some of these participants may have already made a psychological and physical investment in their relationship through repeated contact with their potential partner. They portrayed their relationship in a romanticised fashion, repeating throughout the interview how in love they were with their spouse prior to marriage, indicating they had developed an emotional bond. PF10 stated:

*'I was in love with my husband and we were both from different communities – I a Christian and he a stonecutter'.*

This vastly differed from that of respondents who had undergone an 'arranged marriage'- who only mentioned 'love' within the context of their marital relationship. This could be due to it being socially expected in India for heterosexual couples to slowly develop a loving relationship once married (Kalpagam 2008).

Some of these respondents reported that their husband was rumoured to have had multiple sexual partners in their community. Unlike participants whose husbands had an arranged marriage to avoid scandal attached to pre-marital sex, these respondents commented that they were possibly one of many sexual partners that their spouses were with at the time. PF23 reported that when she was engaged to her partner, her neighbours tried to forewarn her of his sexual history. She stated:

*'When he proposed to me and I was planning to get married to him- all my neighbours and well-wishers advised me from marrying him because he was a womanizer of the first order. I did not believe all this'*

Some respondents who undertook a 'love marriage' reported that they experienced opposition to the match from their natal family and in-laws. These participants had an 'inter-caste marriage', meaning that their husband belonged to a different caste and/or religion than they did. This contravened social norms dictated by the arranged marriage system, in which the individual was supposed to follow the wishes of elder members of their family who chose someone of the same caste and religion; thus, consolidating their family's position within their community. Kalpagam (2008) commented that 'forbidden love' attracts such retribution

as ‘inter-caste marriages more than any other blur the boundaries of caste and shake its foundations, for the reproduction of the caste system requires the maintenance of these boundaries’ (p. 54).

PF10’s family was opposed to her marriage as they occupied a far lower caste and class position than that of her husband’s. Both of the families resistance to the match was so vehement that PF10 and her partner were forcibly separated for a period of two years. She perceived this as yet another romantic trial that she had to overcome to demonstrate her mutual love for her partner. PF10 stated:

*‘For two years we remained so until our marriage was performed. Our people did not like this marriage and we had to face a lot of problems and it took us two years to settle this issue’.*

Other respondents reported that they had to adopt decisive methods to ensure that their partner married them in the face of opposition from both families. For example, PF23 decided to live with her partner for a year before they married as his mother was trying to persuade him to marry a woman from his own caste. She stated:

*‘For one year we lived separately in a rented house and my in laws were giving us a lot of trouble. They would come to my husband and tell him to leave me. They would tell him to marry the girl from their caste. My mother in law was suffering from cancer and she wanted her son to leave me and marry their caste girl.’*

Consequently, a few participants who entered ‘inter-caste’ marriages experienced little to no support from their natal family or parents-in-law. For example, PF1 reported that her mother-in-law would refuse to interact with her as she was still upset that her son had flouted her authority by choosing his own wife. Moreover, PF10 commented that she experienced emotionally abusive behaviour from her own family who remained distressed at her decision to have a ‘love marriage’. She stated:

*‘They (PF10’s parents) told me that since I got married against their wishes, they felt I had got this disease from him. I do not go to my parent’s house often neither do I drink or eat in the house. I cannot expect them to help me as they are not financially sound and they cannot help me in any way. As I know I cannot expect anything from them, I take it lying down without any expectations from them’.*

Respondents' narratives of 'familial' and 'individual' pathways pursued to secure a match highlighted that their choice of partner was affected by a similar set of macro-environmental determinants. Participants' choice of partner in an arranged marriage was influenced by their caste and socio-cultural practices associated with securing a match, such as exchange of dowry. The respondent's choice of partner in a 'love marriage' was affected by similar determinants apart from economic development which enabled their interaction with potential partners from other backgrounds allowing them to engage in a different form of hypergamy. The impact of these determinants on respondents' propensity to contract HIV was further amplified by macro-environmental determinants, e.g. poverty, which inhibited parental choice of partners for respondents since they could not afford an expensive dowry.

The following section will discuss emerging and converging results from the qualitative and quantitative phases of research.

### **7.C COMBINING EMERGING AND CONVERGING RESULTS**

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The previous chapter presented findings from the qualitative phase of research that converged with results from the quantitative stage of analysis. It may seem that findings in chapter 6 were different to that featured in the current chapter. Nonetheless, when both sets of findings are blended, they demonstrate that there is possibly a temporal and communal element to the HIV epidemic in India. Other experts in the field of HIV research have lightly touched upon this phenomenon (Barnett, Whiteside 2002), the most prominent being Ruxruntham, Brown et al. (2004) who argues that the trajectory of the HIV epidemic in Asia is influenced by the time in which HIV first entered the population.

These emerging and converging results illustrate the possible sequence of events leading to qualitative interviewees contracting HIV. These events were divided into four phases in order to correspond to Ruxruntham, Brown et al's (2004) conception of the trajectory of HIV epidemics in Asia. The first phase of infection was when HIV initially

entered the community through *geographical mobility* related to temporary migration of the male population in search of work.

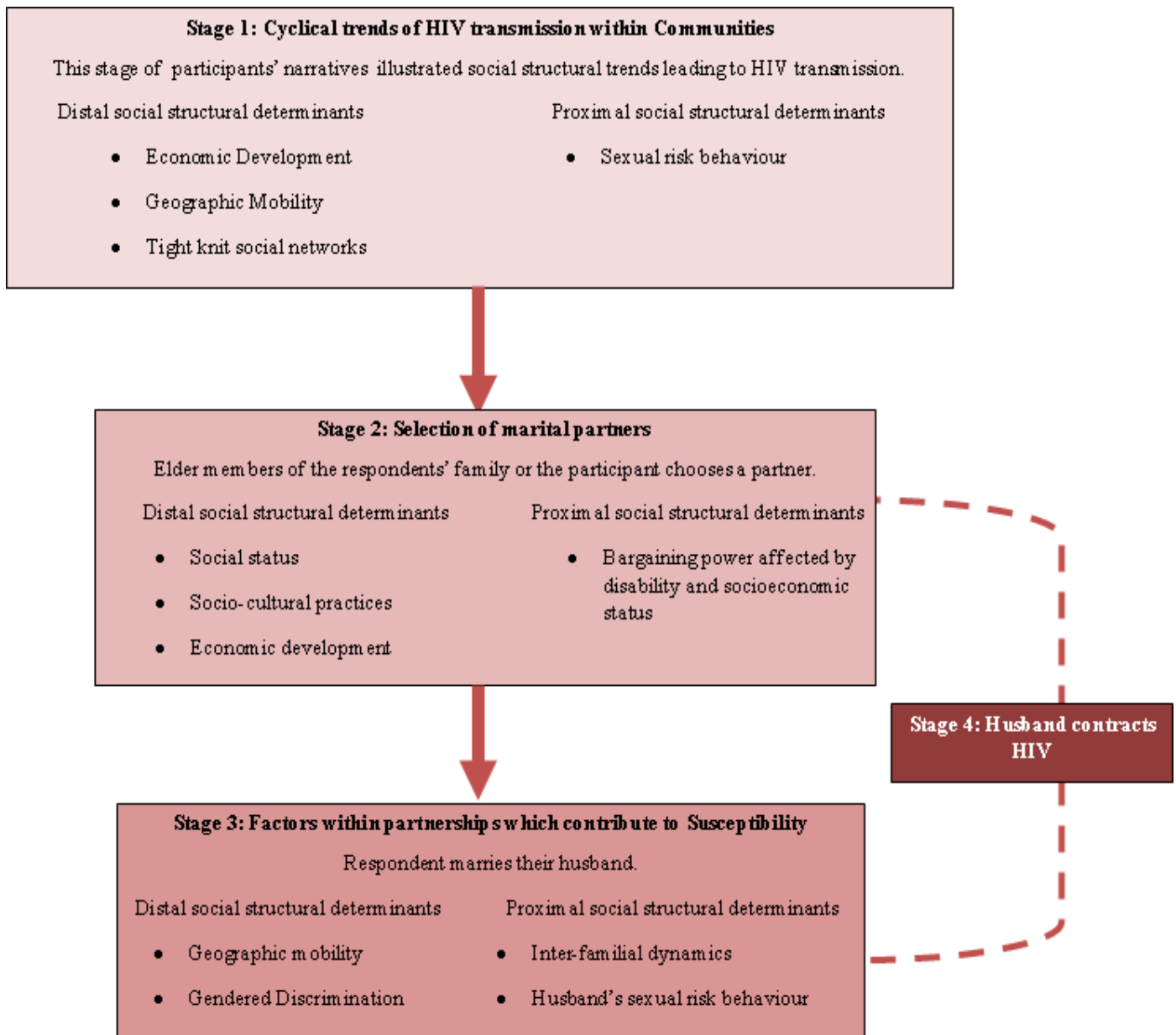
According to respondents' narratives, they belonged to environments which put them at elevated risk of contracting HIV. Some participants commented that there were many other PLWHA in their close-knit communities, indicating that they could be living in an area with a high prevalence of HIV. In addition, other members of their community practised sexual risk behaviour, which resulted in further transmission of the virus. These communal dynamics of HIV-related risk behaviour could have resulted in some participants having a narrow choice of partners who either were already sero-positive or were susceptible to HIV infection.

The second phase involved the respondents or elder members of their families selection of their spouse. Participants' narratives highlighted that a set of 'macro-environmental' determinants, which were closely interrelated, worked in unison to restrict their choice of potential partners. These determinants were: 'caste' and 'socio-cultural practices' associated with securing a match. This affected respondents or their family's ability to make an informed choice of partner and to effectively negotiate the terms of their relationship. For instance, disabled participants who had an arranged marriage reported that they had a narrow choice of potential partners because their parents were too impoverished to afford an expensive dowry. Therefore, these respondents were partnered with spouses who had a history of risky sexual behaviour.

Respondents who had a 'love marriage' were affected by similar social structural determinants, apart from 'economic development' that led to these participants being more able to seek relationships outside their social strata. Their ability to negotiate the terms of their relationship was greatly hindered by familial opposition to these marriages. As 'love marriages' were perceived as a contravention of caste and class divisions within these communities, some of these respondents were forced to virtually forgo all psychological and social support needed from their natal family. This meant that they had little or no familial support when experiencing difficulties within their marriage.

The following phase was when the respondent entered their relationship. At this point of the narrative these respondents propensity to contract HIV intensified as they were expected to have regular sexual contact with their husband. During this phase, respondents' 'susceptibility' was affected by a combination of 'macro-environmental' and 'behavioural' determinants. Participants 'susceptibility' was most directly affected by their spouse's sexual risk behaviour as they were often aware of their husbands' extra-marital relationships with other women in their communities. These respondents commented that members of their husband's family also knew of his risky sexual behaviour. This indicated that these family members were to some extent acquiescing in their husband's behaviour out of a sense of loyalty.

The final phase of these respondents' narratives was when their spouse contracted HIV. During this phase they were most susceptible to acquiring HIV through repeated sexual contact with their already HIV-infected husband. It was difficult to ascertain when respondents' spouse contracted HIV as the virus can be dormant for long periods of time. However, a few participants believed that their husbands may have contracted HIV prior to marriage, as in the case of PP7. Therefore, it is important to keep in mind that the third and fourth phases can be interchangeable due to the fact that in some cases the participants' husband was sero-positive before marriage whilst in others they contracted HIV during their marriage. Figure 7.2 illustrates the social structural determinants affecting participants' propensity to contract HIV according to each phase of their narrative.



**Figure 7.2:** Stages of qualitative interview participants' narratives

## 7.D DISCUSSION AND CONCLUSION

This chapter utilised findings from the qualitative stage of research in order to uncover socio-cultural processes which drive HIV-positive women in India into partnerships with husbands who engage in sexual risk behaviour. These processes were identified through analysis of respondents' accounts of their lives prior to being diagnosed with HIV.

Although there is always a possibility that respondents may not be entirely truthful during their interviews, as would be the case in any qualitative study; results in this chapter

suggest that most qualitative interviewees said that they had contracted HIV from their husband. Respondents' susceptibility to HIV infection was affected by their ability to make a rational and informed choice of partner and to effectively negotiate the terms of their relationship. Participants who had an arranged marriage reported that they had a narrow choice of potential partners due to poverty and disability. Many respondents argued that their parents were too impoverished to afford an expensive dowry. As Banerjee (1999) stated:

*'The escalation in groom-price in recent years constitutes a permanent burden for parents of women. Some families believe that a woman's parents are permanently obligated to meet any monetary demands are made upon them by a husband's family; consequently, a marriage results in a permanent leakage of assets for a woman's family'* (p. 664).

This meant that many participants' parents were forced to marry them to someone from a wealthier family who was not demanding much financial compensation. As a consequence, these respondents' parents had little or no leverage in negotiating the terms of the relationship. Therefore, these respondents were partnered with spouses who had a history of risky sexual behaviour. In some cases, such as PP7, these men may have contracted HIV prior to their marriage.

Respondents who had a 'love marriage' were affected by similar factors. They reported that they had married men who were of a higher socio-economic status in their community. Their ability to negotiate the terms of their relationship was greatly hindered by their parents' opposition to these marriages. Elder family members often view younger relatives who enter these types of partnerships as flouting their familial authority (Rocca, Rathod et al. 2009). As Mody (2008) stated:

*'Love-marriages... are widely viewed as a most unholy union. They challenge "natural"... caste hierarchy and social considerations of class, status and standing. Based on... lust, and far from being social events, they are considered to be anti-social'* (p.8).

The role that each social structural determinant played in their choice of partner and the outcome it had was slightly different depending on the type of marriage they undertook. For instance, within arranged marriages respondents' caste guided the choice of potential

partner. On the other hand, respondents' who self-arranged their partnerships contravened socio-cultural practices related to marriage by choosing a spouse of a higher caste, which later provoked the ire of elder members of their community. Despite choosing different pathways in finding spouses, both types of respondents were matched with husbands who had extra-marital relationships and were physically abusive.

These findings suggest that 'socio-cultural practices' related to marriage may play a crucial role in mediating women's susceptibility to HIV infection in the Indian context. These practices inadvertently influenced their choice of lifetime partner and their ability to negotiate the terms of their relationship<sup>138</sup>. Currently, few studies in developing countries specifically assess the impact that 'socio-cultural practices' of marriage have on women's propensity to contract HIV<sup>139</sup>. Researchers on HIV transmission seem to mostly concentrate on risk behaviour; although, recent research conducted in other developing countries (e.g. Tanzania and Côte d'Ivoire) have highlighted that traditional forms of marriage can mediate sexual behaviours of young people through postponing their sexual debut (White, Cleland et al. 2000, Munguti, Grosskurth et al. 1997)<sup>140</sup>.

These socio-cultural norms on marriage 'make young females more vulnerable as they start unsafe sex during marriage and yet consider marriage to be a guarantee of protection against STIs, including HIV' (Molla, Berhane et al. 2008: 9). This chapter contributes to the literature on HIV transmission in India through exploring the processes which led to some women being coupled with spouses who partake in sexual risk behaviours. This research illustrates that the emphasis on the individual's past risky sexual behaviour could be impractical as a means of conceptualising patterns of HIV transmission amongst

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<sup>138</sup> Few researchers have explicitly taken into account that the traditional form of arranged marriage, still prominent in India, may limit pre-marital sexual contact thus delaying risk-taking behaviour. It has been observed by social scientists that there is a strict observance of purdah prior to a marriage being arranged in India (Olsen, Mehta 2006, Nanda 1992). Under the purdah system sexes are segregated and unmarried women are confined to the private sphere. Therefore, many young heterosexual women have few opportunities to initiate sexual relationships with men.

<sup>139</sup> In contrast, studies on domestic violence in India often take into account the impact that dowries have on women's propensity towards experiencing physical abuse from their husband (Srinivasan, Bedi 2007, Rocca, Rathod et al. 2009, Krishnan 2005, Krishnan, Rocca et al. 2010, Babu, Kar 2010).

<sup>140</sup> Molla, Berhane et al. (2008) noted that in Ethiopia women's virginity was still pertinent in securing a match in rural areas, thus delayed their sexual debut.

women in developing countries, especially India wherein most women do not even choose their own partners.

# PART III



## **Chapter 8 UTILISATION OF HEALTHCARE FACILITIES AND HEALTH BEHAVIOUR OF PARTICIPANTS IN THE NFHS-III**

### **8.A Introduction**

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Part II, comprising chapters 5, 6 and 7, explores the social structural determinants of HIV transmission among women in India using a combination of qualitative and quantitative data. These chapters illustrate how some women's propensity to contract HIV could be affected by their social context, e.g. the rate of sero-prevalence in their area of residence, and traditional gendered norms, such as the justification of husbands' use of violence to control their wives' behaviour. Some of the most illuminating findings indicated that the same social structural dynamics which led to these women's infection may later negatively affect them after diagnosis. For instance, some qualitative interviewees were physically disabled, which may have been linked to these respondents being married to spouses engaging in sexual risk behaviour. These respondents struggled to access HIV-related healthcare services, which were often located a long way from where they lived.

These findings illustrate the way that transmission and treatment of HIV are intrinsically linked, rather than being entirely separate social phenomena. Part III of this thesis, consisting of chapters 8, 9 and 10, uses Barnett and Whiteside's (2002) concept of 'vulnerability' to explore the impact of HIV/AIDS on HIV-positive women. Particular attention is paid to WLHA's access to healthcare facilities. The incorporation of these concepts in this thesis allows the full analysis of how social structural determinants which may influence the transmission of HIV among women in India may later affect their ability to access healthcare services.

I had originally intended to use data from the NFHS-III to assess which social and structural factors affected WLHA's use of healthcare services. Independent variables were to be selected according to Andersen and Aday's (1981) model of access. Unfortunately I was

unable to use all dimensions of access fully as it is not possible to ascertain whether female HIV-infected participants knew of their sero-status because for ethical reasons there were no questions in the NFHS-III which directly addressed whether respondents knew or suspected that they were HIV-positive. Thus, it could not be determined with any certainty whether participant's health-seeking and health-maintaining behaviours were driven by their knowledge of their sero-status or by other variables, e.g. HIV-related or other illnesses.

As a result, the objective of this chapter is to investigate whether female HIV-infected participants in the NFHS-III display different types of health-seeking and health-maintaining behaviours from the general HIV-negative population. This type of information is crucial as female HIV-positive respondents' use of healthcare facilities could differ from their HIV-negative counterparts due to the complex nature of the virus, which manifests itself in the form of many different symptoms during each stage of their illness. It is common for PLWHA to experience 'Opportunistic Infections' (OIs), e.g. TB, during the final stages of their illness<sup>141</sup>. As HIV-related symptoms range widely from minor ones to life threatening illnesses like Kaposi's Sarcoma, it is possible that many PLWHA may seek treatment for these symptoms, especially during the later phases of illness, without being aware that they are HIV-positive. The following section will describe the selection of dependent and independent variables for the purposes of this analysis.

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<sup>141</sup> The primary stage of infection is often accompanied by a short respiratory flu-like illness (Forbi, Forbi et al. 2010). After this stage the virus becomes dormant, with an absence of symptoms.

### 8.A.1 Selection of variables to measure 'vulnerability'

As chapter 8 explores whether sero-positive women display different patterns of health-seeking and health-maintaining behaviours to that of their sero-negative counterparts, the dependent variable selected was participants' HIV-status. Figure 8.1 depicts how Andersen and Aday's (1981) theoretical framework is used to compare use of healthcare facilities and health behaviours between female HIV-positive and negative participants.

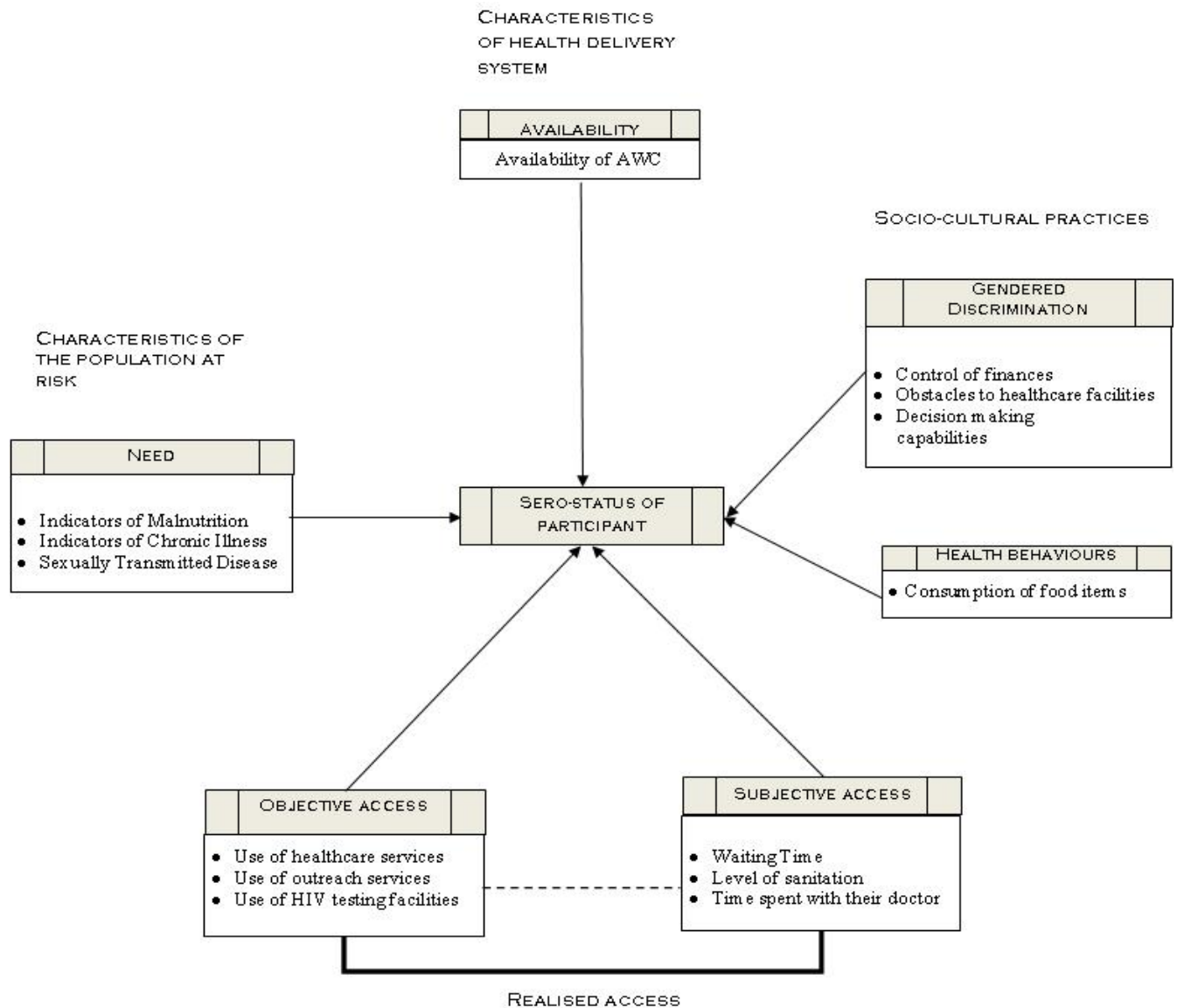


Figure 8.1: Andersen and Aday's model of access with additional adjustments for data analysis

The selection of independent variables broadly follows Andersen and Aday's (1981) model of access, which is modified for the purposes of this thesis. 'Potential' dimensions of access are first examined; these dimensions encompass the 'characteristics of health delivery system', 'characteristics of population at risk' and 'socio-cultural practices'. The 'characteristics of health delivery system' are usually measured by exploring the availability of facilities locally.

As the NFHS-III is a generic survey, covering a wide set of variables not entirely related to HIV prevention or treatment, it did not collect much data on factors affecting access to healthcare facilities, such as cost of transport to the clinic. This issue is particularly problematic in the measurement of 'availability' as the NFHS-III did not collect data on the distance of households from healthcare facilities and the number of working staff per clinic or volume of treatment services available in any given area<sup>142</sup>. This could be due to there being a wide range of unregulated private healthcare facilities available at a local level (Qadeer 2000) which are difficult to identify and collect data on. Information collection centred on the existence of an Anganwadi Centre (AWC) in each of the NFHS-III sample enumeration areas and the date in which it was set up. This type of data was collected since one of the main objectives of the NFHS-III was to provide national and state-level estimates to governmental organisations and research bodies on participants' use of family planning and early childcare services. As the AWC provides antenatal and postnatal healthcare to impoverished pregnant women and lactating mothers, this data provides an indicator of the local *availability* of these types of services for female HIV-positive respondents.

The 'characteristics of population at risk' examines participants' *predisposing characteristics, enabling resources* and *need*. *Predisposing characteristics and enabling resources* were excluded from analysis as these dimensions of access included variables, such as age, which were already covered in Chapter 5 under the rubric of 'susceptibility'. Hence,

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<sup>142</sup> The previous NFHS did offer data on these variables at village level. However, in the NFHS-II conducted in 1998-99 it was problematic to use this as a dataset (IIPS, ORC Macro 2000).

female participants *need* for treatment is assessed through using variables which measure their level of malnutrition, their experience of chronic illness and sexually transmitted infections (STIs). The respondents' level of malnutrition is measured through examining their Body Mass Index (BMI)<sup>143</sup>, the severity of their anaemia<sup>144</sup> (Fondu, Hariga-Muller et al. 1978) and whether they had menstruated in the six weeks prior to the survey or not. In addition, the NFHS-III had several measurements of chronic illness in the Indian population. Participants were asked if they had previously experienced TB, diabetes, asthma and goiter or thyroid disorder. Finally, female participants' experience of sexually transmitted infections was measured through their reported diagnosis of an STI and if they had a genital sore or 'bad smelling' abnormal discharge in the 12 months prior to the survey.

Andersen and Aday's (1981) model of access was altered to address the complexity of factors affecting WLHA's access to healthcare facilities in developing countries. An additional component of 'socio-cultural practices' was added to encompass social norms (e.g. 'health behaviours') which may influence female HIV-infected participants' ability to continually use treatment, such as their diet. Participants' *health behaviours* were tested because recent medical research has illustrated the importance of nutrition and health maintenance in adherence to ART treatment (Kaschula 2011, McMahon, Wanke et al. 2011) and delaying the onset of AIDS (Holzemer 2002, Chou, Holzemer 2004, Nicholas 2005). The NFHS-III collected data on participants' *health behaviours*, such as their consumption of food items and their intake of tobacco. I, therefore, examined how frequently they ate different types of food in order to ascertain their possible level of nutrition.

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<sup>143</sup> The NFHS-III collected data on participant's health-status as part of the individual and household survey. First, as part of the household survey, interviewers recorded all household members' height and weight. This data was converted into a BMI measurement, which is a key index relating a person's height to their weight in order to ascertain if they have a healthy level of fat content in their bodies. The National Institutes of Health (2011) defines people with a BMI of less than 18.5 as underweight, 18.5- 24.9 as normal weight and 25 or more as overweight.

<sup>144</sup> Data was also gathered on household member's level of anaemia through collected blood samples. The NFHS-III recorded three levels of severity of anaemia in participants, which were: mild anaemia (10-10.9 grams/decilitre), moderate anaemia (7.0-9.9 g/dl) and severe (less than 7.0 g/dl).

Within the dimension of ‘socio-cultural practices’, the impact of *gendered discrimination* on sero-positive women’s ability to cope with their condition was also assessed. The NFHS-III collected data from female participants that measured their level of empowerment on four components, the first of which recorded barriers that they experienced whenever they tried to use any type of healthcare facility<sup>145</sup>. The second component measured married employed female respondents’ control over their financial resources<sup>146</sup>, while the third component assessed married female participants’ ability to make decisions on their own healthcare, making large daily and household purchases and visiting their family. The final component of empowerment examined female participants’ freedom of movement in the public sphere<sup>147</sup>.

Finally, ‘objective’ and ‘subjective’ realised dimensions of access are examined. ‘Objective realised access’ assesses respondents’ actual use of healthcare services. This is evaluated through variables which measure participants’ usage of HIV testing facilities<sup>148</sup>, outreach worker services<sup>149</sup> and other types of healthcare providers<sup>150</sup>. ‘Subjective realised access’, meanwhile, explores respondents experience of using healthcare services. This is investigated through a set of indicators which assess the quality of services that female

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<sup>145</sup> Participants were asked if any potential obstacle (i.e. distance from healthcare facilities) posed a ‘big problem’, ‘small problem’ or ‘no problem’ at all.

<sup>146</sup> Married employed female respondents were asked if they had money for their own use, who decided how their income should be spent, how much they earned in relation to their husband and if they were allowed to make any decisions on how their husband’s income would be used.

<sup>147</sup> All female participants were asked if they were usually allowed to go to the market, a healthcare facility and areas outside their community; unaccompanied, with someone else or not at all.

<sup>148</sup> The NFHS-III documented whether respondents had taken an HIV test prior to the survey, whether they had received the results and when and why they had taken it. This set of measurements were included as part of the sexual behaviour and attitudes section of the NFHS-III questionnaire as respondents’ knowledge of their HIV-status allows them to protect their sexual partners from infection and later access the relevant treatment.

<sup>149</sup> The NFHS-III recorded what type of health-worker female participants had contact with and health concerns that were discussed in the three months prior to the survey.

<sup>150</sup> Female participants in the NFHS-III were asked if they had used any healthcare facilities within the three months prior to the survey. Participants who had recently visited a healthcare facility were asked what type of service they had used. Respondents in the NFHS-III were asked what type of services they had sought from the healthcare facility they had recently visited.

participants received at their healthcare provider<sup>151</sup> and when accepting services from an Outreach Worker<sup>152</sup> (ORW) in the three months prior to the survey.

This chapter uses a combination of qualitative and quantitative data in order to fully analyse each dimension of access. I use both types of data as it is not possible to conduct complex multivariate statistical analysis on each dimension of access due to the fact that the prevalence of HIV in India is very low at 0.2% of women. The female HIV-positive sample size for the NFHS-III is therefore very small (N=191), even when unweighted. When the relative weight was used the size of the HIV-infected population fell to around 115 women. Hence, a series of bivariate analyses was conducted on each dimension of access. Multivariate analysis was conducted on variables measuring health behaviours as all participants were questioned on their consumption of food items, unlike other measurements on issues such as gendered discrimination where data was collected only for a small subset of respondents.

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## 8.B Characteristics of Health Delivery System

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### *8.B.1 Availability*

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The Anganwadi Centre (AWC) is part of the Integrated Child Development Services scheme, set up in 1975 in India with the intention of improving rates of morbidity and mortality among impoverished pregnant and lactating women and children younger than six years old (Dongre, Deshmukh et al. 2008). This scheme has an integrated holistic approach to healthcare that provides clients with basic services, referral services for antenatal and post-natal treatment, nutritional supplements and health education (Arora, Bharti et al. 2006)<sup>153</sup>. An Anganwadi worker manages these services, while other ORWs regularly visit patients to keep a record of their health status and ensure that they use the facilities provided (Seema

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<sup>151</sup> They were asked how long they had to wait for treatment, whether the facility was clean, and if their practitioner was responsive to their needs and respected their privacy.

<sup>152</sup> They were asked if they were spoken to nicely and whether their practitioner ensured that they understood the information offered to them.

<sup>153</sup> Space is provided for activities of local women empowerment groups and pre-school education is offered to children aged 3-6 years.

2001). Previous studies have illustrated that this programme has been effective in improving the physical health of women and children belonging to underprivileged communities (Lal, Paul 2003, Kapil, Pradhan 1999, Kapil 2002).

There are currently more than 700,000 AWCs operational in India, meaning that the programme should be functional in almost every block<sup>154</sup> (IIPS, Macro International 2007). However, research indicates these services are quite limited and vary according to state (Davey, Davey et al. 2008, Rao 2005). Narayanan (2008) reported that some AWCs are so inefficient that they are unable to provide nutritional supplements in certain areas of India.

I was initially reluctant to use variables measuring the availability of AWCs as it was not clear how this could be applied to assess the geographical proximity of services providing relevant treatment for PLWHA, such as ART centres. Nonetheless, findings from the qualitative stage of research highlighted that AWCs could be central to close-knit communities in the provision of social and healthcare services to impoverished individuals in these neighbourhoods. Staff employed in these centres were local to these communities, and hence were more likely to be trusted by qualitative interviewees to dispense advice on possible Western treatment for HIV. For instance, one participant reported that she was guided by a local Anganwadi worker, who was her sister's mother-in-law, to a Positive Network (PN) providing HIV-positive patients with treatment for OIs.

Furthermore, some peer providers commented that they learnt of possible employment in PNs and NGOs through activities at their local AWC. This type of employment later assisted their access to healthcare providers, as they were informed by colleagues of the establishment of ART centres. PP7 stated:

*'I left a message with an Anganwadi teacher that if anybody came to you about HIV, please introduce me to them. The Anganwadi teacher told S- and A- that there was a person who has HIV in the village P- and she gave me all her reports to be passed on to you.... Somehow they managed to reach me at V- where I met them on the return from my work in the agricultural*

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<sup>154</sup> A community development block is a rural area designated by governmental administrative services for development. This block usually has a population of around 60,000-80,000 with approximately 80-100 villages (Shah 1974).

field. They recognized me with the reports they had in hand and asked if I was the same person. They assured me not to get worried or upset. “Attend all the meetings and you will get all the information”.

The NFHS-III sample consisted of 3,850 enumeration areas and over 70% of these areas were covered by an AWC. The coverage of AWCs varied very little by participant’s sero-status as the vast majority of both HIV-positive (77%) and HIV-negative (79%) respondents had an AWC in their sample enumeration area. Furthermore, HIV-positive respondents were just as likely to live in areas which had an AWC established for at least nine years (38%) as their HIV-negative counterparts (39%). Table 8.1 displays the rate of coverage and length of time that the AWC has been established according to the participant’s HIV-status.

**Table 8.1:** Coverage of AWCs and sero-status of female participants (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Coverage of Anganwadi centres	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b>Enumeration areas covered by AWC</b>				
Yes	41784	79	88	77
No	10949	21	26	23
<b>Total</b>	<b>52733</b>	<b>100</b>	<b>114</b>	<b>100</b>
<b>Years of coverage</b>				
0-9	15922	39	32	38
10-19	14994	37	28	33
20 or more	9912	24	24	29
<b>Total</b>	<b>40828</b>	<b>100</b>	<b>84</b>	<b>100</b>

## 8.C Characteristics of Population at Risk

### 8.C.1 Need

Participants’ level of malnutrition was first examined using data from the NFHS-III. The majority of female HIV-infected participants had a normal weight (54%). Moreover, HIV-positive respondents were just as likely not to have menstruated in the six weeks prior to the survey (18%) in comparison to those who were HIV-negative (23%). This is a fairly reliable indicator of malnutrition, given that severely undernourished women tend not to

menstruate for long periods of time (França, Ishikawa et al. 2009). Findings on these indicators of *need*, therefore suggest that there is little or no association between female participants' sero-status and their level of malnutrition.

There were similar findings on participants' levels of anaemia. HIV-infected participants were no more likely to experienced moderate (16%) or severe (4%) levels of anaemia than their HIV-negative counterparts. Severe unexplained anaemia was identified by the WHO, Mahe et al. (1990) as a symptom of one of the final stages of HIV infection. These findings further suggest that female HIV-positive respondents tended to have a fairly good health-status and were, perhaps, in the early stages of HIV infection. Table 8.2 shows indicators of malnutrition and female respondents' sero-status.

**Table 8.2:** Indicators of malnutrition and female respondents' sero-status  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Indicators of malnutrition	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>BMI</u></b>				
Underweight	18168	35	44	39
Normal weight	27774	53	62	54
Overweight	6717	13	8	7
<b><u>Anaemia</u></b>				
Severe	951	2	5	4
Moderate	8042	15	18	16
Mild	20212	38	40	35
Not anaemic	23464	45	51	45
<b><u>Menstruated in last six weeks</u></b>				
Yes	40622	77	94	82
No	12116	23	20	18

Moreover, findings on chronic illness suggested that female HIV-infected respondents in the NFHS-III were no more likely to have experienced diabetes<sup>155</sup> (0.9%) or goiter and thyroid problems (0.9%) than those in the general population. None of these chronic

<sup>155</sup> It has been reported by clinicians in developed nations that male HIV-infected patients have a tendency to develop diabetes as a reaction to ART medication, with the liver becoming less able to process glucose (Spollett 2006).

conditions are common illnesses amongst HIV-infected individuals living in developing countries which may explain these findings (Deshpande, Patnaik 2005, Solomon, Hawcroft et al. 2008, Umadevi, Ranganathan et al. 2007).

On the other hand, there is a relationship between female participants' sero-status and their propensity to contract TB<sup>156</sup>. There is a significantly (<.05) higher prevalence of TB among HIV-infected participants (1.9%) in comparison to the general population (0.3%). These findings highlight an important issue in research on HIV/AIDS related care in developing countries. Currently, a third of all PLWHA worldwide are co-infected with TB and it is the leading cause of death in this population (Ruxin, Paluzzi et al. 2005). Table 8.3 displays measurements of 'need' including indicators of chronic illness and STD symptoms according to the participants' sero-status.

**Table 8.3:** Measurements of 'need' including indicators of chronic illness and STD symptoms according to participant's sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measurements of 'Need'	Female participants' sero-status			
	HIV-negative		HIV-positive	
	%	Total number	%	Total number
<b><u>Multiple measures of chronic illness</u></b>				
TB**	0.3	49977	1.9	105
Diabetes	0.9	52125	0.9	112
Asthma	1.7	52479	2.6	114
Goiter or other thyroid disorder	1	52363	0.9	112
<b><u>Indicators of STD symptoms</u></b>				
STD in last 12 months	1.3	52633	1.7	115
Genital sore/ulcer in last 12 months***	1.7	52655	6	114
Genital discharge in last 12 months	8	52656	10	114

Finally, HIV-positive women were significantly (<.001) more likely to have had a genital ulcer (6%) in comparison to the general population (1.7%). These findings were similar to that of other epidemiological studies, which have suggested that people who have

<sup>156</sup> In global terms, India has the largest TB-infected population (Thomas, Dewan et al. 2009, Vijay, Swaminathan et al. 2009, Somma, Thomas et al. 2008).

previously contracted STDs could be more prone to acquiring HIV than those who had no medical history of these conditions (Chen, Jha et al. 2007, Fung, Guinness et al. 2007, Boily, Lowndes et al. 2007)<sup>157</sup>.

Results on most indicators of ‘need’ in the NFHS-III suggested that the majority of WLHA could be in the early phases of their infection. This seems to be a likely explanation, given that only a small proportion of female HIV-positive respondents displayed symptoms which could indicate that they were in the final phase of HIV, which involves severe unexplained weight loss and opportunistic infections (Singh, Bairy et al. 2003). These findings could be a product of female HIV-positive respondents being fairly well-nourished as few displayed symptoms of malnutrition, such as severe anaemia (4%). This hypothesis will be further explored in the following section of this chapter which provides a comparison of health behaviours, including diet, between female HIV-negative and positive respondents.

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## 8.D Socio-cultural Practices

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### *8.D.1 Health Behaviours*

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According to findings in the NFHS-III, the most commonly reported food items eaten on a daily basis in the HIV-negative and positive populations were leafy vegetables (64%) followed by pulses or beans (52%) and milk or curd (40%)<sup>158</sup>. In contrast, only a minority of participants ate chicken or meat (1%), fish (6%) and eggs (4%) daily. A likely explanation for these findings could be that a large section of the Indian population is vegetarian for cultural, religious or sometimes economic reasons (Pada 2010, Singh, Rastogi et al. 2010, Grewal, Bhagat et al. 2008).

Female HIV-positive respondents seemed to eat a wider range of food than those belonging to the general population. These participants were significantly ( $<.05$ ) more likely

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<sup>157</sup> As part of the third phase of NACO’s policy for the containment of HIV in India, there are many prevention programmes aimed at early detection of STIs in at risk populations (Bharat, Mahendra 2007, Jayanna, Washington et al. 2010, Bentley, Parekh 1998, Bentley, Spratt et al. 1998).

<sup>158</sup> Please see Appendix 43 for multiple measures of food consumption and female participants’ sero-status.

than their HIV-negative counterparts to consume eggs (34%), fruits (38%), milk or curd (23%) and chicken or meat (35%) on a weekly basis.

In addition, a food item score was created by establishing a numeric scale for how often respondents ate a particular food item. If a respondent had reported that they had eaten the food item daily then it was allotted a score of 3, while those who had consumed the food item on an occasional or weekly basis were respectively assigned the score of 1 and 3. Finally, if these participants had never eaten a certain food item, the score was 0. If a respondent had a food item score of 21, then, it meant that they had reported that they were eating each type of food recorded in the NFHS-III on a daily basis. HIV-infected respondents had on average a slightly higher food score ( $M= 11.85$ ,  $SD=2.98$ ) than the general population ( $M= 11.17$ ,  $SD= 3.03$ ),  $t (-2.42)= 52753$   $p<.02$ ,  $r=0.01$ ), indicating that they ate a broader variety of food items on a more regular basis than their HIV-negative counterparts.

These findings could be a product of female HIV-positive participants' being more likely to be employed, older, married and slightly better off than their HIV-negative counterparts. It is possible female participants' food consumption could be affected by logical confounders rather than by their HIV-status. These confounding factors are addressed by constructing a binary logistic model which tests the impact of female respondents' sero-status on their food item score, controlling for variables which are deemed to measure socioeconomic (e.g. wealth) and socio-cultural factors (such as caste) which could affect people's diet in the Indian context.

In the first forced model (Step 1) I tested participants' food item score against their sero-status in order to assess the impact of the independent variable on the outcome variable without controlling for logical confounding factors. It was found that WLHA had significantly ( $<.05$ ) higher odds of consuming more food items on a regular basis ( $OR= 1.61$ ,  $CI=1.03-2.51$ ) in comparison to the general population.

In the second forced model (Step 2) the relationship between female participants' sero-status and their consumption of food items remained positive. After controlling for

socioeconomic factors (including employment, wealth, level of education and area of residence), sero-positive participants displayed slightly higher odds (OR=1.69, CI=1.08-2.65) of consuming a wide range of food items in comparison to the previous model. Table 8.4 presents the intercept, with Step 1 comprising HIV-status; Step 2 incorporating socioeconomic factors; and Step 3 which included socio-cultural factors.

**Table 8.4:** Social correlates of food consumption (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

	Step 1	Step 2	Step 3
<b>Intercept</b>	***2.23	***1.86	***1.35
HIV-status			
<b>HIV-status (sero-negative)</b>			
Sero-positive	*1.61 (1.03-2.51)	*1.69 (1.08-2.65)	1.20 (0.76-1.92)
Socioeconomic factors			
<b>Employment (Unemployed)</b>			
Employed		0.96 (0.93-1.003)	***0.91 (0.87-0.95)
<b>Wealth (Poor/poorer/middle)</b>			
Richer/richest		***1.36 (1.30-1.43)	***1.24 (1.18-1.31)
<b>Level of education (No education/Primary)</b>			
Secondary/higher		***1.59 (1.52-1.66)	***1.51 (1.44-1.59)
<b>Area of residence (Urban)</b>			
Rural		***0.67 (0.64-0.71)	***0.73 (0.69-0.76)
Socio-cultural factors			
<b>Age</b>			1 (1.000-1.004)
<b>Marital status (Never married/Currently married)</b>			
Formerly married			***0.85 (0.77-0.93)
<b>Type of caste (Caste/tribe)</b>			
None of the castes listed/DK			***1.35 (1.29-1.42)
<b>Religion (Hindu)</b>			
Non-Hindu			***1.86 (1.76-1.97)
<b>Region of India (North)</b>			
South			***4.65 (4.37-4.95)
Nagelkerke R2	0	0.06	0.15

Female respondents' wealth and level of education had a stronger and more significant (<.001) impact on their consumption of food items than any other variable. Participants who had a secondary/higher level of education were 1.09 times (OR=1.59, CI=1.52-1.66) as likely to have a higher food score in comparison to those who had no

education or attended primary school. Furthermore, female respondents who belonged to the richer/richest categories displayed slightly increased odds (OR= 1.36, CI=1.30-1.43) of having a higher food score than those in the poorer groups. These findings suggested that having a higher level of education and being better off could positively impact the range and frequency of food items that women ate.

The most illuminating finding within the second model (Step 2) was that female participants in the NFHS-III who were living in rural areas displayed significantly ( $<.001$ ) lower odds of consuming a wider range of food items (OR $<1$ , CI=0.64-0.71) in comparison to those living in urban areas. A possible explanation for these findings could be that poverty and malnutrition are likely to be more common in rural areas of India (Pada 2010, Balgir 2006, Aparajita, Ramanakumar 2005) with female agricultural labourers suffering from elevated levels of micronutrient deprivation (Jha, Gaiha et al. 2009).

Qualitative interview respondents living in rural areas commented that they suffered from malnutrition. These participants experienced great difficulties in affording the necessary food items on their income as an agricultural labourer. They believed that they experienced HIV-related symptoms, e.g. 'fever' or 'weakness', because they could not afford to purchase the necessary amount of 'nutrition food', such as yoghurt, to maintain their health-status. PF16, who sowed and harvested chillies on a commercial farm, reported:

*'Since I go to the fields, I keep thinking all the time of my child and husband. When I stay at home and eat two times curd rice, I have no problem, otherwise I get fever. Thinking most of the time of the family, not eating properly, not drinking enough water, not eating nourishing food, this is what is happening to me'.*

Findings from the qualitative phase of research suggest that socio-economic factors could have a major impact on WLHA's health behaviour. However, recent research has indicated that people's diet in India is often mediated by socio-cultural factors, such as religion and caste (Development Gateway 2004). Many people belonging to higher castes, for instance abstain from eating meat (Messer 1997, Behrman, Deolalikar 1990). Hence, the third forced model (Step 3) incorporated variables which measured socio-cultural factors that

could potentially impact female respondents' consumption of food items in the NFHS-III. After controlling for these factors, female participants' sero-status stopped having a significant impact on their food item score. These findings suggested that socio-cultural factors in combination with socioeconomic ones, had a stronger impact on women's consumption of food items than their HIV-status.

Most variables measuring socio-economic factors retained their significance ( $<.001$ ) after controlling for socio-cultural factors. Female participants who belonged to the richer/richest wealth quintiles (OR=1.24, CI=1.18-1.31) and had a secondary/higher level of education (OR=1.51, CI=1.44-1.59) displayed increased odds of consuming a wide range of food items than their counterparts. These findings suggested that socio-economic factors may affect these respondents' ability to purchase the necessary food items.

On the other hand, there was a negative relationship between female respondents' area of residence, employment status and their food item score. Employed participants displayed slightly lower odds (OR $<1$ , CI=0.87-0.95) of consuming a wide range of food items than their unemployed counterparts. These findings suggest that women's participation in the labour market, rather than having an empowering effect through increased purchasing power, could actually negatively impact their consumption of food items (Fuwa, Ito et al. 2006). Recent research has highlighted that Indian women's employment can adversely affect their health, as they are paid low wages (Upadhyay, Palanivel 2011) and often undertake heavy manual work, partake in burdensome caring chores and consume the smallest portions of nutritional food items in their households during times of scarcity (Basu, Sidh 2008).

Variables measuring socio-cultural factors also had a strong impact on female participants' consumption of food items in the NFHS-III. The variable which had the greatest impact was which region of India they lived in. It was found that women who lived in southern regions of India were 2.25 times (OR=4.65, CI=4.37-4.95) as likely to consume a wider range of food items as those residing in northern regions. These findings could be the

product of regional variations in food consumption (Singh et al. 2010), such as the regular consumption of fish by people in Kerala..

There was also a highly significant ( $<.001$ ) relationship between female participants' religion, caste status and their consumption of food. Respondents who identified themselves as not belonging to any government designated caste categories displayed higher odds (OR=1.35, CI=1.29-1.42) of eating a wider range of food items than their counterparts. In addition, non-Hindu respondents were 1.56 (OR=1.86, CI=1.76-1.97) as likely to have a higher food score as Hindu participants. These findings suggest that female participants' consumption of food items could be influenced by religious and caste-based practices.

Finally, there was a negative relationship between female respondents' marital status and their food item score. Formerly married female participants displayed lower odds (OR $<1$ , CI=0.77-0.93) of consuming a wide range of food items than their unmarried and married counterparts. These findings were similar to those of the qualitative phase of research. Many widowed qualitative interviewees experienced great difficulties in affording the food items necessary to ensure full adherence to ART treatment. They had to borrow money from relatives to purchase expensive 'nutrition food' (e.g. chicken) because they had the additional cost of supporting other members of their household on their meagre income from manual labour.

Some widowed participants with adult children living in their households would ensure that these members would contribute to the overall family income by doing unskilled manual labour like working on building sites. On the other hand, widowed participants with young children in school wanted to ensure that their offspring had a high level of education to guarantee that they were able to later procure stable employment, e.g. administrative work. They sacrificed their health by forgoing 'nutrition food' and working for over ten hours a day in order to provide their children with private education or extra tuition after school.

Quantitative and qualitative results regarding *health behaviours* demonstrate that women's diet is affected by a set of socioeconomic and cultural factors rather than their sero-

status, as originally hypothesised. These socioeconomic and cultural factors often symbiotically affected one another to the point that they mediated the range of food items participants ate and how often they consumed them. This complex relationship was most observable in the binary logistic model, in which female participants who were better off and living in southern regions of India displayed increased odds of having a higher food score. It is possible some WLHA with this profile were able to maintain their health-status through the consumption of a wide range of food items. The following section will examine sero-positive female participants' experience of *gendered discrimination*.

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### *8.D.II Gendered discrimination*

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The first dimension of empowerment recorded the barriers which female participants experienced whenever they tried to use any type of healthcare facility. The problems which posed the greatest obstacle to female respondents reaching healthcare providers in the NFHS-III were distance (25%), followed by transport (23%) and low availability of medication (23%)<sup>159</sup>. There seemed to be little or no significant difference in the types of issues that female HIV-positive respondents identified as possible barriers to healthcare access in comparison to their HIV-negative counterparts. This suggests that female HIV-positive respondents may not be any more likely to encounter these barriers to healthcare than those in the general population. However, it is possible that many female HIV-infected participants may have experienced barriers to accessing healthcare services that were not measured in the NFHS-III, such as HIV-related stigma (Green, Devi et al. 2007, Mahendra, Gilborn et al. 2007, Rahangdalea, Banandurb et al. 2010).

It was expected that female HIV-positive participants would generally have less control over their financial resources than other women on all indicators of financial empowerment as Amaro, Raj et al. (2001) identified gender-related poverty as a driving factor in the spread of HIV. This is because impoverished women have limited resources to

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<sup>159</sup> Please see Appendix 44 for a table displaying multiple measures of gendered barriers to healthcare and female participants' sero-status.

negotiate safe sex practices with their male partner. However, married HIV-positive women in the NFHS-III reported similar levels of control over their financial resources on all three indicators to their HIV-negative counterparts<sup>160</sup>. For example, married HIV-infected respondents were just as likely to have money for their own use (50%) as those who were HIV-negative (45%). These findings could possibly be the result of some female respondents acting as the head of the household when their spouse was ill or had died of HIV-related illnesses (Haacker 2009, Dandona. Kumar et al. 2009, Murthy 2008, Freedberg, Kumarasamy et al. 2007, Das, Mukhopadhyay et al. 2009)<sup>161</sup>.

These results suggest that financial empowerment is no more of an issue for HIV-positive women than for the general population. It is possible that these respondents had considerable control over their financial resources because they were one of the main income earners in their household. Results from both the quantitative and qualitative stages of research indicated that the majority of WLHA were employed. Some respondents from the qualitative sample mentioned that they had an occupation prior to themselves or their husband being diagnosed as HIV-positive.

In addition, married female participants' decision-making capabilities within their households were examined. Married HIV-positive participants were significantly (<.05) more likely to have sole responsibility on all measurements of their decision-making capabilities. It is possible that many female HIV-positive participants may have been expected to have control over decisions made within their household as they were older married women with children. Research on intra-household resource allocation in south-east Asian countries has demonstrated that older married women with children have more control over financial decisions within their families than their younger childless counterparts (Quisumbing, Smith 2009, Nobuhiko, Seiro et al. 2006). However, it is important to take into account that in some

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<sup>160</sup> Please see Appendix 45 for a table displaying multiple measures of financial empowerment and female participants' HIV-status.

<sup>161</sup> There were a few qualitative interviewees who claim that they were compelled to seek employment after their spouse died.

cases there could be a degree of reverse causation as many female HIV-positive respondents may have had sick husbands or were widowed, and thus, often acted as the sole earner in their household. Table 8.5 displays multiple measures of female respondents' decision making capabilities and their sero-status.

**Table 8.5:** Multiple measures of female respondents' decision making capabilities and their sero-status (weighted)

(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of decision making capabilities	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Final say on own health care*</u></b>				
Respondent alone	10743	27	30	40
Respondent and husband/partner	14044	36	26	35
Other	14652	37	19	25
Total	39439	100	75	100
<b><u>Final say on making large household purchases*</u></b>				
Respondent alone	3367	9	12	16
Respondent and husband/partner	17382	44	36	48
Other	18689	47	27	36
Total	39438	100	75	100
<b><u>Final say on making household purchases for daily needs*</u></b>				
Respondent alone	12517	32	30	40
Respondent and husband/partner	11037	28	26	35
Other	15883	40	19	25
Total	39437	100	75	100
<b><u>Final say on visits to family or relatives*</u></b>				
Respondent alone	4202	11	13	17
Respondent and husband/partner	19602	50	41	55
Other	15630	40	21	28
Total	39434	100	75	100

Finally, HIV-positive women in the NFHS-III were significantly (<.001) more likely to be allowed to travel unaccompanied to the market, healthcare facilities and areas outside their community in comparison to their HIV-negative counterparts. For instance, a little over a third of HIV-negative respondents were allowed to alone go to places outside their village/community alone. In contrast, over two-thirds of HIV-positive participants were able

to travel alone to the same place. It seems therefore that HIV-positive participants had more freedom of movement than their HIV-negative counterparts. Table 8.6 shows multiple measures of female respondents' freedom of movement and their HIV-status.

**Table 8.6:** Multiple measures of respondents' freedom of movement and their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of respondents' freedom of movement	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Allowed to go to: market***</u></b>				
Alone	27349	52	93	81
With someone else only	18682	35	15	13
Not at all	6685	13	7	6
<b>Total</b>	<b>52716</b>	<b>100</b>	<b>115</b>	<b>100</b>
<b><u>Allowed to go to: health facility***</u></b>				
Alone	25513	48	86	75
With someone else only	24733	47	28	24
Not at all	2475	5	1	1
<b>Total</b>	<b>52721</b>	<b>100</b>	<b>115</b>	<b>100</b>
<b><u>Allowed to go to: places outside village/community***</u></b>				
Alone	20062	38	78	68
With someone else only	28252	54	33	29
Not at all	4404	8	4	3
<b>Total</b>	<b>52718</b>	<b>100</b>	<b>115</b>	<b>100</b>

Findings on *gendered discrimination* suggest that HIV-positive women in India could be more empowered to make decisions within their households and to move in the public sphere. For instance, a little over a quarter of female HIV-negative respondents make decisions on their healthcare alone. In contrast, forty percent of female HIV-positive participants are responsible for their own healthcare. It is possible that some of these findings could have been the product of participants *being* sero-positive, which may result in their having more responsibility over financial and household decisions while their spouse is incapacitated with HIV-related symptoms. Unfortunately, it is not possible to test for reverse

causality by controlling for logical confounders, because the female HIV-positive sub-set is relatively small, resulting in unreliability in the findings of such tests.

These positive findings on *gendered discrimination* run contrary to other studies which illustrate that the low status of Indian women in society promotes the spread of HIV from high risk groups to the general population as they may experience difficulties negotiating their partners' sexual behaviour (Dandona, Dandona et al. 2006). It is possible that female HIV-infected participants' empowered status within their family could have a positive impact on their ability to access healthcare facilities. Hence, the following section examines 'objective realised access', starting with female respondents' use of HIV testing facilities.

## 8.E Objective Realised Access

### *8.E.1 Use of HIV testing facilities*

Statistical results from chapter 5, on respondents' level of 'susceptibility' in the NFHS-III sample, illustrated that the majority of female participants had little knowledge of HIV/AIDS and partook in few sexual risk activities. Hence, they had a low perception of their risk of contracting the virus. As would be expected, the vast majority of female participants had not taken an HIV test (97%). Nevertheless, a significantly ( $<.05$ ) higher proportion of female HIV-positive participants in the NFHS-III (7%) took an HIV test prior to the survey in comparison to their HIV-negative counterparts (3%). Table 8.7 displays female participants' use of HIV testing facilities according to their sero-status.

**Table 8.7:** Female participants' use of HIV testing facilities according to their sero-status (weighted)

Ever been tested for AIDS	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Yes	1658	3	8	7
No	51080	97	107	93
<b>Total</b>	<b>52738</b>	<b>100</b>	<b>115</b>	<b>100</b>

These findings suggest that there could be factors associated with their condition which may have encouraged them to take an HIV test, such as their spouse being diagnosed as sero-positive after displaying HIV-related symptoms (Baghdadi 2005, Patrice, Marija et al. 2010).

Furthermore, the majority of female respondents in the NFHS-III who had taken an HIV test did so in a private hospital (62%), indicating that these respondents may have a preference for this type of treatment. Currently, in order to receive governmental or NGO treatment it is a requirement that one is tested in a public healthcare facility, to guarantee that the result is accurate. Some qualitative interviewees said that they were encouraged by an ORW to seek a diagnosis from the local governmental hospital to ensure that they were able to access free treatment from a public healthcare provider. A few of these participants had initially been diagnosed in a private healthcare facility.

As so few female sero-positive respondents reported undertaking an HIV test, the following univariate analyses were conducted on the whole sample of the NFHS-III. Over a third of all female participants who had the HIV test undertook it two or more years prior to the survey. Moreover, the majority of female participants took an HIV test prior to the NFHS-III, as it had been offered to them by their practitioner (58%). This indicated that these respondents had not taken the test entirely of their own volition. Unfortunately, the NFHS-III did not record events which could have influenced respondents' decision to take the HIV test. Nonetheless, many participants from the qualitative phase of research took an HIV test after other members of their family were diagnosed as sero-positive, indicating that even those who had voluntarily taken the test may have done so not from awareness of their risk of contracting HIV but as a consequence of events outside their control. Table 8.8 presents multiple measurements for female respondents' use of HIV testing facilities, including reasons for taking a test, when it was taken and if they had seen their results.

**Table 8.8:** Multiple measurements of female respondents use of HIV testing facilities (weighted)

Measurements	Count	%
<b><u>Last HIV test was asked for, offered or required</u></b>		
Asked for the test	446	27
Offered and accepted	955	58
Required	215	13
Without consent	42	3
<b>Total</b>	<b>1658</b>	<b>100</b>
<b><u>When previous HIV test was conducted</u></b>		
Less than 12 months	650	39
12-23 months	369	22
2 years or more	631	38
<b>Total</b>	<b>1650</b>	<b>100</b>
<b><u>Type of facility last tested</u></b>		
Public	623	38
Private	1035	62
<b>Total</b>	<b>1658</b>	<b>100</b>
<b><u>Had results for last test</u></b>		
Yes	1531	93
No	120	7
<b>Total</b>	<b>1651</b>	<b>100</b>

The vast majority of those tested for HIV in the NFHS-III stated that they had received their results from their last test (93%). These findings diverged from those of the qualitative phase of research. Qualitative interviewees' experiences of being tested for HIV varied widely with some receiving no counselling, others being given appropriate post-test counselling and a few not even being informed of their HIV-status<sup>162</sup>.

There were a few cases in the qualitative phase of research in which physicians would inform family members of the respondents' HIV-status with the expectation that their relatives would later notify them. These respondents were deemed by their physician as too

<sup>162</sup> Respondents' accounts of being tested did not mention whether they underwent rapid or blood draw testing (Pai, Barick et al. 2008), in which the specimen would have to be sent to a laboratory for analysis and clients would have been required to return. This was because many participants were tested for HIV long before they were interviewed, and hence could not remember specific details. There were a few respondents who mentioned that they underwent blood draw testing, and all of these participants returned for their results. It is doubtful that I would have been able to sample HIV-positive women who did not return for their results as they might not be aware of their sero-status.

emotionally fragile to cope with news of their sero-status. For instance, PP3's family decided that she should not be immediately informed of her HIV-status as she had just given birth and her husband had deserted her. She stated:

*'Nobody told me directly about it (HIV). They revealed it to my mother and brothers. They told my mother to take extra care of me as I was HIV-positive. They also told them to tell me not to breast feed my baby boy and where I should go for medicines'.*

Other qualitative interviewees were not directly informed of their HIV-status because their physician deemed them as not being educated enough to understand the meaning of being HIV-positive. One interesting case was PF26, who had never attended school. She was taken by her brother and his wife to a private healthcare facility to be tested for HIV after learning of her husband's sero-status. She reported:

*'They (the doctor) asked me to sit out and the doctors spoke to my brother and sister-in-law in private. Then itself I got a doubt that something was radically wrong with me. When my sister-in-law came out, I asked her what the doctors had to say. She told me that "There are changes in your blood. You have HIV and must be very careful". I got terribly upset hearing this news and wondered what will happen to my children.*

One prominent element of this narrative is how accepting PF26 is of the behaviour of both the medical practitioners and her relatives who were dictating the terms of her treatment. PF26's sister-in-law, who had a primary level of education, adopted the role of a mediator between PF26 and her physician. In a similar fashion to that of a counsellor, her sister-in-law offered her psychological consolation and presented medical information in a format which was comprehensible to the intended audience.

Both PP3 and PF26 learnt of their HIV-status fairly soon after their test as they had the full support of their natal families, who worked in collaboration with their doctors to ensure their physical and mental well-being. In contrast, PF29 claimed that a local private healthcare practitioner colluded with her husband's family to conceal her HIV-status as her in-laws had arranged her marriage in order to hide her spouse's HIV-status from the rest of the community to enable the arrangement of partnerships for her spouse's younger siblings. She stated:

*'My husband is the eldest son. Everyone in the home knew about it but used me as their scapegoat to marry him. I knew he had HIV because every test taken was hidden from me'*

Participants' narratives from the qualitative phase of research point to a set of cultural factors mediating access to healthcare facilities. Their accounts suggested that the type of advice that they received when tested may have depended upon their gendered position within the family, the practitioners' perception of their ability to understand HIV and informal procedures taken to ensure their welfare. It may not have been possible to capture these cultural factors in the NFHS-III as only respondents who knew that they had taken an HIV test would be able to answer questions regarding their experiences of being tested. The following section will explore participants' use of outreach and healthcare services.

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### *8.E.II Use of outreach and healthcare services*

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Respondents' use of outreach services in the NFHS-III was examined first. Female HIV-positive respondents were no more likely to have had contact with an ORW (13%) than their HIV-negative counterparts (17%). Furthermore, there was little or no variation between HIV-positive and negative participants on what type of ORW they had met. This result is significant, as HIV-positive women could be in more need of outreach services than the general population, and because ORWs could potentially encourage them to be tested for HIV as part of ante-natal care routines or advice on ART. Table 8.9 displays indicators of female respondents' use of services and their sero-status.

**Table 8.9:** Indicators of female respondents' use of outreach services and their sero-status<sup>163</sup> (weighted) (\*\*\*) <.005, \*\*<.01 and \*<.05)

Indicators of use of outreach services	Female participants' sero-status			
	HIV-negative		HIV-positive	
	%	Count	%	Count
<b><u>Ever been visited by an outreach worker</u></b>				
Yes	17	9021	13	99
No	83	43650	87	15
<b>Total</b>	<b>100</b>	<b>52671</b>	<b>100</b>	<b>114</b>
<b><u>Met whom during last/most recent contact</u></b>				
Auxiliary Nurse-Midwives	50	4547		5
Lady Health Visitors	3	296		0
Anganwadi Worker	42	3809		9
Asha	0.3	30		0
Multipurpose Workers	3	252		1
Other	1	117		0
<b>Total</b>	<b>100</b>	<b>9051</b>		<b>15</b>

Peer providers' accounts of their occupation in the qualitative stage of research indicated that ORWs could be crucial for providing pregnant HIV-positive women with the necessary treatment to prevent mother-to-child transmission. A few peer providers worked as antenatal ORWs in Prevention of Parent-to-Child centres. These peer providers were required to regularly monitor the health of pregnant female HIV-positive clients, provide them with prophylaxes to prevent transmission to the child and offer follow-up treatment once the infant was delivered. They would also refer their clients to social services.

There was some variation between female HIV-positive and negative respondents on the health concerns that they discussed with their ORW in the NFHS-III. The most common health issue discussed among HIV-negative women was immunisation (56%), followed by treatment for themselves (13%) and disease prevention (10%). In contrast, the most common health concerns for female HIV-positive participants were immunisation (33%), followed by pre-school education (27%) and nutritional/health education (13%). Table 8.10 shows types of issues that female respondents discussed with their outreach worker and their HIV-status.

<sup>163</sup> I have not presented percentages of what type of outreach workers female HIV-positive participants had contact with. This was because only fifteen HIV-positive participants had contact with an outreach worker three months prior to the survey.

**Table 8.10:** Types of issues that female respondents discussed with their outreach worker in the NFHS-III and their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Types of issues that female respondents discussed with their ORW	Female participants' sero-status		
	HIV-negative		HIV-positive
	%	Count	Count
Family planning	9	839	1
Immunization	56	5105	5
Antenatal care	8	729	1
Delivery care	3	268	0
Delivery preparedness	1	75	0
Postnatal care	1	126	0
Disease prevention	10	889	1
Medical treatment for self	13	1160	1
Treatment for sick child	5	446	1
Treatment for other person	2	179	0
Malaria control	4	341	1
Supplementary food	8	756	1
Growth monitoring of child	6	582	0
Early childhood care	2	226	0
Pre-school education***	5	462	4
Nutrition/health education	5	495	2
Family life education	3	302	1
Menstrual hygiene*	1	103	1
Other	2	215	1

In addition, HIV-positive women in the NFHS-III were no more likely to have used any healthcare services (39%) in this time period than their HIV-negative counterparts (37%). This result could be indicative of most WLHA in this survey not knowing of their sero-status and being at an early stages of the illness; thus, unaware of their need to access services. According to governmental guidelines on the care of HIV-infected patients, those in the early stages of the virus only require medical attention every six months or in cases of emergency (MOHFW, NACO 2007). It is therefore possible that the majority of female HIV-positive participants are not explicitly in need of services as they did not experienced a bout of illness related to their condition in the three months prior to the survey.

There was also very little difference between HIV-positive and HIV-negative respondents' patterns of use of healthcare in the NFHS-III. Table 8.11 displays the multiple

measurements of female respondents' use of healthcare facilities according to their sero-status.

**Table 8.11:** Multiple measurements of female respondents' use of healthcare facilities according to their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measurements of healthcare use	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>In past 3 months, visited a health facility or camp</u></b>				
Yes	19586	37	45	39
No	33141	63	69	61
<b>Total</b>	<b>52727</b>	<b>100</b>	<b>114</b>	<b>100</b>
<b><u>Type of facility visited</u></b>				
Government/ municipal hospital	3018	15	8	18
Government dispensary	279	1	0	0
UNC/ UHP/ UFWC	63	0.3	0	0
CHC/ Rural hospital/ PHC	2135	11	4	9
Sub-centre/ ANM	647	3	1	2
Govt mobile clinic	3	0.02	0	0
Camp	108	1	0	0
Anganwadi/ ICDS Centre	334	2	0	0
Other public medical sector	119	1	0	0
Private hospital	10958	56	26	58
Private mobile clinic	386	2	2	4
Pharmacy/ Drugstore	216	1	2	1
Other private medical	969	5	2	4
NGO or trust hosp/ clinic	138	1	1	2
Other	185	1	0	0
<b>Total</b>	<b>19558</b>	<b>100</b>	<b>45</b>	<b>100</b>

Over half of sero-positive and negative respondents who reported that they recently visited a health facility in the three months prior to the survey had attended a private hospital. The second most common choice of healthcare provider for HIV-positive participants was a government/municipal hospital (18%) followed by CHC<sup>164</sup>/rural hospital/PHC<sup>165</sup> (9%). Female HIV-negative respondents displayed very similar preferences for healthcare providers

<sup>164</sup> Community Healthcare Centre

<sup>165</sup> Primary Healthcare Centre

with the second most common choice of facility also being a government/municipal hospital (15%) followed by a CHC/rural hospital/PHC (11%).

Interviews with peer providers in the qualitative phase of research confirmed that their clients had similar preferences towards healthcare as respondents in the NFHS-III. Their clients' preference towards private healthcare providers may have been driven by lack of knowledge of public healthcare facilities available locally. These clients would often at first travel very long distances to Chennai and Kerala in search of HIV-related treatment on the advice of their relatives. This was because these were the only well-known clinics offering modern and ayurvedic medication for PLWHA until NACO's third phase of policy in 2006. These narratives illustrated the importance of ensuring that appropriate information is disseminated through informal social networks to avoid delays in reaching the necessary facilities.

Furthermore, peer providers' clients believed that private healthcare facilities would provide them with reliable medication and a better quality of service. However, there were private healthcare practitioners who would engage in dishonest practices, such as promising to cure HIV or charging excessively high fees for treatment. PP2 stated that some of her clients had at first attended a local private hospital where they were charged Rs. 3,000-4,000 (£38.73-£51.64) for a CD4 count test. Considering that many participants working in manual labour earned on average Rs. 115 (£1.48) on a daily basis, these additional medical expenses could prove too costly in the long term for many WLHA in this type of occupation. A few peer providers documented the gradual decline in their financial status which was precipitated by their use of private services. They would eventually seek treatment in public healthcare facilities when their funds were exhausted. As PP7 reported:

*'Some having plenty of money in hand at the beginning stages, ran from one private hospital to another for treatment. In this manner, they spent more money than required. Finally, they come to us and tell us that their disease has not come down in spite of spending so much money on private hospitals. I say to them, "Why did you all go to private hospitals? In fact, Government hospitals give you medicines and free check-up and also counselling"'*

Finally, the most common type of service sought by female HIV-positive participants in the NFHS-III was treatment for themselves (71%) followed by a health check-up (18%) and treatment for their child (9%). On the other hand, the most common service sought by female HIV-negative respondents was medical treatment for self (55%), followed by treatment for their children (32%), and health check-up (8%). Table 8.12 shows the type of service that female participants sought according to their HIV-status.

**Table 8.12:** Type of service female participants sought according to their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Type of service sought	Female participants' sero-status	
	HIV-negative	HIV-positive
	%	%
Family planning	1	2
Immunization	7	0
Antenatal care	5	2
Delivery care	3	4
Postnatal care	1	0
Disease prevention	1	2
Medical treatment for self*	55	71
Treatment for child***	32	9
Treatment for other person	3	4
Growth monitoring of child	2	4
Health check-up*	8	18
Other	0.2	0
<i>Total number</i>	1958	45

One possible explanation for these results could be that as there was a far larger number of HIV-negative respondents, they used a wider range of services in comparison to their HIV-positive counterparts. Nevertheless, the results also indicated that HIV-infected respondents have a slightly higher tendency to seek treatment for their own needs than those belonging to the general population who seemed to be more pre-occupied with their children's health condition. These female HIV-positive participants could be using healthcare facilities for HIV-related symptoms, e.g. TB, without knowing of their sero-status.

The following section will examine the quality of services female participants received from their outreach worker and healthcare provider.

## 8.F Subjective Realised Access

Female participants' experiences of using outreach services in the NFHS-III were examined. Table 8.13 displays female respondents perceived level of quality of ORW's service according to their HIV-status in the NFHS-III.

**Table 8.13:** Female participant's sero-status and multiple measures of quality of outreach worker services (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Measures of quality of outreach worker's services	Female participants' sero-status		
	HIV-negative		HIV-positive
	Count	%	Count
<u>Outreach worker spoke to participant nicely</u>			
Nicely	7007	77	13
Somewhat nicely	1888	21	2
Not nicely	154	2	0
<b>Total</b>	<b>9049</b>	<b>100</b>	<b>15</b>
<u>Did the outreach worker ensure you understood information</u>			
Yes	6809	75	13
No	755	8	1
No explanation needed	1476	16	2
<b>Total</b>	<b>9040</b>	<b>100</b>	<b>16</b>

Female respondents were overwhelmingly complimentary regarding services they had received irrespective of their HIV-status. Almost 80% of these participants had reported that their ORW had spoken to them nicely. Moreover, over three quarters of respondents commented that their ORW had ensured that they understood the information offered or that there was no need for any explanation. These results could indicate that the quality of services that HIV-positive women received was uniformly high or at least that they were satisfied with them. It is possible that many of these participants received a good quality of care because neither they nor their ORWs knew of their sero-status.

Qualitative interview respondents' account of the care that they received from ORWs was also positive. They commented that their ORW would offer them the psychosocial support necessary to help them to cope with their condition. PF30 reported that her ORW would regularly visit to offer emotional support when she was suffering from depression.

In the NFHS-III female respondents' assessment of services at their healthcare provider was overwhelmingly positive irrespective of their sero-status. Over 90% of both HIV-positive and HIV-negative participants reported that their practitioner was responsive to their needs. Female HIV-infected respondents were also equally likely to state that their practitioner had respected their privacy (74%) and that the facility was very or somewhat clean (95%).

Finally, there was very little difference between HIV-positive and HIV-negative respondents as regards how long they had to wait for treatment. Female HIV-infected respondents in the NFHS-III were just as likely to have waited for one hour or more (30%) as those in the general population (28%). Table 8.14 displays respondents' perceived level of quality of healthcare services according to their HIV-status.

**Table 8.14:** Female participants perceived level of quality of healthcare services according to their HIV-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of quality of healthcare services	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Time waited before being seen</u></b>				
0-29 mins	5850	30	13	30
30-59 mins	3901	20	9	20
1 hour or more	5471	28	13	30
No wait	4276	22	9	20
Did not receive service	43	0.2	0	0
<b>Total</b>	<b>19541</b>	<b>100</b>	<b>44</b>	<b>100</b>
<b><u>Was person responsive to your problems and needs</u></b>				
Yes	18795	96	43	96
No	711	4	2	4
<b>Total</b>	<b>19506</b>	<b>100</b>	<b>45</b>	<b>100</b>
<b><u>Did person respect your privacy</u></b>				
Yes	11585	59	34	74
No	1606	8	3	7
Says privacy not needed	6313	32	9	20
<b>Total</b>	<b>19504</b>	<b>100</b>	<b>46</b>	<b>100</b>
<b><u>Was facility clean</u></b>				
Very clean	12796	65	32	71
Somewhat clean	6520	33	11	24
Not clean	232	1	2	4
<b>Total</b>	<b>19548</b>	<b>100</b>	<b>45</b>	<b>100</b>

Quantitative results on female HIV-positive respondents 'subjective realised access' suggested that they had received a good quality of care from their previous healthcare provider. Unfortunately, it was not possible to verify how far this was actually the case as most measurements of quality of care employed by the NFHS-III were inadequate as they did not take account of the nature of the respondents' illness, what type of treatment was required and the health outcome (McGlynn 1997, Steel, Bachmann et al. 2008)<sup>166</sup>. For instance, respondents were asked if their healthcare practitioner was responsive to their 'needs' without the interviewer specifying what exactly these 'needs', might be in the context of the

<sup>166</sup> Other surveys on quality of care that patients received in hospitals in the USA included items on physician care, nursing care, medical outcome, courtesy, food service, comfort and cleanliness (Carey, Seibert 1993).

consultation. Hence, it is possible that, had the measurements of care been more specific, findings on 'subjective realised access' could have been more nuanced

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## 8.G .Discussion

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The most striking observation in this chapter is that large sections of the female HIV-positive population were almost certainly not aware of their sero-status as they had not taken an HIV test prior to the NFHS-III. If this is the case, this finding is important as previous research has illustrated that PLWHA who are unaware of their sero-status are far more likely to transmit their infection to others in comparison to those who are aware of being HIV-positive. Marks, Crepaz et al. (2006) estimated that over half of all new sexually transmitted HIV in the USA was contracted from the 25% of PLWHA who were unaware of their sero-status. As the vast majority of female HIV-positive participants appeared to act as if they were unaware of their status, it is possible that they could have unknowingly transmitted their infection to others.

The only possible method to improve this situation would be to encourage much more widespread HIV testing in the female population. Recently, the Indian Ministry of Health and Family Welfare has made considerable effort to increase the availability and accessibility of voluntary testing and counselling centres across India, with a view to preventing mother-to-child transmission and encouraging at-risk populations to take an HIV test (Sheikh, Porter 2009, Sheikh, Porter 2010, Sinha, Peters et al. 2009). However, as noted in chapter 5, these programmes may fail to reach a large section of the female HIV-positive population who are unaware that they are potentially at risk of contracting HIV. Chatterjee and Hosain's (2006) survey on married women's perception of their propensity to contract HIV illustrated that many believed that they were unlikely to acquire it as they did not partake in any 'risk behaviours', such as 'indiscriminate sexual activity or promiscuity' (p.83).

According to findings in the qualitative phase of research for this thesis, some WLHA may not have received their HIV test results from their physician. This was perhaps the result

of many respondents being tested in a private healthcare facility. No known studies have reported similar issues with HIV testing and counselling in other areas of the world heavily afflicted with HIV, indicating that this type of interaction might be more common in a south-east Asian context. These findings were similar to that of Datye, Kielmann et al's (2006) study on private practitioners' communication with patients over HIV testing in India, where it was demonstrated that doctors would adapt their behaviour towards patients according to their perception of the clients' mental health and ability to understand the condition. Patients who were uneducated or perceived as having suicidal tendencies were not directly informed of their HIV-status by their medical practitioner. Amongst these types of client, women and younger people were seen by doctors as being less capable of understanding a sero-positive diagnosis than other patients. This indicates that healthcare practitioners could hold attitudes to their female clients which would make them less inclined to directly inform them of their HIV-status.

Although the NFHS-III did not collect much data on respondents' patterns of healthcare utilisation, findings from the quantitative phase of analysis were, nevertheless, illuminating. Female HIV-positive respondents in the NFHS-III seemed to be no more likely to use any type of healthcare service than their HIV-negative counterparts despite potentially being in greater need of it. For example, HIV-positive women were as likely to have used any healthcare services (39%) in the past three months than the general public (37%).

On the other hand, findings on participants 'subjective realised access' indicated that female HIV-positive participants felt that they had received a good quality of care<sup>167</sup>. These quantitative findings were unexpected as results from the qualitative phase of research highlighted that the quality of care which WLHA received from healthcare practitioners could be negatively affected by HIV-related stigma. For instance, a few peer providers stated

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<sup>167</sup> These results differ to findings in other studies, which have demonstrated that HIV-positive women experienced discrimination from practitioners who either refused to treat them or did not take account of their needs (Bharat, Mahendra 2007, Mahendra, Gilborn et al. 2007, Rahangdalea, Banandurb et al. 2010, Ricketts, Goldsmith 2005).

that some of their clients had complained that staff in governmental hospitals had refused to touch them.

It is possible that quantitative findings on ‘subjective realised access’ were influenced by participants awareness of their HIV-status. As the majority of female HIV-positive participants had not taken a HIV test, it is doubtful that they would be actively seeking treatment for their condition. Consequently, few female HIV-infected participants in the NFHS-III would have experienced stigma from healthcare practitioners, as in most cases the latter would also not know about their condition.

Results on ‘objective’ and ‘subjective realised access’ could be the product of few female HIV-infected participants as yet suffering from symptoms which would indicate to them that they could be experiencing a chronic condition. According to results on most indicators of *need*, the majority of female HIV-positive participants seemed to be largely free of symptoms and possibly not in need of immediate care. There was, however, a significantly ( $<.005$ ) higher prevalence of TB among HIV-infected participants (1.9%) in comparison to the general population (0.3%). This suggests that there could be a minority of WLHA in the final stages of their illness.

These findings were substantiated by results on participant’s *health behaviours*, which suggested that female HIV-infected participants had perhaps inadvertently maintained their health-status by consuming a wide range of food items. Female HIV-positive respondents in the NFHS-III were significantly ( $<.05$ ) more likely to consume fruit (38%) and meat (35%) on a weekly basis than their HIV-negative counterparts. In addition, HIV-infected respondents had on average a slightly higher food score ( $M= 12.43$ ,  $SD=3.07$ ) than the general population ( $M= 11.79$ ,  $SD= 3.03$ ),  $t (-2.94)= 52739$   $p<.005$ ,  $r=0.01$ ), indicating that they ate a broader variety of food items on a more regular basis than their HIV-negative counterparts.

Multivariate analysis of female participants’ *health behaviours* in the NFHS-III suggested that their diet could be mediated by a set of socio-cultural and socioeconomic

factors. For instance, female participants who were in the richer/richest wealth quintiles (OR=1.24, CI=1.18-1.31) and did not belong to a government designated caste (OR=1.35, CI=1.29-1.42) displayed increased odds of having a higher food score. This means that some HIV-positive respondents belonging to a certain social strata might not be at risk of experiencing poor nutrition, hence could maintain their level of immunity better and might not be aware of their sero-status for some time.

Recent research has highlighted the fact that PLWHA have higher nutritional requirements than those who are not infected, even when they are not undertaking ART treatment (Koethe, Lukusa et al. 2010, Colecraft 2008, Avert 2010). Ivers, Cullen et al. (2009) reported that HIV infection increased energy expenditure by 50-100% resulting in PLWHA having higher protein requirements than their HIV-negative counterparts. It is therefore possible that some female HIV-positive respondents in the NFHS-III may have prolonged the dormant phase of their condition by consuming a wide range of food items. These *health behaviours* could have delayed their diagnosis. Haddad and Gillespie (2001) stated that previous research has demonstrated that 'the onset of the disease (AIDS) and even death might be delayed in well-nourished HIV-positive individuals' (p.31).

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## 8.H Conclusion

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The results in this chapter could be suggestive of wider trends in treatment of HIV in the Indian population. The findings established that the vast majority of female HIV-positive respondents had not taken an HIV test prior to the survey, indicating that most WLHA in India are likely to be unaware of their sero-status. HIV-positive people's lack of awareness of their sero-status is a global problem, which also affects patients in developed countries. For instance, Kmietowicz (2010) estimated that a quarter of PLWHA in the UK were oblivious of their HIV-status. Moreover, more than half of recently diagnosed PLWHA in Kmietowicz's (2010) study learnt of their HIV-status after the stage of their illness at which treatment could have been initiated.

Findings in this chapter pointed to a larger trend in the HIV epidemic in India as displayed in chapters 5, 6 and 7. This trend of transmission and policy could be encapsulated by Mann's (1992) theory of the three phases of the international HIV epidemic. In the initial phase of transmission, HIV enters the community or nation without the knowledge of its citizens. Results in this chapter indicate that the HIV pandemic in India is probably within this first phase. These findings are worrying as it seems that the majority of female HIV-positive respondents are not aware of their condition and do not have cause to be as they are in the dormant stage of the illness and do not believe that they could be at risk of contracting HIV. Hence, it is possible that HIV could spread further as PLWHA unknowingly infect others. The aim of the next chapter is to explore what potential dimensions of access could influence female sero-positive respondents' use of HIV testing services.

## **Chapter 9 HIV-POSITIVE WOMEN'S 'VULNERABILITY' TO THE IMPACT OF HIV/AIDS- NFHS-III RESULTS ON ACCESS TO HIV TESTING FACILITIES**

### **9.A Introduction**

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This chapter follows on closely from the previous set of results which illustrated that only a small minority of sero-positive women in India had taken an HIV test; hence, few WLHA may have been aware of their condition. This could be the product of respondents in both quantitative and qualitative samples having a low level of knowledge of HIV/AIDS and thus not suspecting that they were potentially at risk of contracting it. Few female participants in either sample reported that they had partaken in any sexual risk behaviours, with the vast majority of female respondents in the NFHS-III reporting that they first had sexual intercourse when they married. Moreover, many qualitative interviewees commented that they had 'never heard of the name HIV' prior to being tested for it. These findings highlighted the fact that awareness of one's condition may be a crucial component of access, as it is the first step towards finding the correct type of medical treatment for their illness.

These findings led to the principal objective of this chapter, namely to investigate what drives a marginal percentage of female sero-positive respondents in the NFHS-III to take an HIV test. This issue was examined by investigating the impact of theoretical 'potential' dimensions of access (e.g. age) on the use of testing facilities. The following section describes the selection of variables in the NFHS-III in accordance with Andersen and Aday's (1981) model of access adapted for the purposes of this thesis.

### 9.A.1 Selection of variables to measure predictors of vulnerability

As chapter 9 looks at female sero-positive participants' vulnerability to the impact of HIV/AIDS through examining their access to the necessary healthcare services, respondents' use of HIV testing facilities was employed as the dependent variable. Andersen and Aday's (1981) modified model of access guided the selection of independent variables. These independent variables were selected according to their ability to evaluate 'potential' dimensions of access. This dimension encompasses the 'characteristics of health delivery system', 'characteristics of population at risk' and 'socio-cultural practices'.

In this chapter I explore each component of the 'characteristics of population at risk', which are *predisposing characteristics*, *enabling resources* and *need*. I examined these components of the 'characteristics of the population' because the previous chapters had not discussed the impact of these variables on respondents' use of HIV testing facilities. *Predisposing characteristics* assess socio-demographic traits that respondents possessed independently of their condition, including their age, area of residence, state, religion, caste and marital status. Additionally, *enabling resources* measure social and financial means by which patients accessed healthcare services. These variables include level of education, financial status and occupation. Finally, female participants' *need* for treatment was explored through variables which record their level of malnutrition, as well as their experience of chronic illness and STIs. Figure 9.1 depicts how Andersen and Aday's (1981) theoretical framework was adapted and used to analyse female HIV-positive participants' access to HIV testing facilities.

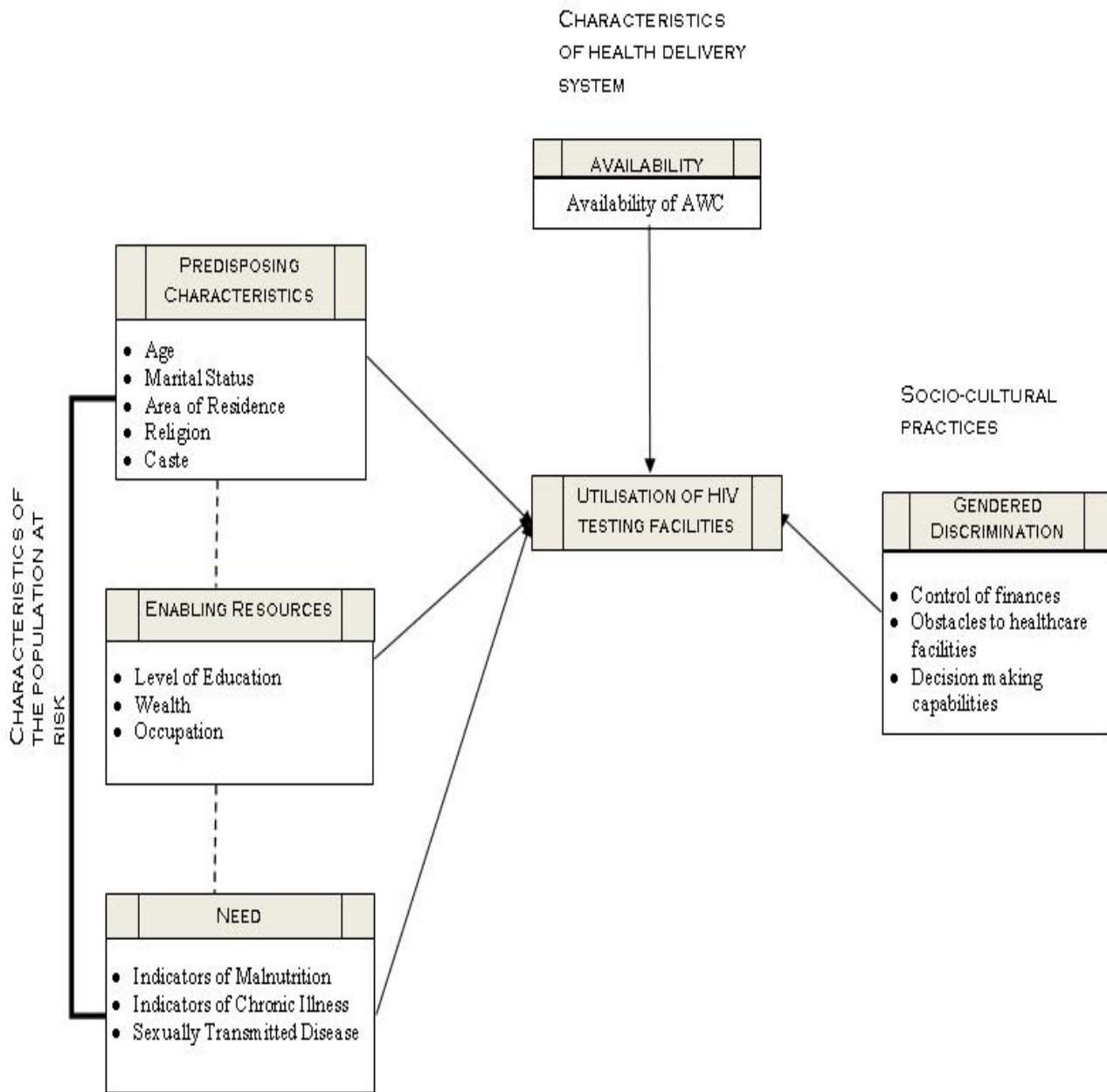


Figure 9.1: Andersen and Aday's model of access with additional adjustments for data analysis

'Characteristics of health delivery system' were evaluated by assessing the *availability* of an Anganwadi Centre (AWC) in each of the NFHS-III sample enumeration areas and the length of time during which these facilities have been operational. This variable was used to measure the geographic proximity of public healthcare services as quantitative and qualitative

findings in the previous chapter illustrated that Anganwadi facilities may have potentially acted as a bridge to HIV related services.

Within the dimension of ‘socio-cultural practices’, the component of *gendered discrimination* was used to evaluate the impact that gendered norms might have had on Indian HIV-infected women’s ability to access the necessary services. This was because qualitative results in the previous chapter suggested that the type of HIV-related counselling that sero-positive women received was partly contingent on their physicians’ perception of their ability to comprehend their condition and their position within their family. For instance, a few participants’ narratives indicated that their physician might have been reluctant to inform them of their sero-status if their parents-in-law had instructed them not to do so. There was therefore a possibility that *gendered discrimination* could also negatively impacted access to HIV testing services.

Although only female HIV-positive participants were analysed in this chapter, the relative weighting system was applied to the sample. As mentioned in chapter 4 (Methods), the relative weighting system compensated for possible biases incurred by the stratified sampling technique in which respondents in low prevalence states were under sampled, while participants in high prevalence states were over sampled. The advantage of using relative weights was that it provided a better representation of the HIV-infected population than the raw data would have, through upweighting underrepresented cases. However, the disadvantage of using relative weights was that it substantially reduced the total number of HIV-positive cases by downweighting overrepresented areas very heavily in some states (e.g. Manipur state).

Application of the relative weighting system to the female HIV-positive sample in the NFHS-III presented difficulties as regards to conducting bivariate and multivariate analyses on social factors which might have influenced WLHAs' use of HIV testing services. The

relative sample weight reduced the sample size of female HIV-positive participants from 191 to around 115. Moreover, the number of HIV-infected female participants who had reported taking a test also dropped, rendering most weighted findings insignificant.

Although the original cases may not have been representative of the female HIV-positive population in India, they could be reflective of some WLHA's experiences of accessing HIV testing services as they are real cases in the raw NFHS-III dataset. The response adopted in this chapter was to analyse both the data with relative weights and the raw unweighted data, focusing only on the HIV-positive cases. Data from the qualitative phase of research was then employed to further examine how 'potential' dimensions of access could affect WLHA's use of HIV testing services. As the size of the female HIV-positive sample was relatively small, multivariate analysis was not conducted on any indicators of 'potential access'.

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## 9.B Characteristics of Population at Risk

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### 9.B.1 *Predisposing Characteristics*

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A set of chi-squared tests was performed between variables measuring *predisposing characteristics* and the use of HIV testing services. When the relative weights were applied to the female HIV-positive sub-sample of the NFHS-III, these chi-squared tests yielded no significant results. Most indicators of *predisposing characteristics* (including area of residence, state, religion, marital status, caste status, type of caste and wealth) seemed to have little or no impact on female HIV-positive participants' propensity to take an HIV test. For instance, respondents living in rural areas were no more likely to report undertaking an HIV test in comparison to those residing in urban areas. Table 9.1 shows multiple measures of *predisposing characteristics* and female HIV-positive respondents' propensity to take an HIV test in the weighted sample.

**Table 9.1:** Multiple measurements of female HIV-positive participants' 'predisposing characteristics' and whether they had taken an HIV test (weighted) (n=115)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measurements of 'Predisposing Characteristics'	Ever been tested for AIDS			
	Yes		No	
	Count	%	Count	%
<u>Region of India</u>				
North/North Eastern States	0	0	13	100
Central/Western states	2	5	38	95
Southern states	5	8	55	92
<u>Area of residence</u>				
Urban	2	4	47	96
Rural	6	9	59	91
<u>Religion</u>				
Hindu	7	7	97	93
Non-Hindu	1	10	9	90
<u>Currently/formerly/never married</u>				
Never married	0	0	4	100
Currently married	4	5	71	95
Formerly married	4	11	31	89
<u>Caste or tribe</u>				
Caste	7	7	100	93
Tribe	1	20	4	80
No caste/tribe	0	0	0	0
Don't know	0	0	3	100
<u>Type of caste or tribe</u>				
Scheduled caste	2	9	21	91
Scheduled tribe	1	6	17	94
OBC	2	4	49	96
None of them	3	10	28	90
Don't Know	1	50	1	50

In contrast, age seemed to have an impact on participants' propensity to undertake an HIV test in the weighted sub-sample of female HIV-positive respondents in the NFHS-III. Participants who had taken the test were on average 5 years older (M= 35.21, SD=7.41) than

those who had not ( $M=30.40$ ,  $SD=8.44$ ,  $t(112)=1.74$ ,  $p=.085$ )<sup>168</sup>. These findings suggest that age could act as a proxy indicator for longer exposure to HIV or events that may trigger testing, such as a spouse displaying HIV-related symptoms<sup>169</sup>.

The weighted findings contrasted with results generated from the raw unweighted NFHS-III dataset. Findings from the raw unweighted dataset indicated that there was a significant ( $<.05$ ) relationship between the region of India where respondents lived in and if they had undertaken an HIV test<sup>170</sup>. A larger number of participants living in north/north-eastern states had reported undergoing a test than those residing in southern regions of India, though the bulk of WLHA lived in these latter states<sup>171</sup>.

It is possible that results from the unweighted sub-sample of female HIV-positive participants in the NFHS-III were influenced by the heavy over-sampling of those living in areas of higher HIV prevalence, which were often in northern states with smaller populations. Public healthcare facilities in southern Indian states, e.g. Tamil Nadu, often provide a better quality of care than in north and north-eastern states (Qadeer 2000, Peters, Rao et al. 2003, Sheikh, Porter et al. 2006, Kumarasamy, Venkatesh et al. 2007). Moreover, southern states have an appropriate infrastructure for provision of adequate HIV-related care, as they were the first areas of India to report a large volume of HIV-infected patients (Baghdadi 2005, Banerji 2005). For instance, YRG CARE<sup>172</sup> in Chennai in Tamil Nadu was

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<sup>168</sup> Age had a significant ( $<.05$ ) impact on participants' propensity to take an HIV test on the weighted subset of the female HIV-positive respondents in the NFHS-III. Female HIV-infected respondents in the NFHS-III who had undertaken the test were on average 4 years older ( $M= 34.14$ ,  $SD=6.74$ ) than who had not ( $M=30.39$ ,  $SD=7.76$ ,  $t(189)=2.12$ ,  $p<.036$ ,  $r=0.15$ ).

<sup>169</sup> It is also possible that age can positively influence Indian women's control over resources, and hence, improve their ability to access HIV testing services. Dev, Jacqueline et al. (2010) found that women's decision making on their own healthcare in Nepal was positively associated with their age.

<sup>170</sup> Please see Appendix 46 for a table displaying unweighted results on which region of India sero-positive female participants lived and whether they had taken a HIV test.

<sup>171</sup> Results on HIV testing and region of India differed vastly between the weighted and unweighted NFHS-III datasets because northern states with high rates of prevalence were downweighted. For example, Manipur was assigned a weight of 0.027. When these types of weights are applied to numerically small sets of data, the numbers can diminish to effectively zero when rounded down.

<sup>172</sup> YR Gaitonde Centre For AIDS and Education is an NGO providing care and support to PLWHA in Chennai, India.

the first NGO clinic in India provide sero-positive patients with both ayurvedic and western treatment for free (Rajasekaran, Jeyaseelan et al. 2009).

Other results from the unweighted female HIV-infected sub-sample in the NFHS-III suggested that there was a significant ( $<.05$ ) relationship between a participant's religion and their tendency to be tested for HIV<sup>173</sup>. It was found that a third of all participants who had taken an HIV test were not Hindu. These results suggested that there was a possibility that female HIV-infected respondents who were Hindu could be less likely than their non-Hindu counterparts to have taken an HIV test. These findings could also be a function of over sampling in high incidence states that have a larger number of non-Hindu respondents.

Nevertheless, these results were similar to those of the qualitative phase of research. It was found that a large percentage of the qualitative sample were Christian. These participants belonged to communities which had strong links to local NGOs providing social and healthcare services to HIV-positive patients. PP7 commented that in her area:

*'HIV is in all castes but the Christians are in majority and they also come forward to seek help and guidance'.*

None of these respondents reported that their local church or faith-based NGO enabled them to reach testing facilities. Nonetheless, many Christian respondents seemed to be in receipt of social and medical support from faith-based NGOs. PF14's child, who was disabled from polio, received free treatment from the Freedom Foundation, an international Christian NGO.

Results generated from the weighted sub-sample of female HIV-positive participants in the NFHS-III suggested that *predisposing characteristics* had no significant influence over respondents' access to HIV testing services. For example, an equal number of participants

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<sup>173</sup> Please see Appendix 47 for a table displaying unweighted results on the religion of female HIV-infected respondents and whether they were tested for HIV.

who were currently married reported having taken an HIV test to those who were formerly married.

On the other hand, findings on *predisposing characteristics* generated from the raw unweighted sub-set of female HIV-positive participants indicated that age, religion and region of India could have a significant ( $<.05$ ) association with respondents propensity to take a test. It was difficult to analyse these findings further as the female HIV-positive sample was numerically very small. These results suggest, though, that in some cases *predisposing characteristics* could influence participants testing behaviours. The following section will examine the impact that *enabling resources* has on participants' ability to reach HIV testing services.

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### 9.B.II *Enabling Resources*

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As with findings on *predisposing characteristics*, bivariate analyses assessing the impact of *enabling resources* on HIV testing behaviours yielded no significant results when conducted on the weighted sub-sample of female HIV-positive respondents in the NFHS-III. Many variables measuring *enabling resources* (e.g. level of education, literacy, wealth and possession of a BPL card) did not seem to have any significant impact on female HIV-infected respondents' propensity to take a HIV test<sup>174</sup>. Table 9.2 displays a cross tabulation of multiple measurements of female HIV-positive respondents' *enabling resources* and their propensity to take an HIV test.

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<sup>174</sup> It is important to take into account the fact that the very small numbers involved might be the main factor behind these findings.

**Table 9.2:** Multiple measurements of female HIV-infected respondents' enabling resources and whether they had taken an HIV test (weighted) (n=115)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measurements of 'Enabling Resources'	Ever been tested for AIDS			
	Count	%	Count	%
<u>Level of education</u>				
No education	5	9	51	91
Primary	1	4	27	96
Secondary	2	7	27	93
Higher	0	0	2	100
<u>Literacy</u>				
Illiterate	5	7	70	93
Literate	3	8	36	92
<u>Wealth Index</u>				
Poorest	1	6	15	94
Poorer	0	0	20	100
Middle	3	11	24	89
Richer	5	13	33	87
Richest	0	0	14	100
<u>Household has a BPL card</u>				
Yes	4	6	63	94
No	4	9	43	91

Further analysis of the weighted dataset revealed that female HIV-positive respondents' employment status had little or no impact on their propensity to be tested for HIV. An equal number of employed respondents had taken an HIV test as those who were not working. Neither did the type of occupations that respondents were employed in had any effect on this variable. Female HIV-infected participants who were employed in skilled occupations were just as likely not to have taken an HIV test as those who were involved in manual labour. Table 9.3 shows multiple measures of female HIV-infected participants' occupation and their propensity to take an HIV test.

**Table 9.3:** Multiple measurements of female HIV-positive participants' occupation and whether they had taken an HIV test (weighted) (n=115)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measurements of Occupation	Ever been tested for AIDS			
	Count	%	Count	%
<u>Employment status</u>				
Yes	4	6	63	94
No	4	9	43	91
<u>Occupation</u>				
Not working	4	9	43	91
Skilled occupations	2	7	28	93
Manual occupations	1	3	36	97

Most unweighted findings on *enabling resources* were very similar to results generated from the weighted female HIV-infected sub-sample in the NFHS-III. The only indicator of *enabling resources* within the unweighted sample that had a significant (<.05) impact on female sero-positive participants' propensity to take an HIV test was household ownership of a BPL (Below Poverty Line) card<sup>175</sup>. A lower than expected number of respondents living in households which owned a BPL card had taken an HIV test, indicating that they could be less likely to reach diagnostic facilities than those residing in households with no card. These findings suggest that WLHA belonging to the poorest sections of society may have possibly experienced substantial barriers to accessing HIV testing services.

Results generated from both the weighted and unweighted datasets in this section suggest that most indicators of *enabling resources*, apart from household ownership of a BPL card, had very little impact on female sero-positive participants propensity to undertake a HIV test. These findings suggest that participants *enabling resources* may have little impact on their treatment seeking behaviours as they are as yet unaware of their HIV-status. It is likely that some female HIV-infected participants may not as yet have displayed any

<sup>175</sup> Please see Appendix 48 for a table displaying unweighted results on whether female HIV-infected participants lived in a household with a BPL card and whether they took an HIV test.

symptoms of their condition. The following section examines the impact of female sero-positive respondents' level of *need* on their propensity to be tested for HIV.

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### 9.B.III    *Need*

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A set of chi-squared tests was performed between variables measuring female HIV-infected respondents' level of malnutrition and their use of HIV testing services in the weighted sub-sample of female HIV-positive respondents in the NFHS-III. Most variables had little or no effect on female HIV-infected participants' utilisation of testing services. Underweight respondents were no more likely to have taken an HIV test in comparison to those classified as having a normal weight. Table 9.4 shows multiple measures of possible malnutrition and female HIV-positive respondents' propensity to undertake an HIV test.

**Table 9.4:** Multiple measurements of female HIV-positive participants' level of malnutrition and whether they had taken an HIV test (weighted) (n=114)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measurements of malnutrition	Ever been tested for AIDS			
	Count	%	Count	%
<u>BMI</u>				
Underweight	2	5	42	95
Normal weight	4	6	58	94
Overweight	2	25	6	75
<u>Anaemia*</u>				
Anaemic	7	11	56	89
Not anaemic	1	2	51	98
<u>Menstruated in last six weeks</u>				
Yes	2	10	18	90
No	5	5	89	95

On the other hand, female HIV-positive respondents' level of anaemia seemed to have a significant (<.05) association with their propensity to take a HIV test. Seven out of eight participants who had taken the HIV test were also anaemic. It is difficult to ascertain the

causal direction of these findings as the NFHS-III did not record the sequence of events leading to an HIV test. This small number of respondents may have tested for HIV after displaying symptoms of OIs given that severe unexplained anaemia has been identified by the WHO, Mahe et al. (1990) as a symptom of one of the final stages of HIV infection.

Unfortunately, it was not possible to examine the impact that female HIV-infected respondents' experiences of chronic illness and STIs had on their propensity to take an HIV test. This was because few of these respondents reported experiencing any of these conditions, meaning that the results would be unreliable. Instead, I explored whether respondents access to HIV testing services was influenced by their family's level of *need*. I assessed whether respondents living in households with a usual resident suffering from TB were any more likely to have taken an HIV test. The majority of participants who did not live in households with a TB infected individual were not tested for HIV. The number of cases was too small to produce a reliable result. Table 9.5 is a cross-tabulation of participants living in a household with a usual resident suffering from TB and whether any female sero-positive respondents had undertaken an HIV test.

**Table 9.5:** Any usual resident of the household suffers from TB and whether any female HIV-positive members of this household had taken an HIV test (weighted) (n=105)

Any usual resident of the household suffers from TB	Ever been tested for AIDS			
	Count	%	Count	%
Yes	1	25	3	75
No	7	7	94	93

These findings were similar to those of the qualitative phase of analysis, whereby none of the respondents had undergone an HIV test *voluntarily* based on their knowledge of their susceptibility to HIV infection. The only consistent factor that promoted their entry into healthcare services was a medical set of procedures conducted to monitor or improve the respondents' or their husbands' health-status. These sets of procedures were not at first

explicitly associated with their sero-status but later resulted in an HIV test. I labelled these serendipitous or accidental episodes as ‘trigger’ events as it was possible that many respondents might not have otherwise learnt of their HIV-status.

One of the trigger events was their spouse exhibiting symptoms of the final stages of HIV infection, such as TB. Their husbands would first seek treatment for HIV-related symptoms without any prior knowledge of their sero-status. PP6 said:

*‘When my husband was suffering with fever, we took him to the hospital when I came to know about this... His nerves in the hands would not work and he had severe pains. At that time they gave him shock therapy which I heard but did not see... Fifteen days later, he could not eat or walk. We then took him to a private hospital and admitted him there. They did a blood test and found that he was HIV-positive’.*

According to PP6’s account her husband’s diagnosis was delayed as physicians attempted to treat his symptoms without awareness of the underlying condition. This is a common issue with chronic illnesses which are often difficult to diagnose either because the patients ignore the symptoms for too long or because doctors tend to misclassify them (Rabe, Hurd et al. 2007, Smith, Cokkinides et al. 2006, Krege, Beyer et al. 2008). In the case of PLWHA, the physicians’ failure to diagnose their condition could cause significant delays in reaching the appropriate services, which could have a detrimental effect on the patient’s treatment outcomes. Sero-positive patients who present late are more likely to be hospitalised for OIs and die in a shorter period of time than those who are tested in the early stages of the illness (Girardi, Sabin et al. 2007).

Nonetheless, it is important to note that participants sampled in the qualitative phase of research were part of a small minority of WLHA in India who were aware of their sero-status and made continual use of public healthcare facilities for their condition. It is possible that many female HIV-infected respondents in the NFHS-III who lived with other members of their family experiencing OIs may have never taken an HIV test as their relative or spouse had not been diagnosed as HIV-positive. The following section will therefore examine how

the ‘characteristics of health delivery system’ could affect WLHA’s access to HIV testing facilities. This is because the *organisation* of medical services might have had an impact on a physician’s ability to effectively diagnose HIV based on the existence of OIs and to ensure that those potentially infected were referred to the relevant testing facilities.

## 9.C Characteristics of Health Delivery System

### 9.C.1 Availability

Outreach staff working for AWCs often offer basic healthcare and referral services for antenatal and post-natal treatment (Davey, Davey et al. 2008, Rao 2005). In some cases, the provision of multipurpose health workers has ensured that many pregnant women utilised antenatal treatment in rural areas (Navaneetham, Dharmalingam 2002). Since HIV testing is often part of antenatal treatment in India (Firth, Jeyaseelan et al. 2010), there is a possibility that the availability of such services locally could affect a pregnant woman’s propensity to be tested for HIV.

Bivariate analysis of *availability* and HIV testing behaviours on the weighted NFHS-III dataset revealed that HIV-positive respondents living in enumeration areas covered by an AWC were just as likely to be tested for HIV as those who did not live in close proximity to one of these centres. Table 9.6 shows a cross tabulation of enumeration areas covered by an AWC and whether female sero-positive respondents had taken an HIV test.

**Table 9.6:** Enumeration areas covered by AWC and whether female HIV-positive respondents had taken an HIV test (weighted) (n=115)

Ever been tested for AIDS	Enumeration areas covered by AWC			
	Count	%	Count	%
Yes	7	87	1	13
No	82	77	25	23
<b>Total</b>	<b>89</b>	<b>77</b>	<b>26</b>	<b>23</b>

Further analysis of the weighted NFHS-III dataset illustrated that female HIV-infected participants living in areas where an AWC had been operational for a longer period of time seemed to be more likely to have been tested for HIV than their counterparts. A large proportion of respondents whose AWC had been functional for 10-19 years had taken an HIV test. In contrast, only one participant living in an enumeration area with an AWC operational for 0-9 years had taken the test. These findings could be the result of the small numbers of female HIV-infected participants. However, it is also possible that AWCs which have been functioning for longer periods of time could be more effective in encouraging women to take HIV tests as part of their antenatal treatment<sup>176</sup>. Table 9.7 displays female HIV-positive respondents' propensity to be tested for HIV against years of AWC coverage of their sample enumeration area.

**Table 9.7:** Years of coverage by AWC and female HIV-positive respondents' propensity to take an HIV test (weighted) (n=84)

Years of AWC coverage	Ever been tested for AIDS			
	Count	%	Count	%
0-9	1	3	31	97
10-19	5	18	23	82
20 or more	1	4	23	96
<b>Total</b>	<b>7</b>	<b>8</b>	<b>77</b>	<b>92</b>

A few peer providers, interviewed as part of the qualitative phase of research, worked as antenatal ORWs in collaboration with Prevention of Parent-to-Child Centres and AWCs. These peer providers' narratives highlighted how AWCs could act as an important bridge to services by encouraging pregnant women to take an HIV test and undergo preventive treatment if sero-positive. These peer providers were only in contact with their client for the

<sup>176</sup> These findings were similar to results generated from the unweighted female HIV-infected sub-sample of participants in the NFHS-III. It was found that female HIV-positive participants living in areas with an AWC operational for 10-19 years were significantly ( $<.05$ ) more likely to have been tested for HIV than those residing in areas with an AWC operational for 0-9 years. Please see Appendix 49 for a table displaying unweighted results on years of coverage by AWC and female HIV-positive respondents' propensity to take an HIV test.

duration of their antenatal treatment, meaning that they were only able to provide impressions of their clients based on the fleeting encounters they had with them. Nevertheless, these respondents' narratives about their clients experiences of using treatment during this time period did provide an illuminating perspective on the type of issues that HIV-positive women face when accessing maternal healthcare services.

Peer providers working in Prevention of Parent-to-Child Centres and AWCs were required to inform HIV-positive pregnant clients of their sero-status, regularly monitor their health, provide them with prophylaxis to prevent transmission to the child and offer follow-up treatment once the infant was delivered. They would also refer their clients to social services, e.g. PP9 would give families who owned a ration card for 35 kg of rice. PP1 stated that:

*'From the beginning of fourth month till their delivery we keep following them up. In a month we visit them six times... As the pregnancy advances, in the 5th, 6th, 7th I go to them monthly twice. After 7th month, I visit them at least four or five times a month... Even after delivery we keep following up the patients... Until the little babies reach 18 months we are following up their cases. After 18 months, we check up the baby also... We find out if the children are being fed properly, given the necessary vaccines and all details regarding paediatrician we inform them.'*

PP1's account demonstrated that *availability* of services for WLHA were not entirely contingent on geographical distance from the healthcare provider. This was because potential spatial barriers to access were overcome through healthcare services being delivered to pregnant WLHA's homes. Her description of activities involved in the provision of antenatal care further illustrated that each medical procedure ensured that clients were sufficiently monitored and offered treatment at every stage of their pregnancy.

This client-focused method of healthcare delivery often requires a high level of organisation as ORWs need to be trained on how to provide specialised HIV-related care and the necessary equipment and medication has to be available to staff (John, Babu et al. 1993). Some outreach workers employed at long established AWCs may therefore have been more able to steer pregnant WLHA towards testing services. The following section of this chapter

will address these issues by exploring how the organisation of services could affect WLHA's access to testing facilities, concentrating purely on data from the qualitative phase of research.

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### *9.C.II Organisation of services*

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As mentioned earlier in this chapter, many qualitative interview respondents were encouraged by a healthcare practitioner to take a test after a 'trigger event' (e.g. their partner or child displaying extreme HIV-related symptoms). In some cases, participants' access to HIV testing services was contingent on their physician's capacity to correctly assess their risk of being sero-positive. This resulted in respondents' pathways to HIV testing facilities being shaped by the organisation of services.

These organisational factors were most apparent with respondents who learnt of their sero-status through the 'trigger event' of a routine HIV test as part of antenatal care when pregnant. Respondents who learnt that they were HIV-positive in this manner reported that they underwent the HIV test without much forethought because it was a standard procedure undertaken during antenatal treatment. PF1 stated that:

*'Usually when pregnant, we do for all the usual tests, and then they did the HIV test when I came to know that I was HIV positive'.*

This indicates that she perceived the HIV test no differently from many other types of physical examinations she was required to endure as part of the antenatal treatment procedures to monitor her health-status, e.g. urine and blood testing (Rani, Bonu et al. 2008).

Other respondents reported that they had willingly taken the HIV test as part of their antenatal care routine for reasons which did not encompass their own risk of contracting the virus. PF19 said that:

*'I got myself tested like all other pregnant women and I did not think so deeply and said to myself, "Why will this disease come to me?"'*

This account indicates that there were two structural factors which encouraged her to take the test. Firstly, there was the relative ease of taking the test as part of antenatal treatment. This meant that she was not required to assess her own risk of being sero-positive, which was relatively low considering that as far as she knew her husband had little or no opportunity to engage in extra-marital sexual relationships for the duration of their partnership<sup>177</sup>. Secondly, the stigma of taking an HIV test was mitigated by it being a common procedure that ‘other pregnant women’ were expected to take.

These respondents’ narratives demonstrated how routine medical procedures associated with antenatal treatment can encourage women belonging to low risk groups to take an HIV test. Recent research illustrated that a policy of routine opt-out HIV testing in developing countries increased the amount of people undertaking the diagnostic procedure (Rennie, Behets 2006, WHO 2003, WHO, UNAIDS 2004). In Kenya routine opt-out testing was increased for pregnant women, hospitalised patients and TB-infected individuals with the result that less than 20% of patients refused to take the HIV test (De Cock, Bunnell et al. 2006).

It is important to take into account that these participants’ narratives of taking an HIV test while pregnant may not be reflective of the experience of many WLHA. Chandrasekaran, Dallabetta et al. (2006) noted that coverage of antenatal services varied widely across India from 34% in northern states to around 90% in southern states. Furthermore, even if some WLHA were to access antenatal facilities, they may not be offered routine HIV tests by their healthcare provider. Some qualitative interviewees stated that they were not tested for HIV when they attended an antenatal clinic.

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<sup>177</sup> Although her husband had a mobile occupation prior to marriage, which may have offered him the opportunity to practice risk-taking sexual behaviour, for the duration of their relationship he had worked in a stable job as a ‘clerk’ in a clothes shop.

Respondents whose ‘trigger event’ was their spouse exhibiting OIs experienced many structural barriers in accessing HIV testing facilities. These participants commented that their husband’s diagnosis was often delayed by their seeking treatment from many different physicians. This could be a product of the pluralistic Indian healthcare system which offers a wide variety of biomedical and alternative treatments (Read, Armstrong-James et al. 2010, Plummer, Mshana et al. 2006). This pluralistic system of healthcare, while offering a lot of choice for consumers, is amorphous and unregulated, and therefore PLWHA with little awareness of their condition may spend a protracted period of time seeking treatment from many healthcare providers prior to learning of their sero-status (Moshabela, Pronyk et al. 2010).

PF8’s spouse sought treatment for OIs in two or three healthcare facilities before eventually being tested for HIV. She said:

*‘We took him to one S- hospital situated at N- where we incurred a large sum of money up to Rs. 30,000. He had very high fever and they wanted to check his blood which would cost them Rs. 1800 for the specific test. So, we decided to get this test done. It was finally revealed that my husband had HIV’.*

This account demonstrated that the pluralistic system of healthcare can impose additional financial barriers to access. Familial *enabling resources* were drained as PF8’s husband sought treatment for debilitating OIs from a few private healthcare providers. After learning of her husband’s sero-status, the few financial resources available were used to search for a ‘cure’ for the condition. These circumstances resulted in PF8 having little time or resources to take an HIV test herself at that time, although she was warned by her doctor that she could be HIV-positive.

Another obstacle to being tested was that their husbands concealed their HIV-status for long periods of time, even when very unwell. PF21, who unlike other respondents was aware of HIV as she was a nurse, reported that she first suspected that her husband could be

HIV-positive after he suffered from hair and weight loss. She commented that when members of her village asked him 'why he was becoming lean', he would answer 'Nothing, there is not enough food and water'. This interaction revealed that he was actively hiding his HIV-status from many others in his community even when experiencing symptoms indicative of being in the final stage of the illness.

Furthermore, PF21 was apprehensive about directly questioning her husband on his sero-status, even when it was obvious that he was using HIV-related healthcare services. She stated that:

*'I saw his friend and I asked him why he did not go to the hospital along with my husband and he said that did not know anything. So, I understood that he was staying somewhere and going. I asked for the medicine and he showed me some slips and prescriptions. "There are not from our area, they are from Tamil Nadu", I said. "The doctor asked me to use these medicines and I didn't go that far because I can't", he said. I believed his whole story. I stayed silent.'*

As with many other respondents, PF21 had previously endured extreme physical violence from her husband. Her narrative revealed that her husband's concealment of his condition could have been a continuation of his abusive and controlling behaviour towards her. Although her husband may have known that she was at risk of contracting HIV from him, he chose to seek treatment for his condition without informing her of his actions. This case illustrates how IPV can continue to negatively affect WLHA after they contract HIV.

This barrier for access to HIV testing facilities was further exacerbated by the fact that medical staff treating PF21's husband were unable to inform her that she could be at risk of contracting HIV. Procedures related to post-test notification of partners of HIV-infected individuals present an ethical dilemma which faces physicians, especially when there is a possibility that partners are experiencing IPV (Macklin 2005). Guidelines set by NACO in 2007 on confidentiality of results stipulate that physicians should inform PLWHA's spouses of their sero-status only with their permission. In the event of the patient's refusal to disclose

their HIV-status to those at risk of contracting HIV from them, the physician is allowed to either disclose their test results to the relevant authorities or directly inform their sexual partners of their HIV-status (NACO 2007a). In the case of many qualitative interview participants, it was possible that the medical staff they were in contact with had little or no knowledge of these guidelines<sup>178</sup>.

A few respondents reported that medical practitioners would attempt to circumvent established guidelines on patient confidentiality by informing them of their spouse's sero-status in indirect and euphemistic terms. One such participant was PF24, who learnt of her husband's HIV-status after his death. PF24 stated:

*'Doctor told me that he had TB but did not tell me anything else. Later, Doctor spoke to my husband and the nurses use to speak to me about HIV but never told me that my husband had HIV. After his death, when I went to collect his death certificate, they then told me that he had HIV.'*

This account revealed that these attempts to indirectly inform PF24 of her risk of contracting HIV failed to encourage her to take an HIV test. This delayed her treatment for an unnecessarily long periods of time, which may have resulted in her child becoming infected with HIV through vertical transmission.

Nevertheless, there were a few cases in which the medical practitioners would ignore NACO's guidelines on testing and disclosure by directly informing the respondent of their husband's HIV-status without seeking his permission first. PF12 stated:

*'He was all right for three months after my marriage and then started having fever. I think he had HIV in his system and it was at this stage it started showing out. At that time, I did not know what HIV meant. Till the last moment of his life, we did not know he had HIV. First my in laws put him into a private hospital. Towards the end of his life, he started getting fits. I then got a doubt and asked the Doctor. The doctors asked me what relationship there was between us and the doctor was told that I am his wife. Then, immediately, he said that I too should be tested. It was then revealed that I too had HIV.'*

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<sup>178</sup> None of the peer providers mentioned ethical guidelines on confidentiality of results, indicating that information on this matter may not have been conveyed to them as part of their training.

The illness narratives of both PF12 and PF24 suggest that the *organisation of services* may be shaped by informal medical practices adopted by doctors. Their physicians seemed to have a different concept of medical ethics to that of their Western peers<sup>179</sup>, in which their allegiance is towards the family as a unit rather than the individual. As Desai notes (1988) ‘the family physician has been... made into an honorary family member. The physician becomes a counsellor and advisor, and a mutuality develops in which the doctor-patient relationship goes far beyond the consulting room’ (p. 245). This could explain why PF12’s and PF24’s practitioners felt duty-bound to inform them of their husband’s HIV-status.

Findings on *organisation of services* indicate that respondents’ access to HIV testing services was shaped by the structure of healthcare facilities and informal practices which medical practitioners adopted towards informing partners of patients on their sero-status. Some qualitative interviewees’ narratives suggested that their practitioner did not consistently follow medical ethical guidelines. These participants’ awareness of their condition was therefore reliant on their physicians’ relationship with themselves and their family. This meant that their practitioners’ decision to notify them of their partner’s HIV-status may have been affected by their gendered position within the family. The following section will examine how *gendered discrimination* could influence WLHA’s access to HIV testing facilities using a combination of qualitative and quantitative data.

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## 9.D Socio-cultural Practices

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### 9.D.1 Gendered Discrimination

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Weighted data from the NFHS-III was firstly used to explore the impact of *gendered discrimination* on female HIV-positive respondents’ ability to reach diagnostic facilities.

Female sero-positive participants’ decision making capabilities had little or no measurable

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<sup>179</sup> The foundation of Western medical ethics is the Hippocratic Oath stipulates that the physician should provide treatment which is beneficial to their patient, they should avoid harming their client and whatever the patient has said during consultation should be kept confidential (Veatch 2000).

effect on their propensity to be tested for HIV<sup>180</sup>. For example, respondents who made decisions on household purchases for everyday needs on their own were no more statistically likely to have been tested than those who did not.

On the other hand, participants' control over their financial resources appears to have had a positive impact on their access to HIV testing facilities. Although the numbers were small, it was found that respondents who decided alone how the money they earned was spent seemed to be more likely to have been tested in comparison to their counterparts. On most of the indicators for this dimension of empowerment a higher proportion of participants with sole control over their finances had used HIV testing services. These findings suggested that there was a possibility that respondents who were financially empowered might be better able to reach HIV testing facilities, though this could be because their husband was incapacitated or had died. Table 9.8 shows multiple measures of female sero-positive respondents' control over financial resources and whether they had taken an HIV test.

**Table 9.8:** Multiple measures of female HIV-infected respondents' control of financial resources and their propensity to take a HIV test (weighted) (n=115) (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measures of control of financial resources	Ever been tested for AIDS			
	Count	%	Count	%
<u>Has money for own use</u>				
Yes	6	11	51	89
No	2	3	56	97
<u>Who decides how to spend money income of respondent</u>				
Respondent alone	1	14	6	86
Other	3	4	64	96
<u>Final say on deciding what to do with money husband earns</u>				
Respondent alone	1	14	6	86
Other	3	4	64	96

<sup>180</sup> Please see Appendix 50 for multiple measures of female respondents' decision making capabilities and whether they had ever been tested.

Female HIV-positive respondent's freedom of movement had barely any impact on their propensity to be tested for HIV<sup>181</sup>. Participants who were allowed to go to the market on their own were no more likely to have taken an HIV test than their counterparts. Moreover, respondents perceived barriers to treatment seemed to have little or no impact on this variable<sup>182</sup>. For instance, participants who reported that distance to healthcare facilities was 'no problem' did not seem to be any less likely to have taken an HIV test than those who believed that it was 'not a big problem' or a 'big problem'. These findings could be the result of the female HIV-positive sample being very small as previous research has illustrated that geographical obstacles to healthcare providers can negatively affect patients' ability to utilise treatment relevant for their condition (Ensor, Cooper 2004, Balarajan, Selvaraj et al. 2011).

Respondents' narratives in the qualitative stage of research suggested that *gendered discrimination* played an important role in their access to HIV testing facilities. These participants' accounts indicated that their gendered position within the family heavily influenced their interaction with their physician. This was most apparent with respondents who were not fully informed of their sero-status by their doctors at the behest of their parents-in-law who were paying for the test. In a few cases, their parents-in-law would use to their advantage that the respondent was illiterate, and conceal from them the fact that they had undertaken an HIV test or what the results were.

In many cases, failure of the physician to notify the participant of their sero-status resulted later in substantial delays in access to healthcare. PF29's parents-in-law arranged her marriage to their HIV-positive son in order to conceal his status from others in their community. She believed that her physicians may have colluded with her husband's family to conceal her sero-status. When she was first tested for HIV during pregnancy, the test results

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<sup>181</sup> Please see Appendix 51 for multiple measures of female respondents' freedom of movement and whether they have ever been tested.

<sup>182</sup> Please see Appendix 52 for multiple measures of female respondents' perceived barriers to healthcare and whether they had ever been tested.

were communicated to her parents-in-law. Due to these successive attempts to conceal her sero-status, PF29 was only able to access services in the late stages of the illness, when she was experiencing OIs and her child had contracted the virus. She said:

*'If, we knew about it earlier, I would have never breastfed my baby and protected her from getting this disease. My life is gone but I would love to protect my little one'.*

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## 9.E Discussion

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The objective of this chapter was to use Andersen and Aday's (1981) model of access to examine how far 'potential' dimensions of access affect female HIV-positive participants' use of HIV testing facilities. Bivariate analysis of the NFHS-III dataset was constrained by the relatively small numbers of participants belonging to the female HIV-infected sub-sample of participants and the very few who had been tested. As a consequence, bivariate analyses conducted on the weighted NFHS-III dataset indicated that most variables measuring 'potential' access had little or no measureable impact on female sero-positive participants' propensity to be tested for HIV.

Within *predisposing characteristics*, female sero-positive respondents who were Hindu were just as likely to have not been tested for HIV as their non-Hindu counterparts. Furthermore, the region in which female HIV-infected participants lived had little or no effect on their propensity to take a HIV test. Respondents living in central or western states were no more likely to have been tested for HIV than those living in southern regions of India.

These findings differed from results generated from the unweighted raw NFHS-III dataset. It was found that there was a significant ( $<.05$ ) association between age, religion, region of residence in India, availability of Anganwadi services and female HIV-infected participants' use of healthcare facilities. These findings suggested that the 'potential' dimensions of access which could have an impact on some female sero-positive respondents'

propensity to be tested for HIV were *predisposing characteristics, need* and *availability*. Unfortunately, it was difficult to draw any definitive conclusions from these results on the raw data, as they may not be reflective of trends in the overall population. The raw sample was very heavily skewed towards states with a higher overall HIV prevalence, including some smaller states.

The only ‘potential’ dimension of access which had an impact on participants’ use of HIV testing facilities in the weighted and unweighted NFHS-III datasets was *need*. When the relative weight was applied to the female HIV-positive sub-sample of the NFHS-III, female HIV-infected participants who were anaemic were significantly ( $<.05$ ) more likely to take an HIV test in comparison to those who were not. Moreover, a higher proportion of respondents living with a household member with TB had taken an HIV test than their counterparts<sup>183</sup>. These findings suggested that there is a possibility that respondents’ and their families level of *need* for HIV-related care could encourage them to take an HIV test.

Data from the qualitative phase of research provided far more illuminating insights into how components of ‘potential access’ could influence respondents’ use of HIV testing services than the NFHS-III results. Peer providers’ narratives from the qualitative stage of research indicated that *availability* of AWCs could play a crucial role in ensuring that WLHA were tested for HIV during pregnancy. Some peer providers employed by their Positive Network as an ORW offering treatment to pregnant HIV-positive patients would contact AWCs for provision of health and social services for their clients. These results indicate that availability of services locally may affect a respondent’s ability to reach health facilities. Finally, participants’ narratives from the qualitative phase of research revealed that their family's level of *need* may influence their access to HIV testing facilities. Many qualitative interview respondents underwent a test after their husband exhibited extreme symptoms of

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<sup>183</sup> Recent research has highlighted that some WLHA in India learn of their status after their spouse suffers from debilitating OIs, such as tuberculosis (John, Babu et al. 1993, Giri, Wali et al. 1995, Bairy, Shivananda 2001).

HIV, including TB and ‘fits’. These participants often sought treatment for their spouses’ symptoms from many different healthcare providers before learning of his sero-status. This illustrated that these participants’ husbands may have had a low perception of their own risk of contracting HIV, and therefore did not access the necessary healthcare services in time. It is likely, then, that many HIV-positive men could also face substantial barriers in access to testing facilities, perhaps as a product of their own lack of awareness.

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## 9.F Conclusion

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Quantitative and qualitative findings in this chapter indicated that Andersen and Aday’s (1981) model of access could be insufficient for measuring social structural factors affecting WLHA’s utilisation of HIV testing facilities in India. Results from both stages of research suggested that many female HIV-infected respondents may not have taken the test entirely of their own volition. Many of these respondents may have learnt of their HIV-status through serendipitous or accidental episodes, such as a routine HIV test during antenatal treatment. As these respondents were not aware that they were potentially at risk of being HIV-positive, it would be unlikely that they would be seeking any treatment for their unknown condition.

These findings highlighted many weaknesses in Andersen and Aday’s (1981) concept of access. The foremost weakness in their theory of access is that it is implicitly assumed that patients are already aware of their condition or its symptoms and are actively seeking treatment for their illness. However, results in this chapter prove that this may not always be the case, especially when the illness remains symptomless for long periods of time as HIV can be. In these cases, patients are often reliant on their physicians’ ability to diagnose their illness and guide them to the necessary healthcare facilities.

The other weakness in Andersen and Aday’s concept of access was that they fail to note how the *organisation of services* may lead patients towards an initial diagnosis.

Furthermore, they did not engage with the way informal practices by physicians may shape an individual's access to diagnostic services. These factors were most apparent in qualitative interview respondents' accounts of the barriers they experienced to reaching HIV testing services. For instance, a few participants commented that their doctors did not inform them of their husband's HIV-status.

Previous research on interaction between HIV-positive patients and their doctors has suggested that most ethical guidelines set by NACO on informing HIV-infected patients of their own or their partners' sero-status may not have always been followed by practitioners (Samuel, Srijayanth et al. 2007, Kurien, Thomas et al. 2007, Solomon, Venkatesh et al. 2008b). Sheikh and Porter (2010) attributed this behaviour to doctors being resistant to medical regulations imposed in a 'top down' fashion by NACO. They stated:

*'Doctors conceal their divergent practices, and comply superficially with policies in spite of disagreeing with them, and often fail to engage with the principles of the guidelines they enact' (p.1).*

Research on Indian physicians' practices on HIV testing does not examine the detrimental impact that doctors' failure to follow ethical guidelines could have on their HIV-positive patients' physical and mental health. Results from the qualitative phase of research indicate that physicians' failure to inform respondents of their husband's HIV-status after the initial trigger event delayed some participants' diagnosis for unnecessarily long periods of time. In a few cases, this resulted in respondents' children becoming infected through vertical transmission from mother to child or taking an HIV test only in the final stages of their illness.

In consideration of weaknesses highlighted in Andersen and Aday's (1981) theory of access by both the quantitative and qualitative sets of results, the following chapter will focus primarily on trends emerging from the qualitative interviewees' narratives. The chapter will

examine factors which mediate participants' 'continual access' (Mechanic 1995) to healthcare services, starting from when they were diagnosed.

## **Chapter 10 HIV-POSITIVE WOMEN'S 'VULNERABILITY' TO THE IMPACT OF HIV/AIDS ACCORDING TO QUALITATIVE DATA FROM THE SECOND STAGE OF RESEARCH**

### **10.A Introduction**

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The previous two chapters used a combination of qualitative and quantitative data to reveal that there were weaknesses in Andersen and Aday's (1981) conceptual framework of access. One issue was that none of the 'potential' dimensions of access took into account the complex nature of HIV as a chronic illness. HIV is a particularly devastating illness for PLWHA living in resource poor settings due to its slow and debilitating nature (Stallard 1991, BUPA 2011). During the course of their illness PLWHA may use different healthcare services repeatedly in order to treat opportunistic infections. However, Andersen and Aday's model of access only seems to take into account respondents' utilisation of one healthcare provider at a time rather than their 'continuous access' (Mechanic 1995) to services<sup>184</sup>.

In order to ameliorate these issues, data from respondents' narratives on their utilisation of healthcare was examined from the qualitative phase of research. This data provided a unique perspective on WLHA's access as these respondents belonged to a small minority of HIV-positive women who were not only aware of their condition but also were regularly using some type of HIV-related care.

Moreover, as the interviews were conducted from December 2009 to March 2010 it was possible to observe the impact that the third phase of NACO policy, established in 2006, had on participants' use of relevant healthcare facilities. Currently, there is little or no known research on the impact that this policy has had on female HIV-positive patients' access to

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<sup>184</sup> This issue could also be the product of the NFHS-III being a cross-sectional rather than longitudinal dataset.

services. Hence, findings from this chapter will contribute to literature charting the influence of healthcare policy on HIV-positive women's well-being in a south-east Asian setting.

Qualitative data was collected through narrative interviews, meaning that respondents were encouraged to provide a biography of their experiences dealing with HIV or an 'illness narrative'. These interviews uncovered respondents' pathways through treatment by examining their chronological usage of services starting from their experiences of being tested and ending with their current use of healthcare services.

This chapter is organised according to participants' descriptions of their pathways through treatment. It first examines participants' experiences of their initial entry into treatment, paying particular attention to their accounts of barriers to access. Then, it explores their narratives of using treatment at their current healthcare provider. Due to the structure of HIV-related services, most respondents were encouraged to use governmental clinics for ARV treatment and NGO healthcare providers for the overall maintenance of their health<sup>185</sup>. Finally, I analyse respondents' concurrent use of private healthcare facilities on an episodic basis to ameliorate minor HIV-related symptoms, e.g. 'body pains'.

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## 10.B First entry into HIV-related care

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Many respondents started biomedical treatment for their condition a long time after they were diagnosed as HIV-positive. There were a variety of reasons why this happened, the primary reason being that there were little or no governmental healthcare facilities offering treatment for their condition prior to 2007. Moreover, few participants who were tested for HIV after their husband experienced debilitating opportunistic infections were informed by their practitioners of healthcare services offering treatment relevant for their condition. Hence, respondents' first entry into treatment was modulated by the type of 'trigger' event

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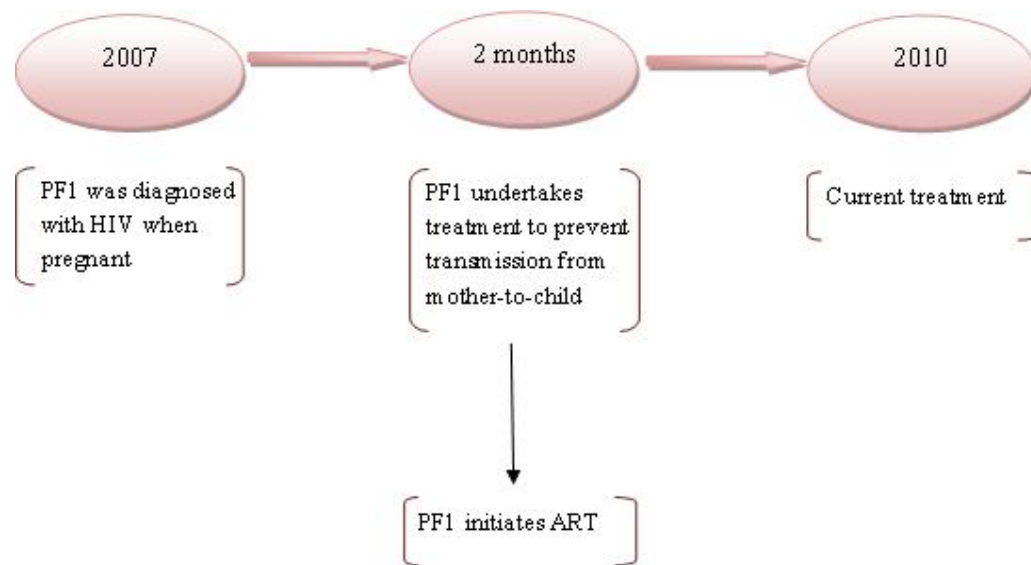
<sup>185</sup> It is possible that many qualitative interviewees were using NGO healthcare services as they were sampled from local Positive Networks and NGOs.

which incurred their diagnosis and the availability of HIV-related treatment facilities in their local area.

Participants who were tested in a public healthcare provider for HIV as part of antenatal treatment after 2006 experienced a fairly smooth transition into HIV-related care due to a new set of programmes established as part of NACO's third phase of policy concerning prevention of mother-to-child transmission. These programmes stipulated that all HIV-positive pregnant mothers should be given a single dose of Nevirapine whilst in labour followed by Zidovudine and Lamivudine postpartum (Firth, Jeyaseelan et al. 2010). Those who qualified as needing first line ART were encouraged to undertake an elective caesarean to reduce risk of transmission. These respondents were swiftly referred to local governmental healthcare facilities which provided ART treatment.

PF1 was diagnosed as part of a routine antenatal HIV test at a governmental healthcare facility during her 7<sup>th</sup> month of pregnancy in 2007. Unlike many other respondents she received post-test counselling and was referred to the nearest facility offering treatment to prevent vertical transmission of HIV from parent to child. At this healthcare facility she underwent a CD4 count test and was informed that she was eligible for ART as her count was below 200. During her pregnancy she was receiving guidance from an ORW who regularly monitored her health-status and ensured that she adhered to preventative medication.

As PF1 was in constant contact with healthcare practitioners, she was receiving an array of HIV-related treatment a short time after being informed of her sero-status. She was easily able to access HIV prevention and treatment services as the necessary organisational features were in place to ensure that such facilities were locally available. These large structural changes were undertaken as part of NACO's third phase of policy in which ART centres were established after 2006. Figure 10.1 demonstrates PF1's swift transition from being diagnosed as HIV-positive to her current treatment.



**Figure 10.1:** PF1's pathway through treatment

In contrast, respondents diagnosed before 2006 experienced protracted time periods in which they were not using any type of HIV-related care as there were few governmental services available locally providing HIV-related healthcare. PF22's account of her experience of being diagnosed as sero-positive when pregnant at the age of 13 in 2001 demonstrated how structural inefficiencies can result in substantial delays in treatment. She reported:

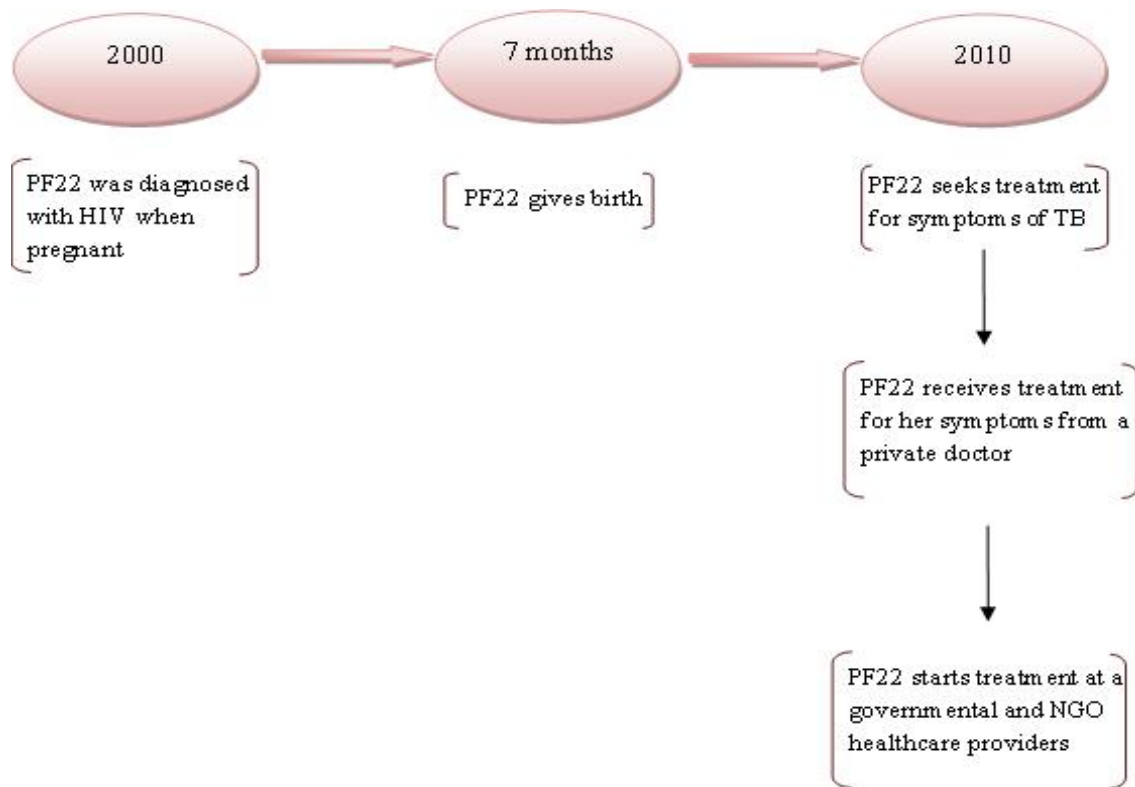
*'After the delivery the doctors did not bother about me or my baby. The nurses neither washed my baby on being born and all showed an indifferent attitude to me and the baby. At the time of the delivery, my mother was asked to remove all my clothes and made her throw away the clothes. No personnel in the hospital touched my belongings... Public too were not aware of this disease and doctors also looked down on patients suffering with HIV. At that time, we did not know anything about this disease and thought everything was true'*

During this segment of PF22's narrative it is apparent that the most crucial barrier to HIV-related treatment was that healthcare practitioners had a low awareness of routes of transmission. They seemed to believe that it was possible to contract HIV through being at close proximity to a PLWHA; hence, they treated her in a stigmatising manner in order to prevent transmission. Furthermore, she was not informed of measures to prevent vertical

transmission of HIV from parent-to-child or of possible western treatment for HIV. This could be a product of these medical practitioners being unaware of medical interventions to prevent or treat HIV. It is possible that if these healthcare practitioners had received training on how to deal with HIV-infected pregnant women appropriately, PF22 would have received a far higher quality of care.

As PF22 had no awareness of what type of treatment was required for her condition, she did not attend another healthcare facility for nine years after she gave birth to her child. PF22 eventually sought treatment when a large ‘boil’ in her neck rendered her incapable of working in her local rice mill factory. At first, she attended a private healthcare provider and was given medication to treat her TB. This was ineffective and costly. Thus, following the advice of a relative she attended a recently established ART centre, wherein she undertook a CD4 count test revealing she had an extremely low count of 30. The disquieting aspect of this narrative is that due to structural inefficiencies and poor quality of care, PF22 was only able to access treatment when she may have been in the final stages of the illness.

Figure 10.2 illustrates PF22’s complex temporal pathways through treatment. Unlike PF1, who was diagnosed in 2007, PF22’s transition into HIV-related care was protracted as she did not know what treatment was needed for her condition and there were no healthcare facilities offering HIV-related care locally until around 2008.



**Figure 10.2:** PF22's pathway through treatment

Respondents' whose 'trigger event' was their husbands exhibiting extreme symptoms of HIV experienced substantial barriers to entering HIV-related healthcare. Similar to participants who were diagnosed when pregnant they experienced spatial and social obstacles in the form of low levels of awareness of types of modern treatment relevant for their condition and lack of availability of healthcare facilities providing HIV-related care in their district. However, unlike respondents who were diagnosed when pregnant, they experienced an additional layer of barriers related to their husband's urgent need for medical attention for life-threatening OIs, such as tuberculosis. Many of these participants' husbands were in the last stages of the virus and in many cases died within a year of diagnosis.

During the time period between their spouses' diagnosis and death, the respondents' need for treatment was largely set aside as they invested their emotional and physical resources on attempting to 'cure' their husbands' disabling symptoms. This had two outcomes

the first being that respondents' entry into HIV-related care was delayed for protracted time periods as treatment was sought for their husbands' symptoms<sup>186</sup>. Secondly, vast amounts of money were spent on their husbands' treatment before the participant even had the opportunity to enter healthcare. Consequently, these respondents had few 'enabling resources' (Andersen, Aday 1981) once they were in urgent need of medication for HIV-related symptoms.

PP4's pathways through healthcare demonstrated the types of barriers to treatment that this category of participant experienced. Her husband was diagnosed as HIV-positive in 1999 after visiting a private clinic for persistent 'fever' and 'allergy'. Following the advice of practitioners from this clinic PP4 underwent an HIV test soon after. As neither PP4 nor her spouse had any knowledge of what type of modern medication was relevant for their condition, they first sought ayurvedic treatment from a clinic in Kerala on the advice of her brother-in-law<sup>187</sup>. This medication was ineffective at ameliorating PP4's husband's persistent symptoms, so they sought treatment in a governmental healthcare facility. She reported:

*'I use to get the medicines (ART) more for him than me. We took them for nearly two months but did not find any difference. It instead affected his brain. He became very serious. Then we went again to Dr S-. He checked him up and told me that the disease had spread to his brain and there is no use treating him here but instead I should take him to the Government Hospital'.*

After this incident PP4's spouse was cared for at home as her sister-in-law believed that physicians at the hospital might deliberately inject him with a lethal poison. PP4 claimed at this point her husband was so debilitated that he was 'bed ridden and everything had to be done in his bed'. He eventually died after 15 days. PP4 stopped using ART treatment after her spouse's death as it was not freely accessible in 2001 and there were no facilities available locally providing treatment for HIV. Since most of her familial financial resources had been

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<sup>186</sup> I estimated that PF8 waited for over a year before seeking treatment from a governmental hospital. Meanwhile, her husband had been receiving ayurvedic medication specifically tailored for his condition for around six months.

<sup>187</sup> PP4's brother-in-law (a lorry mechanic) learnt of this facility from other truck drivers in his social network.

used for her partner's treatment, it was not possible at that time to afford the cost of continual HIV-related care to maintain her health-status.

One striking element of PP4's narrative is that most decisions on treatment for herself and her husband were made by her in-laws. This is a continuation of a theme recurring through participants' narratives on their diagnosis whereby elder or powerful members of the family received instruction from medical practitioners on their condition after diagnosis. In these cases, the practitioners perhaps rightfully held the cultural assumption that powerful members of the patients' family would make most decisions concerning treatment. PP4's spouse deferred most decisions on his treatment to his brother and sister who knew little of his condition, thus in some instances made misguided choices. The most obvious example was when he was not taken to hospital when dying, out of fear that medical practitioners would murder him. PP4's parent-in-laws tried to ensure that she received some form of treatment whilst her husband was alive<sup>188</sup>.

There were other participants whose in-laws would only provide healthcare for their husband, which meant that they were unable to enter treatment until after their spouse's demise. A few of these participants entered treatment at the behest of their natal family. These respondents trusted their natal family's advice on treatment and relied on their emotional support. PF26 credited her brother and his wife with providing her with technical and psychological guidance throughout her treatment<sup>189</sup>. She stated:

*'First and foremost, you must give courage to a person. And in my case, it was my sister-in-law who gave me all the support and strength. We need such people in the community and we should go out of our way to help such people. This gives patients moral strength and support'*.

Other respondents were guided to local healthcare facilities providing HIV-related treatment by governmental and NGO outreach workers. PP6 went to a governmental

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<sup>188</sup> This could have been because her natal family were contributing towards direct costs of treatment.

<sup>189</sup> After diagnosis she attended a private clinic with her sister-in-law and was prescribed ART medication.

voluntary counselling and testing centre for an HIV test after receiving advice from her local ‘Anganwadi teacher’ in her village on how to seek HIV-related treatment from governmental healthcare services. She stated, ‘the Anganwadi teacher told me all about it and advised me to go to the Government Hospital’.

The distinctive feature in both PF26 and PP6’s narratives were that they used trusted sources of information within their communal networks, such as their natal family or local ORW, to discern which healthcare provider offered them treatment relevant to their condition. They may have believed that these people were more able to decipher multiple and often confusing messages on HIV-related care resultant from a pluralistic healthcare system in which western, traditional and alternative treatments were all readily available. This was because these people were either working for a trusted organisation or had a powerful status within their family.

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## 10.C Current treatment

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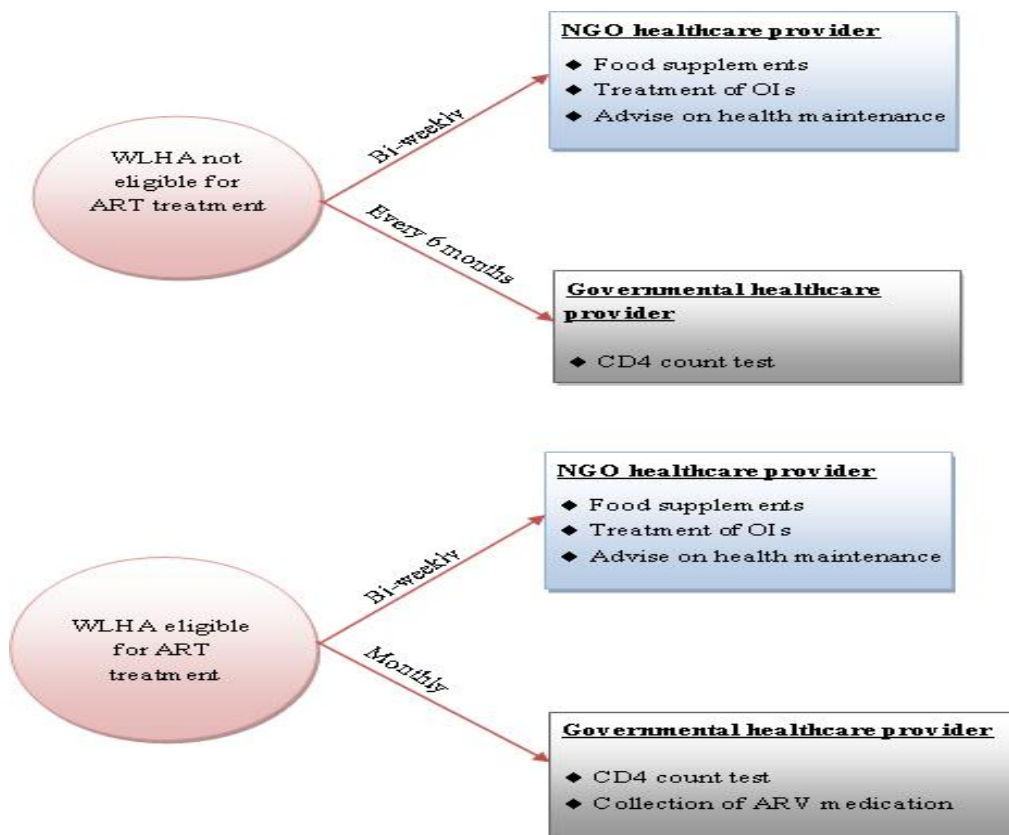
Almost all of the participants were using governmental healthcare facilities in conjunction with NGO services at the time of the interview<sup>190</sup>. This was due to the multi-sectoral system of distributing healthcare, whereby different HIV-related needs were catered for by NGO and governmental providers. The type of facilities that respondents continually used depended on whether they were eligible for ART treatment or not. Those who were using ARV medication were obliged to visit an ART centre on a monthly basis in order to collect their medication. These participants also attended NGO healthcare facilities in order to collect ‘nutrition food’, food supplements and receive advice on how to maintain their current level of immunity. This type of treatment was geared towards health maintenance. Moreover, as their immunity was low, they would also attend these clinics in order to treat mild to major

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<sup>190</sup> This could be the product of most participant being sampled from NGOs and PNs in which staff advise beneficiaries to attend governmental and NGO healthcare providers.

HIV-related symptoms, e.g. pleurisy. Therefore, these respondents had a lot of contact with governmental and NGO practitioners.

The other category of respondent who was in constant contact with different types of healthcare providers were those with an HIV-positive husband and/or child. These respondents acted as the main caregiver of these family members, especially in the case of their HIV-infected children. Since HIV is a chronic illness with a myriad of symptoms, their caregiving role encompassed a wide range of duties other than attending the clinic with members of their family who were sero-positive. They were expected, even by healthcare providers, to aid their HIV-positive family members' maintenance of their health-status through provision of 'nutrition food', assist them in adhering to the strict regime of ART and care for them when extremely ill. Figure 10.3 displays the structure of HIV-related healthcare facilities.



**Figure 10.3:** Respondents' patterns of healthcare utilisation

Six months prior to the interview, PF30's husband experienced debilitating STD symptoms of large genital warts (or what she described as 'cancer wounds') and a 'high fever'. During this period of time she took on the burden of caring for her husband despite suffering from similar yet slightly less debilitating symptoms. She stated:

*'I use to look after him very well. I would take him to the bathroom, I would put the food into a mixie and then feed him. I use to boil eggs and feed him, I would give him fruit juice. Though he never looked after me well, yet I use to take good care of him'.*

This account demonstrated that there was a gendered dynamic to this caregiving relationship. As the matriarchal figure in her family, she was expected to expend physical and emotional energy caring for her husband even when she believed that he would not do the same for her<sup>191</sup>. This caring dynamic was clear in other respondents' narratives when they were speaking of their first entry into HIV-related care or of the efforts they took to ensure that their child received an adequate education. A striking element within these narratives was that healthcare practitioners reinforced respondents' caring role within their family through imbuing them with the responsibility to care for other members of the family, even when they knew that the respondent was themselves quite ill.

Previous literature on WLHA's burden of care within the household has demonstrated that it could have a negative impact on their ability to reach services as they have little time to take care of their own needs (D'Cruz 2003, D'Cruz 2004, Alex 2011). However, some participants' narratives illustrated that this may not always be the case as they used treatment in conjunction with other HIV-infected family members. Consequently, they were in more

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<sup>191</sup> This heavy burden of care could adversely affect WLHA's mental health. Research on care-givers of PLWHA demonstrated that they suffer from substantial loads of stress and anxiety. Clark (2002) described carers within the family as displaying a tendency towards clinical depression as a consequence of substantial workloads. Other studies have illustrated that HIV-infected patients suffer from depression (Lee, Kochman et al. 2002, Holzemer 2002, Cook, Cohen et al. 2002). In addition, Chandra, Ravi et al. (1998) found that there was a higher prevalence of mood disorders, depression and suicidal tendencies in heterosexual HIV-infected patients in India than in Western studies.

contact with healthcare practitioners from both NGO and governmental facilities than their counterparts. This in some cases improved the quality of care that they received.

Finally, interviewees not eligible for ARV treatment were only required to attend the ART centre every six months for a CD4 count test. Between these consultations it was expected that they would attend an NGO or PN healthcare provider on a bi-weekly basis in order to have their health-status monitored and receive other similar services to that of their counterparts. PF33, who was receiving treatment in an NGO in Elluru, reported that she was expected to visit this healthcare provider every other week. During the times that she visited, she received food supplements and medication for minor symptoms, e.g. a headache<sup>192</sup>.

The rest of this section focuses on respondents' experiences of using NGO and governmental healthcare facilities as their main sources of treatment. These healthcare providers were dealt with separately as they provided different types of HIV-related treatment for sero-positive patients' needs. Governmental and NGO healthcare services, therefore, affected respondents' access to treatment in a distinctive manner dependent on what their treatment needs were.

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### *10.C.I Non-governmental treatment*

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The previous section on respondents' first entry into healthcare facilities illustrated that many participants started their HIV-related treatment in a clinic run by an NGO or PN. According to participants' narratives most ART centres were not established until around 2008 or 2009. Prior to NACO's third phase of policy PN and NGO healthcare providers were only able to offer HIV-positive patients food supplements, advice on how to maintain their health-status and treatment for opportunistic infections, e.g. tuberculosis.

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<sup>192</sup> Staff at the clinic would weigh the patients in order to check that their health-status was stable and they were not dramatically losing weight, which is an HIV-related symptom.

Positive Network and NGO healthcare providers played a crucial role in ensuring that respondents eventually accessed governmental healthcare services providing ART treatment. Firstly, these organisations acted as a ‘temporal bridge’ to these governmental healthcare facilities by offering participants ‘counselling’ on how to maintain their level of immunity for protracted time periods without the aid of medication. It is probable that the services offered by these clinics, although limited, aided respondents in preventing their illness from progressing from HIV to AIDS in a short period of time<sup>193</sup>. Therefore, this type of service may have enabled them to survive their illness long enough to be in a position to start using ARV treatment when it was freely available in their local area.

Most advice that respondents received on the maintenance of their health-status revolved around their need to consume a wide and varied range of food items that have nutritious properties, e.g. peanuts and guava (WHO 2008b, WFP, WHO et al. 2008). These respondents reported that they received instruction on what food items to consume and how to prepare this ‘nutrition food’. They were advised to be cautious about food and water hygiene, in order to avoid potentially dangerous infections. In most cases, respondents were instructed to drink ‘warm water’, which had been boiled in order to kill germs and bacteria, and avoid food made in unhygienic street stalls or cafes. PF11 stated:

*‘They asked us to take ragi flour, drink warm water, eat guava instead of an apple. I was told not to eat any street food. They tell us not to eat any food left over from yesterday.’*

The physicians’ emphasis on health maintenance as a form of treatment for HIV may have fitted with participants’ own perceptions of health and illness. Respondents perceived health maintenance as integral to their medical regime with as much importance as any other type of HIV-related healthcare, such as ARV treatment. When asked what type of treatment they were taking, participants who were not using ARV treatment would answer that they

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<sup>193</sup> Previous research has illustrated that there is a link between under-nutrition and the advanced progression from HIV to AIDS. This is because the immune system is weakened by malnutrition (Gillespie 2008, França, Ishikawa et al. 2009, AVERT 2010, WHO 2011b).

were using ‘B-complex’ vitamin pills, ‘iron tablets’ or ‘eating nutrition food’. PF13 believed that her overall health-status had improved since she started to eat ‘nutrition food’ and take consideration of her well-being. She reported:

*‘There is a lot of change. I am feeling much better now. Earlier I used to not eat food on time and take care of my health, now I am eating on time and taking nutrition food. I was weighing 35kg earlier now I am 45kgs.’*

This account indicated that PF13 could have a perception of health more similar to that of the ayurvedic system of medicine than that of the biomedical. Ayurvedic medicine is orientated towards the preservation of health rather than just treating diseases, which are believed to be rooted in imbalances in the body (Kurup 1983)<sup>194</sup>. This perception of health and illness could positively impact respondents’ access to facilities as they would understand the importance of improving their level of immunity and therefore, adhere to the holistic demands of HIV-related treatment.

As explained in the previous chapter, many respondents complained that they were unable to afford all food items which physicians had advised them to consume on a daily basis. This indicated that they fully understood the importance of maintaining nutritional requirements whilst adhering to HIV-related treatment. They argued that it was especially challenging to buy costly meat products for regular consumption, e.g. chicken. Staff at NGO healthcare providers tried to ameliorate these financial difficulties by tailoring their nutritional advice according to participants’ current socio-economic circumstances. PF5 reported:

*‘They (the doctors) will tell us what foods to take, since your present financial situation does not permit you to take meat, chicken daily, it does not matter. Instead, you should take regularly green vegetables, fruits and egg which is easy to buy’*

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<sup>194</sup> The biomedical model of healthcare focuses mostly on the elimination of ‘biological defects’ (Good, Good 1981).

According to respondents' accounts there was a limited provision of free 'nutritious' food items, e.g. 'ragi' flour and 'dhal', for widowed WLHA and families with Children Living with HIV/AIDS (CLHA) under the Balasahayoga and CHAHA programmes in various districts of Andhra Pradesh<sup>195</sup>. Although this programme was designed to distribute social services to HIV affected families most vulnerable to poverty, it also served to reinforce gendered stereotypes of women acting as carers and men being breadwinners within the family. Consequently, there were crucial gaps in the provision of food items for participants not belonging to either category. PF30 reported:

*'When both husband and wife have HIV, no assistance comes from Government. It would be helpful if some assistance is offered to people like us also... If the Government could extend a loan for us to put up some business or other it will be beneficial'*

PF30's narrative illustrated that if one was widowed without children or married then a whole array of social services, including nutritional assistance, was unavailable. This was problematic as PLWHA have higher nutritional need than their HIV-negative counterparts, in particular protein and energy (Haddad, Gillespie 2001). Although recent research has highlighted that widowed WLHA in India are vulnerable to poverty (Pradhan, Sundar et al. 2006); PF30's account revealed that some HIV-infected women who were married can be equally impoverished, especially when they are acting as the main breadwinner and carer in their household as their partner is sick or dying<sup>196</sup>. This type of participant was forced to borrow money from neighbours and relatives in order to afford all the food items recommended for treatment.

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<sup>195</sup> These programmes' objectives were to provide integrated HIV care, support and treatment for CLHA and their families (Coutts-Buys 2007, Honoured 2007).

<sup>196</sup> Household surveys focusing on families affected by HIV in sub-Saharan Africa illustrated that HIV-infected patients from these households faced substantial difficulties in procuring food items which were necessary for continuation of ARV treatment (Ngwira, Bota et al. 2001, Haddad, Gillespie 2001). Hence, the World Bank called for nutritional interventions to be scaled up along with increasing availability of ART (The World Bank 2006).

The second way in which NGO healthcare providers acted as a ‘temporal bridge’ of access to ART centres was through provision of treatment for opportunistic infections. Under the Balasahayoga programme these organisations provided free integrated care for sero-positive members of families affected by HIV. Consequently, respondents could seek treatment for life threatening illnesses, e.g. TB, for themselves or HIV-infected members of their family without incurring much expense. PF27 reported:

*‘Only recently the child has been complaining of her legs getting numb and her legs turning and could not walk. The Medical college people came and gave her medicines... (they) come and give her injections and also gave her saline transfusion’.*

There were, however, a few cases in which the respondents OIs were so complex that they required expensive diagnostic tools or medication which the NGO was incapable of providing free of cost. PF31 has been unable to work as a ‘flower seller’ for a long period of time as she has been suffering from severe headaches and ‘back pains’. She visited a local NGO but none of the treatment alleviated any of her symptoms. She stated:

*‘I experienced severe back pain, headache and slight blur in my eyes. I use to find it very difficult. I wanted to get myself treated but I was told that I had to spend Rs. 1800 for a scan which I could not afford’.*

PF31’s narrative indicated that there could be gaps in treatment services for debilitating illnesses. There were other respondents who reported that as their symptoms did not fit into the criteria of an OI, they were unable to receive free treatment for it. For instance, PF32 commented that she was unable to work for long periods of time as she needed glasses for her poor eye-sight. Unfortunately, she was unable to afford the lenses due to the high cost. These cases illustrated that NGO health interventions related to treatment of opportunistic infections did not eliminate all barriers for WLHA to receiving the necessary treatment services.

Finally, these NGO and PN healthcare providers acted as a ‘structural bridge’ between the participants and governmental healthcare facilities. Many respondents reported that staff from their local NGO or PN would explain to them what types of diagnostic tools were used to measure their level of immunity, e.g. CD4 count, which modern treatment they should use and where their nearest ART centre was located. PF9 reported that she was informed by an outreach worker that a CD4 count test measured the ‘percentage’ of white blood cells in one’s body<sup>197</sup>. This type of service could be crucial for participants who had little or no awareness of HIV before being infected with it.

Interviewees reported that information on the availability of ARV treatment was disseminated to female HIV-positive patients either through outreach workers attached to NGOs or group counselling sessions set up by PNs. The ORWs would visit the respondents’ home if they had not been using any form of treatment for a long period of time. During the visits outreach workers would provide their clients with psychosocial support and would inform them of social and healthcare interventions for PLWHA. Group counselling sessions served the same type of purpose, except that psychosocial support was imbued by WLHA sharing their accounts of dealing with their condition. These two means of dissemination were fairly efficient at conveying information on HIV-related treatment to respondents.

Nonetheless, there were a few participants living in the coastal areas of A.P. who seemed to have very little understanding of what type of modern treatment was required for their condition. One such example was PF26, who said at the beginning of the interview that she was taking ART medication twice a day. However, later in the interview it was revealed that she had not yet attended an ART centre for her first CD4 count test as she could not afford the ‘indirect expense’ of travel (Ensor 2004)<sup>198</sup>. Hence, PF26’s narrative indicated that

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<sup>197</sup> She said that HIV-positive patients were prescribed medication according to how many white blood cells were existent in the body.

<sup>198</sup> She had for a short time utilised ART treatment from a private hospital but stopped taking the medication after experiencing ‘side-effects’, e.g. headaches.

staff at her NGO may have not conveyed the information in a manner that she understood. This resulted in her being unable to distinguish between ARV medication and vitamin tablets.

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### *10.C.II Governmental treatment*

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The majority of respondents attended governmental ART centres either to receive ARV medication or for a CD4 count test. According to many respondents' accounts most local ART centres had been established one to four years prior to the interview, hence were still adapting to the demands of the patients. These centres were poorly organised with long waiting times for treatment or collection of ART medication and there was little interface with medical staff.

Guidelines set by NACO stipulated that HIV-positive patients should be provided with 'adherence counselling' as soon as they were enrolled in a local ART centre (NACO 2008c, Chhabra, Anand 2010, Engender Health 2006). However, most respondents reported that their ART centre was so overcrowded that there was very little time for them to receive any advice on their treatment from a physician or counsellor. PP6 stated that her ART centre was so overcrowded that 'at the most doctors can talk to us only for 5 to 6 minutes and no longer because of the rush of patients'. Subsequently, the only patients who were permitted by staff to speak to a doctor at length were those who had just started ARV treatment or were experiencing extreme symptoms.

Some respondents already held low expectations of the quality of care that they were going to receive in governmental healthcare facilities<sup>199</sup>. They were accepting of the long waiting times that they experienced for fairly simple procedures in ART centres, e.g. collection of medication, as they believed that it was 'compulsory' for them to attend the ART centre. This type of wording indicated that they assumed that their attendance of the

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<sup>199</sup> Public healthcare providers have a reputation for providing a poor quality of treatment amongst the general population in India (Bhatia, Cleland 2001).

ART centre was an essential and unavoidable part of their overall treatment. As a result they felt that they had little choice but to accept the poor quality in services that they were currently receiving. These interviewees would attempt to justify the low quality of care they were receiving through arguing that the overcrowded environment caused healthcare practitioners to feel ‘irritation’ at the lack of control they had over patients, which resulted in them acting in a ‘reckless’ manner to herd the crowd of PLWHA.

Other respondents argued that staff at their ART centre purposely treated them in a disrespectful manner. PP5 reported:

*‘They call us in a serial order and after seeing 10 patients, they go off to drink and eat and come back after quite some time... I thought that if any officer came to ART centre, I would definitely complain about this. They don’t realize that they live because of us and see how they treat us. Recently, an old lady approached them to give her medicines, the helper got angry and pushed her down. Then I intervened and saw that the medicines were given to her and sent her away’.*

According to this narrative, the low quality of care at the ART centre was a product of staff being ‘rude’ and negligent towards patients, rather than simply being unable to cope with the overcrowded clinic. PP5 believed that the ART centre was overcrowded because staff would attend to very few patients and take long breaks to eat and drink. The most worrying aspect of this account was that some of the staff were aggressive towards their patients, indicating that they may use sometimes violence and intimidation to control their patients’ behaviour.

Likewise, PF4 (another user of ARV treatment) commented that doctors were very inattentive to the needs of patients attending her local ART centre. She reported that physicians would behave towards their patients in a paternalistic and controlling manner. These doctors would silence the patients whenever they mentioned any of their symptoms and insist that they should instead listen to their unsolicited advice. This behaviour resulted in patients being ‘frightened’ to directly address their physician. PF4 stated:

*'The doctors at the ART Centre do not treat us kindly. They keep on talking to themselves without treating us. They do not listen to our woes and insist that we should listen to them'.*

PF4's narrative of using ART centre services illustrates that this paternalistic behaviour can result in poor communication between doctors and patients. As a consequence, many female HIV-positive patients may not feel inclined to continually utilise governmental healthcare services as they have a low opinion of the quality of treatment that they are receiving<sup>200</sup>. For instance, PF4 witnessed a patient tearing up medical records and leaving the ART centre out of frustration at the poor services being rendered.

Furthermore, it is possible that some WLHA may experience difficulties in diagnosing complex OIs which require the close attention of medical practitioners. PP5's account of her experience seeking treatment for TB from a governmental hospital demonstrates how the negligent behaviour of doctors could result in HIV-positive patients seeking treatment from private providers. She reported:

*'I went with pain in my stomach and they ran me round the hospital for scanning and gave me tablets saying that it would disappear but nothing like that happened. But whichever hospital I visited, I frankly told them I have HIV and expected them to treat me well. Finally seeing the way the Government Hospital was treating me, I decided I would take treatment from a private hospital.'*

It was probable that the doctors in the government hospital were not able to identify that she had TB as she could not speak to them at length. She believed that staff treated her in an inappropriate manner by making her 'run' around the hospital for repeated scans and offering medication that failed to alleviate her symptoms. It is possible that she believed that this behaviour was stigmatising as she felt that staff were treating her in a negligent manner after she 'frankly' informed them of her HIV-status and had 'expected' to be treated well.

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<sup>200</sup> In some cases patients were so upset at the low level of care that they were receiving that they would 'go outside and complain'.

Consequently, PP5 was compelled to pay for treatment at a private hospital through the financial assistance of a ‘micro-finance’ loan of Rs. 10,000 from her PN, which was compensated through a monthly repayment of Rs. 500. Payment for this treatment resulted in a double loss of income as she was less able to work during that time due to her painful symptoms. This narrative demonstrated how poor quality of healthcare can inhibit an individual’s access to the relevant treatment for their condition.

Finally, one of the most crucial barriers to participants’ ‘continual access’ was structural. Many respondents, especially those living in rural areas, had to travel great distances to reach the ART centre<sup>201</sup>. This was problematic for interviewees who were using ARV treatment as they were required to visit these healthcare providers on a monthly basis to collect their medication. PF13 stated:

*‘I have to pay around Rs.50/-. I start by around 0900hrs. I pack and take lunch along, as it gets delayed sometime. I return back by approximately 1400hrs.’*

Other respondents reported that transport costs to the ART centre were high, ranging between Rs. 30 and 100 (£0.39-1.29). This was expensive for participants in manual occupations who had a daily income of Rs. 100<sup>202</sup>.

This barrier was compounded by the fact that few allowances were given by hospital staff for HIV-positive patients dealing with these time pressures and indirect expenses. PP4 said that many patients who were unable to queue for a long period of time would send their relatives to the ART centre to collect the medication. They would be allowed to do this once but were informed that they could not do this again.

According to PP7, this type of behaviour compromised the quality of care that uneducated patients received as they lacked the time and resources to adhere to the strict regime of the ART centre. She reported:

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<sup>201</sup> This did not cause undue difficulties for respondents who were not using ARV treatment, as they were only expected to attend the facility every six months to undergo a CD4 count test.

<sup>202</sup> They also spent a large portion of their time travelling to the ART centre and back.

*'Some of them do not bring along their reports, ration card and other related papers like PCTC in Xerox form. Then, the Doctor tells them to go back and bring all these papers. They all come from long distances and to ask them to go back and come again is too heavy on their purses. They cannot afford spending much on travel'*

PP7's narrative illustrated that physicians' inflexible behaviour caused additional difficulties for illiterate patients who may not be able to decipher which documents are relevant for their treatment or afford the additional travel expenses.

Nevertheless, PP10 (a project coordinator for her local PN) reported that she had conducted discussions with practitioners in her ART centre about the quality of treatment that uneducated patients received. She believed that doctors often found it difficult to communicate with their uneducated patients in a manner which ensured they understood what was being said to them. It was suggested to medical practitioners working in the ART centres during this meeting that they should 'mould themselves to the patient's manner' and 'speak to them at length'. The fact that there is a dialogue between peer providers and governmental healthcare practitioners on the treatment of uneducated patients illustrates that there is acknowledgement of this issue.

Furthermore, PP10 emphasised that it was possible to improve the quality of care at ART centres through activism. She reported:

*'They (the staff at the ART centre) did not care much for them neither did they give them good treatment. They would say up to the face of the patient, 'You please sit far or move far because you have AIDS. Don't touch us and keep a distance'. Many of the patients complained to the outreach workers of this type of attitude. We tell them not to feel frightened about them but to treat them in the normal way as you would treat anybody who has fever or colds. Giving this type of teaching helped the patients to go regularly to the hospital'.*

This account demonstrates that hospital staff's stigmatising attitudes and behaviour can be ameliorated through dialogue with PNs. This considerably improved the quality of care so that patients were able to continuously access services. However, it is doubtful that this issue would be fully resolved unless structural factors are dealt with, such as long waiting

times for treatment, flexibility of hospital staff towards PLWHA in manual occupations and distance to healthcare facilities.

## 10.D Concurrent treatment

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Many respondents used treatment in private healthcare facilities concurrently with NGO and governmental providers. They would visit a private doctor on an episodic basis for treatment of minor symptoms, e.g. ‘headaches’ or fever. Some of these respondents used these services as they had forged a close relationship with this physician as their ‘family doctor’, who had treated them before they were diagnosed with HIV. Many medical practitioners were informed by the participant of their HIV-status. They would offer treatment which was perceived by the respondent as being the most potent form of medication, e.g. ‘injections’, in the alleviation of minor symptoms. As these doctors were aware of these respondents HIV-status, they would offer them advice and medication which would not interfere with their current treatment. PF28 reported:

*‘He (the private doctor) keeps telling us to be brave, eat well, be clean and take your medicines timely and regularly and take the medicines from E- and if you take these medicines regularly, you will improve in health.’*

This quote illustrated that PF28’s physician offered her medication, guidance on treatment and psychological support. The previous chapter revealed how private doctors can sometimes inhibit respondent’s access to healthcare facilities through informing their parent-in-laws of their HIV-status instead of them. However, PF28’s case demonstrated how private doctors who have a close relationship to the natal family can aid WLHA’s access to services. For instance, PF28 reported that her doctor had recently referred her to an NGO facility indicating that his medical advice was not purely driven by commercial interest.

The other reason that respondents used private healthcare services in conjunction with other types of treatment was due to structural deficiencies inherent in the provision of treatment by public and NGO healthcare providers. As PF23 stated:

*'If we go to the government hospitals where the doctors see us only on Wednesday and Thursday- could we wait so long with this fever? If, we go to the government hospital, they give us only one tablet for all illnesses. So, they give us paracetamol tablets and for everything they give paracetamol. That is why we do not show ourselves anywhere'.*

This quote indicates that most NGO and governmental healthcare facilities would only provide HIV-related treatment on specially allotted days or times. Moreover, due to lack of resources, these healthcare providers would distribute the same type of pain relief medication without any consideration for what the symptoms were. These structural deficiencies impelled PF23 to use the services of private healthcare providers in order to receive fast and efficient treatment to alleviate minor symptoms.

Some interviewees used private healthcare facilities in juxtaposition with public healthcare services in order to compensate for the structural deficiencies inherent in provision of treatment by governmental and NGO healthcare services that they continually used. These participants would visit a private healthcare provider if treatment at a public healthcare facility failed to ameliorate or diagnose minor symptoms. For example, some respondents reported that they would visit a doctor at a private healthcare facility if they were experiencing recurring symptoms. They did this to check that the diagnosis of their symptoms by the physician at the governmental healthcare provider was correct. A few participants would again visit their current healthcare provider in order to receive more treatment for these recurring symptoms<sup>203</sup>.

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<sup>203</sup> Some interviewees were astute enough to check with doctors in governmental healthcare facilities that the medication they were prescribed by physicians in private hospitals was not interfering with their current treatment.

This practice, commonly known as ‘doctor shopping’, has been recorded by other researchers examining the health-seeking behaviour of patients in India (Bhatia, Cleland 2001, Bhatia, Yesudian et al. 2006). Due to the fact that there are a variety of different types of healthcare facilities available, some patients have become adept at manipulating the system towards their advantage (Vissandjee, Barlow et al. 1997, Kunstadter 1980, Cant, Sharma 1998). Subsequently, some participants were adept at switching between private and public healthcare services when they needed to. One respondent who used private healthcare facilities in juxtaposition with public services was PF30. She reported:

*‘I use to feel giddy and my fever would not come down. Then joined V- hospital but still it did not come down. I was in hospital for one month. I told my husband I cannot continue to be in this hospital, please take me back. My husband in his anxiousness would take me to hospital after hospital. How much medicine I took, it did not come down. Finally, I went to a private hospital and got an x ray taken of me. It showed in the x ray that one side was full of pleura. We went to the big Government Hospital with these reports. Seeing all these reports, the doctor got me to take a sputum test. Then wrote out medicines’.*

As with PP5, PF30 was forced to use private healthcare services when the physicians in the public hospital were unable to diagnose her symptoms. It is unclear from PF30’s account why physicians in the NGO hospital were unable to identify her illness. As illustrated in earlier sections of this chapter it could be due to lack of resources or poor communication with their physician. Nevertheless, PF30 was eventually able to utilise the diagnostic tools available in a private healthcare facility in order to ensure that she was receiving appropriate treatment from the physician currently treating her. This incident illustrated that it was possible for WLHA to utilise the pluralistic Indian healthcare system to their advantage when unable to access treatment relevant for their OI.

Finally, some respondents did not receive appropriate treatment from physicians in private healthcare facilities because they did not inform them of their HIV-status as they feared that their physicians would refuse to treat them. Consequently, these physicians treated

these participants' symptoms without knowledge of their underlying condition or what other types of medication they were using. One such case was PF23, who visited two private healthcare providers seeking treatment for a fever. She reported:

*'In D- I visited an Ayurvedic doctor and also to... (a private) doctor in the village and had an injection but it did not subside. Then, we went to V.N. Hospital and without seeing anything, he gave me the treatment and took Rs. 50/- as fees, for tests Rs. 150/- and since I did not have sufficient money, I did not get the tests done as I had only Rs. 100 in hand, out of which Rs. 60 went towards the fees. So, I did not get the test done. Then I did not go to work also and my mother gave the money. I did not want to get the test done because where the Doctor would come to know that I have HIV. We returned home and went instead to a... (private) doctor and got an injection given'.*

One distinctive feature of PF23's narrative of her pathways through private healthcare is that her fear of others learning of her condition led to her making unwise decisions which could have endangered her own as well as others' health. She could have detrimentally affected her own condition by being prescribed medication which would have interfered with other types of treatment that she was using<sup>204</sup>.

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## 10.E Discussion and Conclusion

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Respondents' 'illness narratives' illustrated that WLHA's access to HIV-related treatment was a complex and varied process. Many of the participants' narratives demonstrated that their access to healthcare services was a continual process that was difficult to capture within the narrow remit of Anderson and Aday's (1981) model of access. This is because their utilisation of healthcare facilities is aided by a combination of factors which were not necessarily resource-based as they would be in that model.

Respondents' 'illness narratives' captured social structural processes that determined their utilisation of healthcare facilities at each stage of their treatment. The early stages of

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<sup>204</sup> Previous research on hygiene practices in private hospitals in India illustrated that some providers utilised unclean needles on patients which have been used on other clients (Kielmann, Deshmukh et al. 2005, John, Rajagopalan et al. 2006, Solomon, Batavia et al. 2009). A few respondents stated that they were asked by private healthcare providers to supply their own needles for injections to avoid transmission of HIV to other patients. However, there is still a possibility that there could be transmission of HIV through contaminated needles.

accessing healthcare services were heavily influenced by culturally ascribed medical practices. This was evident in the physicians' behaviour towards the participants and their family. Their doctor would tailor their medical advice towards the family rather than the patient. This meant that the doctor would sometimes adopt the role as a mediator between themselves and the family. In the case of a few participants, this culturally sanctioned role served to reinforce gendered stereotypes of the female patient being a caregiver. These cases demonstrated the importance of researching culturally sanctioned practices in the medical sphere and its effects on treatment.

In addition, respondents' first entry into HIV-related care was shaped by structural factors, e.g. recent changes in governmental healthcare policy towards treatment of HIV-positive patients. Respondents diagnosed before 2006 experienced long time periods in which they were not using any type of treatment. This was as a consequence of there being few governmental services available locally providing HIV-related healthcare. In contrast, participants who were diagnosed after 2006 seemed to experience a swift transition from diagnosis to treatment. For example, PF1 (who was diagnosed as part of a routine antenatal HIV test in 2007) was referred to the nearest facility offering treatment to prevent vertical transmission of HIV from mother-to-child.

The next stage of access, their current treatment, was also heavily influenced by structural factors. The multi-sectorial system of care formed through a partnership of governmental and non-governmental organisations as part of the recent phase of NACO policy encouraged respondents and their clients to use many healthcare providers. This was because each stakeholder provided a different type of healthcare service tailored to the need of the patients. For instance, asymptomatic HIV-positive patients used NGO healthcare facilities for treatment of opportunistic infections and counselling on how to maintain their health until it was deemed necessary for them to undertake ART. This system of healthcare

delivery was reported to be fairly effective in distributing treatment to PLWHA by some participants.

The participants' ability to access HIV-related treatment at governmental hospitals was affected by low quality of care. It was reported that doctors in ART centres were inattentive to respondents' needs. Other studies have reported similar findings indicating that HIV-positive patients in Indian governmental hospitals receive little attention from medical staff and were often afforded no privacy when speaking to adherence counsellors (Chakrapani, Newman et al. 2009, Sharma, Singh et al. 2007, Bhatia, Anand 2009, Sharma, Wanchu et al. 2007).

Datye, Kielmann et al. (2006) attributed this type of behaviour to a historical precedence in the Indian setting whereby their profession has been accorded with respect and high-status. This means that 'medical consultations are commonly characterized by paternalism whereby doctors make decisions on behalf of patients who display an almost blind faith in the doctor' (Datye, Kielmann et al. 2006:345). Subsequently, the type of complaints that doctors in India commonly received from patient consumer groups were due to communication failure. According to Kumar (2003) these complaints were due to the fact that 'doctors do not talk, explain or discuss' (p. 2).

Finally, many respondents reported that they used private services concurrently with public healthcare facilities. In most cases these participants visited doctors at private clinics in order to alleviate minor symptoms, such as 'fever'. However, there were participants who were impelled to seek treatment in private healthcare facilities due to structural deficiencies inherent in the public healthcare system. PP5's narrative on undergoing treatment for TB illustrated that the public system of healthcare delivery could be ineffective in the treatment of OIs. She recounted how the uncaring behaviour of staff at the governmental hospital forced her to use private facilities. PP5 and other respondents' narratives indicate that other WLHA

who were experiencing life threatening OIs might be impelled to use private clinics as their current healthcare providers are inefficient at treating their symptoms. These results are significant as WLHA might be compelled to spend more of their own money in an effort to treat various OIs as their condition progresses from HIV to AIDS.

In conclusion, results in chapter 10 suggest that qualitative interview participants' continual usage of healthcare is more complex than Andersen and Aday's (1981) model of access would suggest. Respondents' narratives of their health seeking behaviours indicated that there was a strong temporal component to access. This was illustrated by the fact that many participants experienced substantial barriers to treatment in the early phases of their narratives in the form of culturally ascribed medical practices and lack of local healthcare services. In the later phases of their narratives they were more able to continually use healthcare services as they were controlling financial resources as the main breadwinner of their family. Although it is doubtful that most respondents would have had access to healthcare facilities without the provision of free ARV treatment, their narratives do illustrate that access changes in nature as the patient adapts to their condition over time.

# PART IV



## Chapter 11 FINAL ANALYSIS

*'AIDS constitutes one of the most serious crises currently facing human development, and threatens to reverse progress in the most severely affected countries by decades'*

Piot, Bartos et al. (2001), p.968.

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### 11.A Introduction

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HIV has cast a long shadow over developing countries with an estimated 25 million people dying of HIV/AIDS since 1981 (Walensky, Wood et al. 2010). The virus has had a particularly devastating impact on sub-Saharan African countries, e.g. Kenya, where the life expectancy has decreased from 59 in the late 1980s to under 45 years in 2000 (Piot, Bartos et al. 2001). As so many people are still affected by HIV globally it is crucial to prevent further spread of the virus and ensure that PLWHA receive treatment.

As discussed in chapter 2, the nature of the HIV epidemic in India is so complex that it is best analysed as a continent. The Indian HIV pandemic consists of many simultaneous HIV epidemics. These epidemics are driven by drug injecting use in North Eastern states and heterosexual sexual risk behaviours in southern states (Kumar, Virk et al. 2008, Kumar, Wanchu et al. 2008, Nagelkerke, Jha et al. 2002). Furthermore, current estimates indicate that in India HIV-prevalence is higher among men (0.36%) than women (0.22%) with a female to male ratio of 0.61 (NACO 2010, UNAIDS 2006).

This ratio vastly differs from that in Sub-Saharan African countries, where HIV-prevalence is higher among women than men. Sero-prevalence is six times higher amongst sexually active women aged 15-19 living in Zambia and Kenya in comparison to their male counterparts (Glynn, Caraël et al. 2001). Recent research has highlighted that women in these countries are more predisposed to HIV infection despite the fact that they are no more likely to partake in sexual activities than men (Pettifor, Rees et al. 2005, Gregson, Todd et al. 2009).

Experts in the field of HIV prevention in developing nations have argued that the same gendered dynamics which leave women predisposed to HIV infection in sub-Saharan African countries could possibly affect Indian women (Patrice, Marija et al. 2010, John, Babu et al. 1993). The vast majority of women in India are infected by their husband, who is usually their only lifetime sexual partner (Mehta, Sodhi 2008, Nayak, Korcha et al. 2010)<sup>205</sup>. These women are difficult to identify as they do not engage in any type of risk behaviour and they display very similar socio-demographic characteristics to the rest of the population (Solomon, Mehta et al. 2010, Panchanadeswaran, Johnson et al. 2008, Ghosh, Wadhwa et al. 2009). This thesis uses a combination of quantitative and qualitative methods to investigate how social structural determinants related to gendered discrimination may affect an individual woman's 'susceptibility' to HIV infection.

It is possible that the same social structural determinants that predispose Indian women to HIV infection, could negatively affect WLHA once they are infected and need to access treatment. Many HIV-positive women may have a low level of knowledge of their own condition due to lack of access to education. For instance, Shrotri, Shankar et al. (2003) illustrated that pregnant women in Pune were aware of primary transmission routes of HIV yet few knew how to prevent it<sup>206</sup>.

Moreover, recent research highlighted that many WLHA are offered very little emotional or financial support by members of their husband's family after their sero-status is disclosed (Pallikadavath, Foss et al. 2004). Pallikadavath, Garda et al. (2005) demonstrated that some WLHA were evicted from their homes by their parents-in-laws after their husband's death. This type of research shows that it is important to examine socio-cultural factors mediating women's access to HIV-related services.

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<sup>205</sup> It has been predicted that HIV could spread further among the female population in India, as it is transmitted by men belonging to 'high risk groups' (e.g. MSM) to their wives (Venkataramana, Sarada 2001). This transition has been noted in the sub-Saharan African HIV epidemic by de Bruyn (2004) and Hunter (2010).

<sup>206</sup> Other studies have illustrated that many pregnant women in India did not know that it is possible to prevent vertical transmission from mother-to-child (Ramchandani, Mehta et al. 2007, Chomat, Wilson et al. 2009).

As outlined in chapter 3, the methodology was influenced by a combination of theories related to the possible social determinants of HIV transmission and patients' access to healthcare services. The primary theoretical framework was Barnett and Whiteside's (2002) model for assessing the social structural determinants of HIV transmission and their later impact on communities in resource-poor settings. Social structural components of HIV transmission were conceptualised as affecting the individuals' 'susceptibility' to HIV infection rather than their 'risk', in order to reflect the fact that many people may not be able to exert sufficient control over their social environments to the extent that they can prevent HIV transmission.

Barnett and Whiteside's (2002) conceptual framework of 'susceptibility' placed determinants of disease transmission on a spectrum based on their structural component and distance from risk. In this model, 'distal' social determinants of HIV-related risk influenced people's behaviour through wider structural processes. On the other hand, 'proximal' factors more directly affected individuals' propensity towards HIV infection. I adapted this model to be more reflective of possible determinants of disease transmission in the Asian context based on current research on the HIV epidemic in India (Gupta, Reed et al. 2011, Rajesh, Sanjay et al. 2011, Beattie, Shetty et al. 2009). Social status, for instance, was added to the 'macro-environmental' dimension of susceptibility as recent research highlighted that women from low caste backgrounds may partake in transactional sexual relationships due to extreme poverty (Becker, Ramesh et al. 2007).

The concept of *post-infection* 'vulnerability' encompassed the impact of HIV/AIDS on the social welfare of individuals and communities. Piot, Bartos et al. (2001) described the relationship between pre-infection 'susceptibility' and post-infection 'vulnerability' and why they are interlinked:

*'Although it is universally the case that HIV transmission results from very particular risk behaviours, the capacity of individuals to control their level of risk... varies widely according to the social environment in which the risk occurs. In turn, HIV vulnerability (post-infection) and the impact of HIV are proportionally related, as an increasing impact depletes social stability, support and cohesion' (p. 972).*

As Barnett and Whiteside's (2002) concept of post-infection 'vulnerability' encompassed such a wide range of possible outcomes for PLWHA, which would be difficult to fully analyse in this thesis, it was decided that only a small component of this concept would be studied. Andersen and Aday's (1981) model of 'access' therefore was employed to analyse which socioeconomic, cultural and structural factors influenced HIV-positive women's ability to utilise the necessary healthcare services. This model was also adapted to be more reflective of the subject that this thesis was addressing. For instance, I added a 'health behaviours' component to the theoretical framework as biomedical research has shown that nutrition is an important element of ARV treatment (AVERT 2010, WHO 2011b).

These theoretical frameworks were used to guide the research questions and methods. The first two research questions sought to examine which social structural determinants affected women's propensity to contract HIV in India and what processes may have contributed to their 'susceptibility'. The next two research questions explored what factors influenced female HIV-positive patients' access to healthcare services, and the processes involved in choosing treatment as expressed by qualitative interviewees.

The research method followed a 'sequential explanatory design', in which the research was conducted in two stages with the first being quantitative and second qualitative. This model was chosen because the principal aim of the research for this thesis was to establish what social structural factors might have affected WLHA in India, rather than to generate *theories*. The following section will examine issues related to using mixed methods research and how results from both phases of analysis were brought together.

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## 11.B Combining quantitative and qualitative results

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Women's 'susceptibility' and 'vulnerability' to HIV/AIDS can be affected by many factors including: their socio-demographic characteristics, the structure of medical services, patients' knowledge of their condition, and the severity of their symptoms. These factors encompass both *subjective* and *objective* components of the social phenomenon of HIV/AIDS in India. As qualitative techniques are commonly used to examine respondents' *subjective* experiences (Sale, Lohfeld et al. 2002), while quantitative methods are usually employed to evaluate factors which are possible to *objectively* measure (Morris, Leung et al. 1999), it would be difficult to use just one method to measure such a multifaceted subject.

In the initial phase of research, quantitative data was used to identify which social structural factors might predict women's HIV-status, examine the relationship between 'potential' and 'realised' components of access, and evaluate WLHA's consumption of food items according to socio-demographic factors. Data from the NFHS-III, a multi-round survey collecting information on emerging health issues and maternal health, was particularly useful in detecting systematic mechanisms which contributed to the complex social phenomena of Indian women's 'susceptibility' and 'vulnerability' to the impact of HIV (Maxwell 2004). For instance, it was established that women who were formerly married had a five-fold increased odds of being HIV-positive in comparison to those who were unmarried or currently married.

It was difficult to quantitatively analyse fully the factors associated with 'vulnerability', due to limitations in data collected in the NFHS-III. Because of ethical constraints during collection, there was limited information on female HIV-positive participants' health seeking behaviours. In order to ensure participants' anonymity and confidentiality, respondents who were tested for HIV as part of the NFHS-III were not asked if they knew of their sero-status. This meant that it was not possible to evaluate whether they had knowingly sought treatment for their condition, or were indeed even aware of it.

On the other hand, the advantage of using this type of data was that it provided information which may not have been observable through qualitative methods alone. The NFHS-III sampled HIV-positive women who may not have been aware of their sero-status, meaning that it was possible to evaluate the social structural determinants of HIV transmission among female sero-positive participants without their behaviour being affected by knowledge of their HIV-status.

There were a few other limitations to the NFHS-III which occurred during the data collection. The principal constraint was that the sample of female HIV-positive respondents was fairly small at 191<sup>207</sup>, which was a product of sero-prevalence among women being quite low in India, at 0.2%. This type of limitation in the data, rather than curtailing research, is actually reflective of conditions in the real world. Many chronic or terminal illnesses have a relatively low prevalence in most populations, making it difficult for social theorists and epidemiologists to ascertain with statistical certainty causal mechanisms related to disease prevention or treatment (Draper, Vincent et al. 2005, Feychting, Jonsson et al. 2003).

As the size of the female HIV-positive sample was small, it was difficult to conduct highly complex statistical analyses, such as structural equation modelling. Nevertheless, it was still possible to conduct slightly less complex multivariate analyses. These analyses were fruitful in identifying individual-level variables associated with ‘susceptibility’ and ‘vulnerability’, while controlling for the effect of logical confounders. For example, multivariate analysis of all female participants’ health behaviours revealed that respondents living in southern areas of India displayed a higher odds ratio (OR=4.65, CI=4.37-4.95) of consuming a wider range of food items than those residing in northern regions.

Furthermore, a few of the variables provided by the NFHS-III were inadequate for measuring *subjective* types of social phenomena, which included the quality of healthcare

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<sup>207</sup> As noted in chapters 4 and 9, when the relative weighting system was applied to the NFHS-III dataset, the female HIV-positive sample size fell from 191 to around 115.

services and stigmatising attitudes to HIV. This is because the primary objective of the NFHS-III was to document a wide range of issues related to maternal health, which could later be used by researchers to examine their own area of interest. The NFHS-III therefore often provided measurements which touched lightly on emerging health issues rather than examining the social problem in more detail. Quality of healthcare services, for instance, was evaluated by asking participants whether they thought that their health practitioner was responsive to their problems and needs<sup>208</sup>.

These limitations in the NFHS-III data were compensated for by employing qualitative methods to examine issues that are often difficult to measure using quantitative methods alone, e.g. HIV-related stigma. Participants' 'illness narratives' from the qualitative stage of research were successfully employed in this thesis to explore the possible sequence of events which may have affected outcomes, revealed in the quantitative phase of analysis. For instance, qualitative interviewees' narratives were fruitfully employed to trace social structural processes which may have led to female HIV-positive respondents in the NFHS-III living in areas of high sero-prevalence.

As discussed in chapter 4, there were some weaknesses in the qualitative data, the most crucial being that it was not possible to conduct research in North-Eastern states with high rates of HIV-prevalence as these areas had a recent history of political violence (Suykens 2010). Moreover, literature on HIV/AIDS in this region indicated that it could be difficult to sample female respondents as the large majority of PLWHA were men due to HIV being transmitted primarily through drug injecting use in this area of India (Mahanta, Medhi et al. 2008).

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<sup>208</sup> It is important to note that issues such as HIV-related stigma are often difficult to measure in surveys, as they are dependent on participants' subjective experiences of the phenomena. For example, it was noted in the qualitative phase of research that interviewees experienced stigma in the form of silent behaviours (e.g. relatives refusing to touch food utensils they had just used).

Additionally, it was only possible to sample qualitative interview respondents from NGOs and PNs who were aware of their sero-status and were accessing governmental HIV-related healthcare services. As HIV prevalence is fairly low in India, it would have been very difficult, if not impossible, to sample respondents by any other means<sup>209</sup>. Measures were taken to prevent bias in participants' responses to questions on healthcare, such as employing a translator from outside the organisation and ensuring that participants knew that their answers would not affect their care. However, many participants seemed to provide narratives which were favourable towards these organisations, indicating that these measures were perhaps not enough to avoid bias in the data. These biases within the qualitative dataset were reduced through the use of data from the NFHS-III, which sampled the wider population of WLHA who may not necessarily have been undergoing any form of treatment for their condition.

Quantitative and qualitative methods were used in combination, with a view to minimising the weaknesses inherent in each dataset. An additional benefit of using both datasets was that I had access to two populations which are rarely discussed in literature on HIV/AIDS in India. Within the NFHS-III dataset, I was able to examine the behaviour of the wider population of WLHA, who are mostly unaware of their sero-status and in the early phases of their illness. The qualitative sample, on the other hand, contained a smaller section of the WLHA population who had already been diagnosed as HIV-positive and had been making continual use of healthcare services for their condition. These two samples offered a unique insight into social structural determinants affecting respondents' 'susceptibility' and 'vulnerability'.

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<sup>209</sup> It is often argued that qualitative findings are not generalizable as small samples are used which would incur bias in the data (Hollway, Jefferson 1997, Starks, Trinidad 2007, Wray, Markovic et al. 2007).

The following section brings together findings from chapters 5, 6 and 7, which explored women's 'susceptibility' to the impact of HIV using a combination of quantitative and qualitative data.

## 11.C Women's 'susceptibility' to HIV infection

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Recent research has highlighted that the HIV epidemic in South East Asia has followed a very different trajectory from that of Sub-Saharan Africa and Europe (Mahanta, Borkakoty et al. 2009, Kumar, Natale et al. 2009, Suresh, Richard et al. 2009). It was suggested that the HIV epidemic in Asia has not become generalised because the populations in these countries are large, dispersed over vast geographical areas and heterogeneous in nature, especially in the cases of India and China (Ruxrungtham, Brown et al. 2004, Gillespie 2008, Molla, Berhane et al. 2008). As Cohen (2004a) stated:

*'The scale of Asia's epidemic has more to do with the size of the continent's population than the explosive spread of the virus. In the past few years, it has become clear that the epidemics in Asia and Africa are surprisingly different. HIV has not spread rapidly by heterosexual sex to cause an African-styled "generalized" epidemic anywhere in Asia, and many epidemiologists now believe it is unlikely to do so in most parts of the continent'. (p. 1932)*

One of the most crucial findings from the NFHS-III in chapter 5 indicated that 'macro-environmental' determinants of 'susceptibility' could have a predictive impact on female participants' sero-status. Results within the 'macro-environmental' component of 'susceptibility' indicated that HIV infection among women could be concentrated into geographical pockets in India. Over half of WLHA lived in southern high prevalence states, e.g. Andhra Pradesh and Karnataka. There was a significantly ( $<.01$ ) higher rate of HIV-prevalence amongst women living in urban (0.29%) than rural areas (0.18%). Furthermore, multivariate analysis of social structural predictors revealed that female participants who lived in areas with a higher level of sero-prevalence were 3.45 times as likely to be HIV-positive than those who lived in states with a low HIV-prevalence (OR=3.48, CI=2.19-5.54).

This was reinforced by similar results in the qualitative phase of analysis, mentioned in chapter 6, in which participants seemed to belong to communities with high levels of sero-prevalence. Many qualitative interview participants recounted living in communities in which they witnessed other members experiencing the debilitating symptoms of HIV, e.g. extreme weight loss<sup>210</sup>.

Further analysis of the NFHS-III indicated that other ‘macro-environmental’ determinants may also impact female respondents’ sero-status. It was found that many female HIV-positive participants could belong to socio-economically deprived sections of the population. There were significantly (<.005) higher rates of HIV-prevalence amongst female participants who were illiterate (0.29%) and who had not completed primary school (0.48%). Moreover, participants who had low levels of education (OR=2.27, CI=1.40-3.68) and were employed (OR=1.45, CI=0.96-2.18) displayed significantly (<.005) higher odds of being HIV-positive than their counterparts.

Findings from the qualitative phase of research highlighted processes within participants’ communities which may have led to these findings. According to some qualitative interviewees’ narratives, they lived in impoverished areas in which the local labour market had little demand for stable work. Their accounts indicated that processes associated with economic development may have created unstable environments for people living in these communities. Male members of these communities were compelled to migrate to find more lucrative or stable forms of employment.

Early literature on HIV transmission in India highlighted the fact that men who migrated in search of work were more likely to engage in sexual risk behaviour (i.e.

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<sup>210</sup> These findings could be a product of sampling bias, as most respondents were sampled from PNs and NGOs. It is possible that these organisations may have targeted these respondents’ communities because they were known for having high levels of sero-prevalence.

unprotected sexual contact with CSWs), as they were away from their wives and families (Nag, NCEPH 1995 Nagelkerke, Jha et al. 2002)<sup>211</sup>. Thappa, Singh et al. (2007) commented:

*'Indian truck drivers and their helpers who spend the major part of the year on or near highways are generally known to visit many prostitutes during their stopovers'* (p. 70).

Findings in both the quantitative and qualitative phases of research indicated that many WLHA form part of the formal cash economy through their work as manual labourers and domestic workers. These types of jobs could offer WLHA the opportunity to interact with people outside their immediate social strata and potentially form sexual relations. For instance, female participants who were employed in the NFHS-III displayed significantly ( $<.05$ ) higher odds (OR=1.45, CI=0.96-2.18) of being sero-positive than those were not employed. Moreover, many qualitative interview participants mentioned that they first met their spouse through their occupation, which suggest that working in the public sphere could widen their sexual network.

Once HIV had entered the qualitative interview participants' communities through migration, it may have been further spread through these communities via close knit sexual networks. According to quantitative and qualitative findings female respondents 'susceptibility' was further heightened by unequal gender dynamics within their relationship, which often left them unable to negotiate safe sexual practices. Findings in the NFHS-III revealed that female HIV-positive respondents were significantly ( $<.001$ ) more likely to have experienced severe violence (45%) than the general population (26%)<sup>212</sup>. Nevertheless, as HIV-prevalence is very low amongst women in India, it is the case that there could be many

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<sup>211</sup> A study of 263 truck drivers/assistants recruited at a highway clinic in southern India in 1999-2001 reported frequent CSW contacts, alcohol consumption, and the presence of various STDs (Godbole, Mehendale 2005).

<sup>212</sup> Many experts on HIV prevention have posited that HIV transmission from men to women is fostered by unequal gendered dynamics within marital relationships, which make it difficult for women to protect themselves against STI infection (Mlay et al. 2008, Panda et al. 2005 and Dallabetta et al. 1993).

women who belong to these marginalised communities and experience domestic violence, and yet never contract HIV.

As findings from chapters 5 and 6 highlighted the fact that female respondents propensity to contract HIV was mostly affected by distal macro-environmental determinants rather than their own sexual behaviour, chapter 7 sought to examine respondents' pathways into relationships with partners who exhibit high risk sexual behaviours. One of the key findings was that participants 'susceptibility' was influenced by their ability to make an informed choice of partner and negotiate the terms of their relationships. Participants who entered into 'love marriages' were often partnered with spouses who were older, more sexually experienced and belonged to a higher social strata than they did. As these respondents may have flouted the authority of elder members of their family by choosing their own husbands, they had access to few social and financial resources if they did experience domestic violence.

Meanwhile, participants who underwent an arranged marriage reported that their pool of potential partners was severely curtailed by family poverty, as their parents could not afford an excessive dowry. Consequently, some respondents had unknowingly entered into a 'deviant marriage' (Minturn 1993, cited in Kaur 2004) with a spouse who was already sero-positive. Their spouse's parents had arranged this marriage in order to avoid scandal falling on their family through being associated with HIV.

These results suggested that 'socio-cultural practices' related to negotiating marriages could mediate women's 'susceptibility' in the Indian context. In order to establish precisely what role 'socio-cultural practices' played in female respondents 'susceptibility', I blended results from the quantitative and qualitative phases of research. This type of analysis indicated possible sequences of events leading to participants contracting HIV. These findings underlined the temporal element to the HIV epidemic in which different social

structural determinants of ‘susceptibility’ operated at various stages of their narrative. In the first phase of ‘susceptibility’ respondents’ propensity to contract HIV was affected by ‘macro-environmental’ social structural determinants (such as *geographic mobility*), while in the later stages it was influenced by more proximal factors (e.g. *sexual behaviour*).

These results revealed that social structural determinants of ‘susceptibility’ may not operate in a simple linear fashion as proposed by Barnett and Whiteside (2002), whereby ‘macro-environmental’ determinants of risk affect the individual’s behaviour through a long chain of events. This model, while useful for guiding quantitative analysis of the NFHS-III, could also be perceived as deterministic in the same manner as Farmer’s (2001) concept of ‘structural violence’. Instead, respondents’ narratives seemed to suggest that social determinants on different structural levels appeared to work in unison with one another. This was evident in participants’ descriptions of events leading to their arranged marriage, in which ‘distal’ determinants associated with socio-cultural practices of coordinating partnerships acted alongside more ‘proximal’ factors like sexual behaviour.

As discussed in chapter 3, the individual’s ‘susceptibility’ to HIV infection is one part of the spectrum created by Barnett and Whiteside (2002) to evaluate the impact of HIV/AIDS on developing countries. Once HIV enters the population, its impact can be devastating as communities struggle to cope with the demands of the epidemic. According to Farmer (2001), HIV has overtaken the worldwide 1918 influenza pandemic as the infectious illness which has caused most adult deaths. In South-East Asia, HIV prevalence is low but the overall population of PLWHA is large, meaning that treatment is a crucial component of dealing with the epidemic. The following section brings together findings from chapters 8, 9 and 10, which explore female sero-positive respondents’ ‘vulnerability’ to the impact of being HIV-positive. Particular attention is paid to these participants’ experiences of accessing healthcare services.

## 11.D Women's 'vulnerability' to the impact of HIV/AIDS

As discussed in chapter 2, the latest estimates of HIV-prevalence have indicated that the rate of HIV transmission has plateaued or decreased in many of the worst affected regions of the world. The UN Joint Programme on HIV/AIDS concluded that 'global HIV incidence likely peaked in the late 1990s', due to 'natural trends in the epidemic as well as the result of prevention programmes' (cited UNAIDS, WHO 2007b: 6). During this time period worldwide HIV-prevalence has stabilised at marginally below 1% and has recently declined further to 0.8% (Bongaarts, Over 2010). It has therefore been argued that more effort should be made by policy makers to ensure that PLWHA receive ART treatment. Farmer (2001) stated that:

*'There is an unmentioned elephant in the conference rooms of many scientific meetings: the prospect of providing HAART to those living with both poverty and HIV. Even though this describes 90% of the potential beneficiaries of recent therapeutic developments, use of HAART in poor countries is rarely the primary topic of discussion in scientific congresses. Access to treatment is, however, the primary topic of discussion in communities beset by HIV, just as it is the primary topic of discussion among AIDS activists.'* (p. 358)

Other experts in the field of HIV/AIDS have posited that continual provision of ART treatment for HIV-positive patients could be too costly in resource-poor settings which barely have the infrastructure to care for other infectious diseases that are curable through modern medicine, e.g. typhoid. This is because HIV is a complex chronic illness which is difficult to treat even in a resource-rich setting<sup>213</sup> (Siegfried 2003).

ART treatment can potentially prolong HIV-infected patients' lives through postponing the onset of AIDS. Even with the introduction of generic drugs this type of treatment is still costly for HIV-infected patients at an estimated \$227 a year in India for first line treatment (Over 2009). Until recently, some donor organisations (e.g. the World Bank)

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<sup>213</sup> In the initial and the dormant phases of HIV there is little need for treatment, as the patients' level of immunity is stable. In the final stages, though, HIV-positive patients require additional treatment for potentially dangerous opportunistic infections, such as TB or Kaposi's Sarcoma (Forbi, Forbi et al. 2010).

therefore believed that it would be less costly to only provide treatment for OIs (Weissman 2003). Over, Heywood et al. (2004) commented that:

*'Opponents of government financing (ART treatment) argue that the lifeboats in poor countries are already full. Allowing antiviral therapy patients on board would force the government to push out children currently saved by vaccination programmes, and poor people currently saved from a lifetime of poverty' (p. 5).*

There are many additional costs associated with care for HIV-infected patients that are necessary for ensuring their long term survival (WHO 2009, Das, Mukhopadhyay et al. 2009, Dandona, Kumar et al. 2008)<sup>214</sup>. Gupta and Trivedi (2009) calculated that the cost per client in governmental ART centres was Rs. 970-1,850 per month (approx. £12.71-24.24), out of which CD4 count testing kits comprised 25% of expenditure. It is therefore possible that many developing countries heavily afflicted with HIV may not have a healthcare infrastructure able to sustain the demands of a chronic illness that requires the constant attention of qualified practitioners, expensive equipment and medication.

During NACO's third phase of policy, HIV-positive pregnant women, HIV-infected children under 18 years old, and patients with a CD4 count of less than 200 became eligible for free ARV treatment provided by governmental hospitals (Steinbrook 2007a). HIV-infected patients not eligible for ARV treatment receive palliative care from healthcare providers managed by local and international NGOs. According to NACO (2008a), these healthcare providers have been effective in allocating care according to patients' needs and in adapting to the setting. A recent report produced by the Indian government for UNGASS demonstrated that the proportion of patients who were lost on follow-up had been reduced to 7% with the provision of home-based counselling by district level PNs, staff at CCCs and HIV-testing facilities (NACO 2010).

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<sup>214</sup> These costs include: training of physicians in ART management, support from a multidisciplinary team (e.g. nutritionists and administrative staff), equipment for diagnosis and palliative care for OIs and regular clinical and laboratory-based monitoring of patients (comprising CD4 count, toxicity and viral load tests) (Over 2009).

On the other hand, according to estimates compiled by the WHO (2009) a far lower proportion of HIV-infected patients eligible for ART were receiving it in India in comparison to many sub-Saharan African countries. It was estimated that around 41% of PLWHA in need of ARV medicine were covered in 2009<sup>215</sup>. However, in other developing countries (e.g. Zambia, Zimbabwe, Botswana, Namibia and Rwanda) over 80% of HIV-infected patients were covered. These figures are contestable, as the report produced by the WHO (2009) did not specify the meaning of coverage or ‘access’. Many of the countries that were included in the report were unable to provide HIV-positive patients with free ART, meaning that many PLWHA may discontinue treatment due to the high cost of medication.

It is possible that coverage of ART treatment was low in India as few WLHA may even know of their sero-status. The key finding in chapter 8 is that less than 10% of female HIV-positive respondents reported that they had taken an HIV test. Many female respondents may not have been inclined to take an HIV test as they did not believe that they were at risk of contracting the virus, although some did know of their spouses extra-marital sexual relationships. Some participants in the qualitative phase of analysis commented that their level of knowledge concerning possible routes of transmission was low, with many believing that it was only transmitted through ‘illegal contact’, meaning pre- or extramarital sexual relations. As many of these participants had never engaged in any of these activities, they had no reason to believe that they could possibly contract HIV. Most of these respondents therefore learnt of their sero-status either through a routine HIV test as part of antenatal treatment, or after their husband had been hospitalised for debilitating HIV-related symptoms. These findings suggest that there could be a very large number of HIV-positive women (and men) unaware of their sero-status, as neither of these trigger events has yet happened to them.

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<sup>215</sup> Under new guidelines for treatment by WHO, which stipulates that HIV-infected patients with a CD4 count of less than 350 should be initiated on to ART (Walensky, Wood et al. 2010), only 21% of eligible patients were covered.

Findings in chapter 8 highlighted a possible weakness in Andersen and Aday's (1981) model of access, namely that it failed to acknowledge that an individual's access to healthcare for chronic illnesses could be dependent on their awareness of the condition, their risk of contracting it and their physicians' ability to diagnose their illness based on sometimes indistinguishable symptoms. As with HIV, many chronic illnesses at first present few symptoms: some people suffering from Alzheimer's, for instance, may not be aware that they are losing their short-term memory in the initial stages of their condition. As the condition progresses and the symptoms become more pronounced, it may become more difficult to treat the underlying illness.

Recent research has highlighted that access to HIV testing facilities is a worldwide issue (Kmietowicz 2010, Forbi, Forbi et al. 2010, Larson, Brennan et al. 2010). Kamalika, Madhu et al. (2010) conducted a retrospective study of patients attending a clinic in Delhi providing HIV-related healthcare between 2001 and 2007. It was found that the vast majority of patients were late presenters, defined as having an extremely low CD4 count or experiencing opportunistic infections. Male patients were twice as likely to present late in comparison to their female counterparts. These findings indicate that diagnosis is a crucial component of access as it is not possible for an individual to seek the relevant treatment for an illness without first knowing of its existence. According to the WHO (2003) knowing one's HIV-status is the 'first step to accessing care and preventing further infection' (p.1).

The objective of chapter 9 was to analyse which factors influenced the use of HIV-testing facilities by female HIV-positive respondents in the NFHS-III. Statistical analysis of the NFHS-III dataset was constrained by the relatively small numbers of participants belonging to the female HIV-infected sub-sample of participants. These analyses indicated that most variables measuring 'potential' access had little or no impact on female seropositive participants' propensity to be tested for HIV, and that the only 'potential' dimension

of access which did have an impact on participants' use of HIV-testing facilities was need. It was found that female HIV-positive respondents who were anaemic were significantly ( $<.05$ ) more likely to take a HIV test than those who were not.

Qualitative findings in chapter 9 revealed that the most substantial barriers that female respondents experienced in accessing healthcare services was during diagnosis. In 1997, HIV testing and counselling services were established in India to provide ethical and confidential care to patients taking an HIV test (NACO 2007a). These services were supposed to follow the strict guidelines on provision of HIV testing set by WHO and UNAIDS (2004) and NACO (2007c), which stipulate that testing should be voluntary, that counselling should be offered before and after the test, and that the results must be kept confidential unless the patient wishes otherwise. During the pre- and post-test counselling session, physicians or counsellors should provide information on how to prevent transmission of HIV, modern medication available to treat the virus, and means of coping with the psycho-social consequences of being HIV-positive (Sinha, Roy 2008).

It was striking that many participants were not directly informed of their HIV status by their practitioner because as young illiterate housewives they were deemed incapable of coping with their condition. This finding highlighted the fact that access to healthcare may be dependent on the physician's perception of their patient. Wood, Montaner et al. (2003) reported that physicians in first-world settings were reluctant to prescribe ART medication to patients who they perceived as non-adherent, such as those with a history of drug use or mental illness.

Quantitative and qualitative findings in chapter 9 illustrated that Andersen and Aday's (1981) model of access may not be adequate for evaluating factors which could affect PLWHA's use of healthcare facilities. Andersen and Aday's (1981) concept of access failed to grasp how the nature of a patients' illness could impact the types of healthcare services

they used and for what purpose. In the case of HIV, an individual may initially use testing services to diagnose their condition. During the early phases of their condition, PLWHA's use of healthcare services may not be dictated by their level of 'need', as they are often symptomless. They would, instead, continually access healthcare services in order to monitor their condition and maintain their current health-status through adherence to a strict ART regime.

The final empirical chapter addressed WLHA's 'continual access' (Mechanic 1995) to HIV-related care through analysis of respondents' narratives in the qualitative stage of research. As with results in chapters 8 and 9, participants face substantial barriers in accessing healthcare services during their initial entry into treatment. Many respondents who were diagnosed after their husband exhibited debilitating OIs reported that there was a long period of time in which they did not receive any form of healthcare.

This could be attributed to a cumulative set of factors including a lack of HIV-related healthcare services, poverty induced by the costs of their husband's treatment, a lack of bargaining power within their family, and a low level of knowledge of the treatment required for their condition. These participants started to use HIV-related treatment continually after ART centres were established as part of NACO's third phase of policy. The findings indicate that the provision of free ARV medication enabled respondents' access to treatment by increasing local availability of healthcare providers<sup>216</sup>.

Participants' current use of treatment was influenced by the structure of healthcare services and family level of 'need' for healthcare. Many of the respondents were using governmental healthcare facilities in conjunction with NGO and PN services. This was a product of a multi-sectoral system of healthcare, whereby different types of HIV-related needs were catered for by NGO and governmental providers. Participants who were eligible

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<sup>216</sup> Cost of treatment often plays a role in patients choice of healthcare provider. Balarajan, Selvaraj et al. (2011) noted that poor patients in rural areas of India were reluctant to seek treatment for their condition due to cost.

for ARV treatment or who had other family members using ARV medication were expected to visit an ART centre once a month. In addition, they would attend an NGO or PN healthcare provider on a bi-weekly basis in order to collect food supplements and receive ‘counselling’ on how to maintain their current level of immunity. Respondents who were not eligible for ARV treatment were only required to visit the ART centre every six months, in order to take CD4 counts to establish their health status. Many of these participants were also attending an NGO or PN healthcare facility.

Participants’ narratives on their current use of healthcare indicated that the quality of care they received varied widely between different providers. Many respondents complained that they received a poor quality of care in ART centres, where they were expected to wait for long periods of time for simple procedures (e.g. collection of medication) and received very little advice on their treatment from doctors. This was partly the result of the ART centres being recently established and thus unable to cope with the volume of patients. The bulk of responsibility for care seemed therefore to shift towards NGOs and PN providers, which offered patients comprehensive advice on how to manage their condition. Many participants were complimentary of the care that they received from these facilities, commenting that they were offered the psychological tools to cope with their condition. Peer providers believed that NGO providers were better able to deal appropriately with PWHAs’ needs, as these organisations have been offering services to HIV-infected patients for some time.

These respondents’ narratives revealed another weakness in Andersen and Aday’s (1981) concept of access, which was that little consideration was given to the impact that quality of care can have on patients’ use of healthcare services. This is because quality of care is considered to be an outcome of access rather than as a factor which could drive repeated use of healthcare services. Andersen and Aday (1981) failed to note that ‘subjective realised access’ plays an ambiguous role in patients’ treatment outcomes. In some cases, receiving a

low quality of healthcare may not adversely impact patients' ability to cope with their condition. For example, many qualitative interviewees continued to use ART centres despite having to wait for long periods of time to collect medication. In other cases, poor quality of healthcare could negatively impact patients' condition. This was apparent in respondents' accounts of doctors in ART centres being unable to diagnose an OI because they were unable to interact with them for more than five minutes. A possible future direction in research could therefore be to further refine theories of access to examine the ambiguous role played by quality of care in the continual use of healthcare services.

Finally, a few participants reported that they used private healthcare facilities on an episodic basis to treat minor and major HIV-related symptoms. There were some participants who had a close relationship with their 'family doctor', who would tailor their prescription according to what type of care they were already receiving. On the other hand, there were other participants who were reluctant to inform their physician of their sero-status in case they were refused treatment. These patients were in danger of receiving strong doses of medication which could possibly interfere with their current treatment. As Das and Hammer (2004) stated:

*'Public sector providers are more likely to commit errors of omission- they are less likely to exert effort compared with the private counterparts. In the private sector, providers are prone to errors of commission- they are more likely to behave according to the patient's expectations, resulting in the inappropriate use of medications, the overuse of antibiotics, and increased expenditures.'* (p. ii)

Findings on 'vulnerability' could have many implications for future social interventions and programmes. The key finding on 'vulnerability' was that many WLHA may not know of their sero-status. Among the few WLHA who managed to access diagnostic facilities, some were not even informed of their sero-status by physicians who may have believed that they were unable to cope with their condition. These types of issues could be addressed through concerted efforts by governmental and non-governmental bodies to ensure

that WLHA can access HIV testing services and are sensitively informed of their sero-status. The following section, then, goes on to further examine the implications of quantitative and qualitative findings on ‘susceptibility’ and ‘vulnerability’ for future social interventions.

## 11.E Implications for future social interventions or programmes

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Experts have argued that an evidence-based response has been adopted in the implementation in India of programmes for the prevention of HIV transmission (Wilson, Claeson 2009). The primary method of prevention has been ‘Targeted Interventions’, in which high-risk groups (e.g. clients of sex workers) have been offered HIV-related education and treatment for STIs (Mahanta, Medhi et al. 2008). Targeted Interventions are based on the premise that it is possible to halt the chain of HIV transmission between ‘high-risk groups’ and the ‘general population’ by ensuring that individuals in the former group are able to prevent others from contracting the virus. Rajesh, Sanjay et al. (2011) reported that the number of Targeted Interventions for CSWs increased in the high-incidence southern states from 5 to 310 programmatic efforts between 1995 and 2008. During this time there was a significant decline in prevalence of HIV and syphilis among CSWs and pregnant women attending antenatal clinics.

Another method of HIV prevention which has been successfully adopted in the Indian context is the ‘Structural Intervention’ model. The objective of these interventions is to address the social structural determinants of disease transmission by creating ‘enabling environments’ for those most susceptible to HIV infection (Gupta, Parkhurst et al. 2008). The best example of this type of intervention in India is the Sonagachi project (Ghose, Swendeman et al. 2011). CSWs in the Kolkata red light district collectivised other female sex workers to mobilise against harassment and other forms of violence. Currently, this project provides a wide range of services for around 20,000 sex workers in its local area.

Nevertheless, findings in chapters 5, 6 and 7 indicate that a large proportion of WLHA are 'traditional housewives' who have little or no history of engaging in risky sexual behaviour. Currently, there are no known interventions which directly address the needs of this population at risk. This could be because these women are difficult to target. However, results in these chapters imply that some of these WLHA may live in areas which have pockets of high HIV incidence, and therefore it could be fruitful to initiate structural interventions within these communities in order to empower female members with sero-positive husbands to avoid HIV infection.

On the other hand, findings from chapters 8 and 9 indicated that much needed to be done to improve WLHA's access to healthcare facilities. The vast majority of female HIV-infected participants in the NFHS-III reported that they had not taken an HIV test prior to the interview. One possible explanation for this finding could be that these respondents were unaware that they were susceptible to HIV infection as they had engaged in little or no risky sexual activity. This is a cause for concern, as PLWHA who do not know of their sero-status are more likely to transmit their infection to others than those aware of their condition (Marks, Crepaz et al. 2006). Furthermore, knowledge of one's own sero-status is usually the first step towards making use of the relevant healthcare facilities. Macklin (2005) stated that:

*'HIV testing is not an end in itself. It is instead a means to an end, in which the ethically acceptable ends are care and access to treatment for people found to be infected and access to adequate preventive means for those who are uninfected'* (p.27)

Findings in the qualitative phase of analysis indicated that none of the respondents had voluntarily taken an HIV test out of knowledge of their own risk of contracting HIV. Many respondents undertook the test as part of antenatal care when pregnant or at the behest of their doctors after their husband had experienced debilitating OIs. One crucial result was that participants in the former category commented that they had taken the test as it was part of a

medical routine common for most pregnant women, indicating that the possibly stigmatising nature of being tested for HIV was mitigated by these procedures.

There have been similar findings in other countries, whereby 'opt-out' testing during antenatal treatment has increased the number of women identified as sero-positive (Sinha, Dyalchand et al. 2008, Choudhury, Kutty 2007). In many of these countries, however, there is still a low proportion of sexually active individuals voluntarily undertaking a test, perhaps as a product of the stigmatising nature of HIV (Kigozi, Dobkin et al. 2009, Larson, Brennan et al. 2010). In a report for the Centres of Disease Control and Prevention, therefore, Branson, Handsfield et al. (2006) advised that patients aged 13-64 years should be routinely tested for HIV in order to ensure that more PLWHA learn of their sero-status at an early and manageable phase of their illness.

Unfortunately, results in chapter 9 illustrated that some participants were treated in an unethical manner by their practitioners, who would not directly inform them of their sero-status. Recent research has highlighted that this practice is fairly common in India, with many physicians reluctant to inform patients of their sero-status if they believe that they are incapable of understanding their condition (Sinha, Dyalchand et al. 2008). It is therefore possible that, even if a policy of routine 'opt-out' HIV testing was established for most of the population, there could still be a section of WLHA denied access to healthcare services through culturally-sanctioned medical practices.

One key advantage of data from the qualitative stage of research was that it was possible to analyse how recent changes incorporated in NACO's third policy phase influenced respondents' access to healthcare services. Many participants faced substantial barriers in accessing ART centres due to poor quality of care and distance from healthcare facilities. Nonetheless, these respondents were eager to overcome these barriers in access to healthcare facilities in order to ensure that they were able to use services regularly.

Additionally, many qualitative interview respondents followed nutritional advice from their physicians and counsellors and would attempt to buy expensive 'nutrition food' even when in debt. It is possible that these respondents' adherence to treatment was guided by their 'traditional' health beliefs, which were orientated towards preservation of health rather than treatment of symptoms (Atre, Kudale et al. 2004, Pugh 1991). Other studies have also illustrated that HIV-positive patients in developing countries are good adherents to ART medication (Cantrell, Sinkala et al. 2008, Rajasekaran, Jeyaseelan et al. 2008, Munro, Lewin et al. 2007). In Gupta and Trivedi's (2009) study of Indian HIV-positive patients' use of care, almost a quarter of respondents' out of pocket medical expenditure was on nutritional food items.

It has been argued by donor organisations, e.g. the World Bank, that provision of free ARV medication for PLWHA in developing countries could be an unnecessary expense as many patients would be unable to adhere to the strict regimen of ART treatment due to poverty and poor nutrition (Wanchu, Kaur et al. 2007, Over, Heywood et al. 2004). However, findings in chapter 10 illustrate that even illiterate WLHA understand the importance of good nutrition and adherence to medication in the management of their condition.

This type of research could also be applied to the study of other chronic illnesses in a developing country context. Recent research has illustrated that diagnosis and management of chronic illness is a worldwide issue, as people now have longer lifespans (Rabe, Hurd et al. 2007, Jones 2006). Lopez, Mathers et al. (2006) reported that almost half of the disease burden in middle to low income countries was from non-communicable diseases, e.g. heart disease. Furthermore, a study conducted in 45 villages in Andhra Pradesh established that over half of the deaths in this area were from chronic illness (Joshi, Cardona et al. 2006).

Some experts have posited that lessons learnt from developing countries provision of ARV therapy to HIV-positive patients could also be applied to the provision of treatment for

other chronic diseases (Harrington 2010, Tiamson 2002, Evans, Atim 2011). Farmer, Frenk et al. (2010) noted that almost two-thirds of deaths from cancer occurred in low and middle income countries. Nevertheless, as in attitudes to the care of HIV-positive patients in the past, there is a reluctance to treat cancer in these settings due to scarcity of resources. However, Farmer, Frenk et al. (2010) argued that:

*'Advocates should not assume that global health resources for cancer care and control are limited to present levels. Efforts to control HIV infection, tuberculosis, and malaria have shown that substantial, life-saving investments can feasibly be raised from public and private sources for research in and implementation of global health interventions, saving millions of lives'* (p. 1189).

It could therefore be argued that the provision of care for HIV could actually pave the way for treatment of other non-communicable illnesses, rather than creating a lop-sided healthcare system dedicated purely to the management of one chronic disease. In Cambodia, two centres were established in 2004 to provide integrated care for HIV, diabetes and hypertension, in order to 'reflect epidemiological realities' (Janssens, Van Damme et al. 2007:881). It was found that similar skills that staff acquired for treatment of HIV, such as instruction on adherence to medication, were also applicable to the care and management of diabetes.

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## 11.F Conclusion

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This thesis has shed light on factors affecting women's 'susceptibility' towards HIV infection in India, while also contributing to literature on their 'vulnerability' to the consequences of being HIV-positive. Most research on HIV/AIDS tends to separate transmission and treatment of HIV as if they are entirely different phenomena which have little relation to one another. When medical researchers attempt to connect these phenomena, it is often in terms of treatment acting as a form of prevention (Dieffenbach, Fauci 2009, Granich, Crowley et al. 2010). However, an important finding of this thesis is that

‘susceptibility’ and ‘vulnerability’ are closely linked and often affect one another symbiotically.

The relationship between ‘susceptibility’ and ‘vulnerability’ was most apparent in qualitative interviewees’ narratives of their diagnosis. Respondents who had unknowingly undertaken a ‘deviant marriage’ (Minturn 1993, cited in Kaur 2004) experienced substantial barriers to treatment. These participants’ parents-in-law often went to great lengths to ensure that they did not learn of their sero-status, even after they had been tested. For instance, PF29’s parents-in-law used to their advantage the fact that she was illiterate, and thus unable to read the test results. Her narrative illustrated how some women’s initial ‘susceptibility’ to HIV infection, which in her case was poverty which led to a ‘deviant marriage’, can later exacerbate their ‘vulnerability’ if they contract the virus. PF29’s ‘vulnerability’ to the impact of HIV was aggravated by her in-laws’ multiple attempts to conceal her condition from herself and others. The disquieting aspect of this narrative was that it was possible that physicians who were meant to be treating her colluded in this act. This resulted not only in PF29 accessing services only in the late stages of the illness, when she was experiencing OIs, but also in her child contracting the virus.

Unfortunately, Barnett and Whiteside’s (2002) theory did not seem to fully examine how ‘susceptibility’ and ‘vulnerability’ could affect one another at an individual level. They adopted a historical view of the epidemic, using the concept of ‘vulnerability’ to examine the impact that HIV can have on populations at a macro level. As a consequence, the concept of ‘vulnerability’ was poorly defined, as it covers a wide range of outcomes from household poverty to orphanhood. This meant that it was often difficult to examine how factors associated with the transmission of HIV may later affect the treatment of the disease.

On the other hand, Barnett and Whiteside’s (2002) concept of ‘susceptibility’ was effective in examining social structural determinants of HIV transmission. In contrast to the

concept of ‘vulnerability’, ‘susceptibility’ was clearly defined, as it seeks to examine social factors which lead to disease transmission. As the concept of ‘susceptibility’ was so well defined, it was possible to use it effectively in quantitative analyses to examine social structural determinants of HIV transmission in the Indian context. Statistical analysis of the NFHS-III dataset revealed that macro-environmental predictors may have a greater impact on female participants’ sero-status than their recent and indeed lifetime sexual behaviour. These results suggested that social structural dynamics within their communities and networks could predispose them to HIV infection.

Furthermore, findings from the qualitative phase of analysis showed that there was a temporal dimension to ‘susceptibility’ in the Indian context, which could be reflective of patterns of prevalence in South-East Asian countries. One of the most striking findings was that participants’ propensity to HIV infection started before they had even had the opportunity to find a partner. This is due to a number of factors outside their sphere of control, like low bargaining power, which resulted in them having a narrow choice of potential partners, many of whom had engaged in sexual activity prior to marriage. These respondents’ susceptibility was further exacerbated by the fact that they belonged to communities in which HIV prevalence may have been high.

To sum up, findings from both the qualitative and quantitative phases of analysis indicated that current conceptual frameworks of access may need to be adapted to reflect the treatment needs of patients suffering from chronic illnesses in resource-poor settings. Andersen and Aday’s (1981) theory of access was useful for allocating variables according to their ability to influence respondents’ use of healthcare services. However, the theory seemed to divorce the ‘potential’ dimensions of access from their social context by ignoring how patients’ healthcare preferences and the structure of facilities in developing countries might shape what type of services they would have access to.

The pluralistic nature of healthcare services in India was particularly crucial in mediating female sero-positive respondents' access to HIV-related services<sup>217</sup>. Results from the quantitative phase of analysis suggested that many WLHA had a preference for private healthcare facilities, and respondents' narratives from the qualitative phase of research indicated that this was due to the low quality of care from public healthcare providers. Many qualitative interviewees were therefore only persuaded to use governmental healthcare services when outreach workers persuaded them to do so. These findings suggested that the pluralistic system of healthcare, while offering many different types of services, can be confusing to navigate.

In conclusion, this thesis used a combination of quantitative and qualitative methods to contribute to the literature on HIV/AIDS in India by highlighting strengths and weaknesses inherent in the theories used to guide research, demonstrating that transmission and treatment of HIV can affect one another, and illustrating how socio-cultural factors may determine participants' response to their condition. These findings also clarified possible new directions in research, including the need to refine models of access to encompass the experiences of chronically ill patients in developing countries, and to facilitate further study on the impact of cultural practices of marriage on women's susceptibility to HIV infection.

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<sup>217</sup> Literature on public health policy in India has shown that there has been a proliferation of private hospitals due to the cuts in public expenditure by the Indian government in the 1990s (Qadeer 2000). As a consequence, there is a wide range of unregulated healthcare facilities available for consumers of such services.

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## Appendix

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### **Appendix 1: Demographics Sheet**

Demographics Sheet

#### Details of the Interview

Date of Interview:

Time at start of interview:

Time at finish:

Setting:

#### Details of participants

Pre ART or ART no:

Age:

Marital status:

Age of marriage:

Village/Town of residence:

Religion:

Ever attended school:

Highest standard you completion:

Currently working outside the home:

Occupation:

How many hours do you work a week?

Working for member of family, someone else or self employed:

If in an agriculture occupation, are you working your own land, on family land, or on land that you rent from someone else?

Are you paid in cash or kind for this work, or are you not paid at all?

Income:

Husband Occupation:

Husband's income:

How many people live in your household?

Who lives with you?

Details of Medical history

Date of HIV diagnosis:

At what age were you diagnosed:

Where were you diagnosed:

What is your current treatment:

When did you start your current treatment:

Is your husband HIV-positive?

Are any of your children HIV-positive?

Do you have any other relatives who are HIV-positive?

## Appendix 2: Telegu version of Demographics Sheet

## Demographic details of Participants

## Details of the Interview

ఇంటర్వ్యూ తేది :

ఇంటర్వ్యూ ప్రారంభించిన సమయం :

ఇంటర్వ్యూ ముగిసిన సమయం :

**Setting** :

**Participants వివరాలు** :

**Seen Art Booklet** :

వయస్సు :

పెళ్ళి అయ్యిందా :

పెళ్ళికి మీవయస్సు :

పల్లెటూరు / పట్టణప్రాంతం :

రిలీజిన్ (తెగ) :

మీరు స్కూల్కి వెళ్ళారా :

మీరు ఎంత వరకు చదువుకున్నారు :

మీరు ఇప్పుడు బయట పనికి వెళ్తున్నారా :

వృత్తి :

వారంలో ఎన్ని గంటలు మీరు పని చేస్తారు :

కుటుంబం కోసం పనిచేస్తున్నారా? (లేదా) ఎవరైనా చేస్తారా (లేదా)

స్వయంగా మీరే పని చేసుకుంటారా? :

మీ వృత్తి వ్యవసాయం అయితే సొంత పొలంలో పనిచేస్తున్నారా? (లేదా)

మీరు కవులు తీసుకున్నారా? (లేదా) పొలం పనికి వెళ్ళారా? :

మీరు చేసే పనికి డబ్బులు ఇస్తారా? (లేదా) రోజుకి భోజనం లెక్కపెట్టారా?

(లేదా) ఆసలు డబ్బులు ఇవ్వారా? :

అదాయం :

మీ భర్త వృత్తి :

మీ భర్త అదాయం :

మీ ఇంటిలో ఎంతమంది ఉంటారు? :

మీతోపాటు ఇంకా ఎవరు ఉంటారు? :

### Details of Medical History

- మీరు **HIV-positive** అని తెలిసిన తారీఖు :  
 మీకు **HIV** వచ్చినప్పుడు మీ వయస్సు ఎంత :  
 మీకు **HIV** అని తెలిసింది ఎక్కడ :  
 మీ ప్రస్తుత చికిత్స ఏమిటి :  
 మీరు ప్రస్తుతం తీసుకుంటున్న చికిత్స ఎప్పుడు ప్రారంభించారు :  
 మీ భర్త కూడా **HIV-positive** ? :  
 మీ పిల్లలకు ఎవరికైనా **HIV-positive** వచ్చిందా? :  
 మీకు **HIV-positive** ఉన్న బంధువులు ఉన్నారా? :

### Appendix 3: Service User's Topic guide

#### Introduction

*Thank you so much for offering to contribute your time to this interview. I am doing a study on how HIV-positive women find and use treatment for their condition. I would really like to learn about women's experiences using healthcare services. You would offer a vital contribution to my study by telling me as much as you would like to about your experiences of living as an HIV-positive woman and how this has impacted on your ability to use healthcare services. There is no right or wrong answer to any questions that I ask and you can speak at length about anything that interests you on this topic as you would in a normal conversation. If you have any questions of your own about my study please feel free to ask me and I would be happy to answer.*

*The interview should take around one and a half hours. I would like to take notes on what we talk about and also tape-record your answers to help us remember what you tell us. All of these notes and tapes will be stored in a locked file cabinet and only I, my interpreter and supervisor can look at this information. I will not reveal your identity to anyone else. You do not have to answer questions which make you feel uncomfortable and you can stop the interview at any time that suits you. If you do not want your answers to be tape recorded, then please tell us.*

*The interview will be conducted in two stages. Firstly, we are going to fill out a sheet with details on your age and marital status. This should take only 10 minutes. Then we will ask you to recount your experiences of using healthcare for your illness as if you are telling a story beginning from just before you were diagnosed and ending with your current health status and how you think that services can be improved to make it easier for you to use them. I have a set of questions to help you to tell your story as I understand that it is difficult to speak to someone you do not know well. I may ask questions during the interview to elicit more information.*

#### **1. Socio-economic circumstances before diagnosis**

*For the following questions, I will be asking about your financial and social status before you were diagnosed with HIV. I am asking these questions so that I can understand how having HIV may have changed the way that you live.*

- a. May I ask about your relationship with your parents?
  - i. How would you describe your relationship to them before you were diagnosed?
  - ii. Are you still in close contact with them?
- b. May I ask about your relationship with your parents-in-law?
  - i. How would you describe your relationship to them before you were diagnosed?
  - ii. Are you still in close contact with them?
- c. Do you mind me asking about your financial situation before you were diagnosed with HIV?
  - i. Did you work for a wage before you were diagnosed as HIV-positive?
  - ii. What was your husband's occupation before the diagnosis?
  - iii. Do you feel that there has been a change in financial status since your diagnosis?
- d. Do you remember what you knew about HIV before you were diagnosed?

- i. What did you think about HIV as an illness before you were diagnosed?
- ii. Did you know how HIV is transmitted?
- iii. Did you know about the symptoms of HIV?
- iv. Did you know about medication to prolong HIV-positive people's lives?

## 2. Burden of care

*For the following questions, I will ask about how having HIV has affected your ability to care for your family.*

- a. Please describe what type of chores you do at home on most days.
  - i. Does anyone assist you in them?
  - ii. Do you ever feel too ill to do these chores?
- b. Do you receive any care or support from any relatives or friends when you are ill?
  - i. How do they support you?
- c. How do you take care of your husband and children when they are ill?
  - i. Do you receive any help from your husband or relatives in caring for children when they are ill?

## 3. Diagnosis

*For the following questions, I will be asking how you learnt that you were HIV-positive.*

- a. How did you come to know of your HIV-status?
  - i. Did you experience any symptoms before diagnosis?
  - ii. After experiencing these symptoms, how long did it take you to seek a diagnosis?
- b. Do you remember who first informed you of your HIV-status?
  - i. What did this person say to you?
  - ii. What was their behaviour towards you when they told you of your status?
  - iii. How did you feel when you were told about your HIV-status?
- c. Were you given any counselling before or after the test?
  - i. What did the counsellor say to you?
- d. What do you know about HIV now?
  - i. Do you know how HIV is transmitted?
  - ii. Do you know of the symptoms of HIV?

## 4. Disclosure

*For the following questions, I will be asking about your experiences of telling others of your condition.*

- a. Would you disclose your condition to your friends and family?
  - i. Why or why not?
- b. Is it important that you disclose your condition?
  - i. Why?
- c. Have you told anyone of your condition?
  - i. Who did you tell?

- ii. What did you say to them?
- iii. Describe their reaction to what you told them.

### **5. First entry point into treatment**

*For the following questions, I will be asking you about the first clinic or hospital that you went to after you were diagnosed with HIV.*

- a. How long after your diagnosis did you start to seek treatment?
- b. Where did you first go for treatment?
  - i. Why did you choose this place?
  - ii. How did you come to know of this place?
  - iii. What type of treatment did you receive?
- c. Did you face any difficulties reaching this clinic or hospital, such as cost, distance, time or something else?
- d. How would you describe the quality of care you received at this hospital or clinic?
  - i. How long did you have to wait till you are seen by a doctor or counsellor?
  - ii. How would you describe your relationship with the doctor or counsellor who you see there?
  - iii. How long does s/he talk to you?
    - i. Do you feel that s/he listens to your concerns?
- e. Did you receive any help, like a loan, from a NGO, or charity, at this point?
  - i. What kind of help did they give you?
  - ii. If not, did you receive NGO help later?

### **6. Current treatment**

*For the following questions, I will be asking you about your current treatment.*

- a. Have you used any other hospitals or clinics between your first and current treatment?
  - i. Where did you go?
  - ii. Why did you choose this place?
  - iii. How did you come to know of this place?
  - iv. What type of treatment did you receive?
- b. Where do you currently go for treatment?
  - i. Why did you choose this place?
  - ii. How did you come to know of this place?
- c. How long have you been using this treatment?
  - i. How often are you expected to go the clinic or hospital?
  - ii. Describe what you do when you go there.
- d. Have you suffered from any side effects from the medication, such as a rash, stomach illness or any other type of symptom?
  - i. Have these symptoms ever affected your ability to work?
- e. Have you faced any difficulties reaching this clinic or hospital, such as cost, distance, or something else?
- f. How would you describe the quality of care you received at this hospital or clinic?

- i. How long do you have to wait till you are seen by a doctor or counsellor?
  - ii. How would you describe your relationship with the doctor or counsellor you see there?
  - iii. How long does s/he talk to you?
    - i. Do you feel that s/he listens to your concerns?
- g. Are you receiving any financial or any other type of assistance from the government?
  - i. What type of assistance are you receiving?
  - ii. Do you believe that this assistance has helped you?
- h. Do you go to meetings held for HIV-positive people?
  - i. Do you find going to these meetings beneficial?
  - ii. Are you involved any other activities for HIV-positive people?

### **7. Other sources of treatment**

*For the following questions, I will be asking you about any other doctors you may have seen for treatment.*

- a. Have you used other sources of treatment?
  - i. Why?
  - ii. Have you ever used Ayurvedic or any other type of alternative medicine?
- b. Have you ever used this treatment at the same time as another?
  - i. Why have you chosen to do this?
- c. Do you suffer from any opportunistic infections, such as a cold, rash or any other type of illness?
  - i. What are the symptoms?
  - ii. Did you ever seek treatment for these symptoms?
  - iii. Have you ever been hospitalised for these symptoms?
- d. Have you ever been ill with TB?
  - i. Did you seek treatment for it?
  - ii. Where did you receive this treatment?
  - iii. What type of treatment did you receive?
  - iv. How would you describe the quality of care you received?
  - v. Have you ever been hospitalised for TB?

### **8. Outcome of accessing treatment**

This is the final section of the interview. I will be asking about your current health status and how you believe access to services can be improved for other HIV-positive women.

- a. How would you describe your current health status?
  - i. Do you suffer from HIV-related symptoms, such as tiredness, physical pain or any other types of symptoms?
  - ii. Do they interfere with your ability to work?
- b. Do you feel that there has been an improvement in your health-status since you started your current treatment?
  - i. In what ways has your health status improved?
  - ii. Has it improved your ability to work?
  - iii. Has it improved your ability to care for others?

- c. How do you believe you are going to use healthcare services in the future?
- d. What do you believe can be done to improve other HIV-positive women's access to services?

*Thank you so much for taking the time to participate in this interview. If you would like to give any feedback on the interview or discuss the topic with us further then you can contact us either through a member of staff at VMM or by using the contact details listed in the consent form.*

## Appendix 4: Peer Provider's Topic Guide

### Introduction

*Thank you so much for offering to contribute your time to this interview. I am doing a study on how HIV-positive women find and use treatment for their condition. I would really like to learn about women's experiences using healthcare services. You would offer a vital contribution to my study by telling me about your experiences living as an HIV-positive woman and providing social and healthcare services to other HIV-positive women. There is no right or wrong answer to any questions that I ask and you can speak at length about anything that interests you on this topic as you would in a normal conversation. If you have any questions of your own about my study please feel free to ask me and I would be happy to answer.*

*The interview should take around one and a half hours. I would like to take notes on what we talk about and also tape-record your answers to help us remember what you tell us. All of these notes and tapes will be stored in a locked file cabinet and only I, my interpreter and supervisor can look at this information. I and the translator will not tell anyone else anything that you have said in this interview. I will not reveal your identity to anyone else. You do not have to answer questions which make you feel uncomfortable and you can stop the interview at any time that suits you. If you do not want your answers to be tape recorded, then please tell us.*

*The interview will be conducted in two stages. Firstly, we are going to fill out a sheet with details on your age and marital status. This should take only 10 minutes. Then I will ask you to recount your experiences using and providing healthcare services. In the first half of the interview I will ask you about your usage of HIV-related healthcare services. Then in the second half I will ask you about your activities as a peer healthcare provider and your client's experiences accessing healthcare services.*

### **9. Diagnosis**

*For the following questions, I will be asking how you learnt that you were HIV-positive.*

- a. Do you remember what you knew about HIV before you were diagnosed?
  - i. What did you think about HIV as an illness before you were diagnosed?
  - ii. Did you know how HIV is transmitted?
  - iii. Did you know about the symptoms of HIV?
- b. How did you come to know of your HIV-status?
  - i. Did you experience any symptoms before diagnosis?
  - ii. After experiencing these symptoms, how long did it take you to seek a diagnosis?
- c. Do you remember who first informed you of your HIV-status?
  - i. What did this person say to you?
  - ii. What was their behaviour towards you when they told you of your status?
  - iii. How did you feel when you were told about your HIV-status?
- d. Were you given any counselling before or after the test?
  - i. What did the counsellor say to you?

### **10. Family relations after diagnosis**

*For the following questions, I will ask about how having HIV has affected your relationship with your family.*

- a. Did you tell anyone in your family about your HIV-status after you were diagnosed?
  - i. Who did you tell?
  - ii. What did you say to them?
  - iii. Describe their reaction to what you told them.

- b. Do you believe that disclosing your condition to your family has changed your relationship with them?
- c. Do you receive any care or support from any relatives or friends when you are ill?
  - i. How do they support you?
  - ii. Do they support you in caring for others in your family?

### **11. Current treatment**

*For the following questions, I will be asking you about your current treatment.*

- a. Have you used any other hospitals or clinics between your diagnosis and current treatment?
  - i. Where did you go?
  - ii. Why did you choose this place?
  - iii. How did you come to know of this place?
  - iv. What type of treatment did you receive?
- b. Where do you currently go for treatment?
  - i. Why did you choose this place?
  - ii. How did you come to know of this place?
- c. How long have you been using this treatment?
  - i. How often are you expected to go the clinic or hospital?
  - ii. Describe what you do when you go there.
- d. Have you suffered from any side effects from the medication, such as a rash, stomach illness or any other type of symptom?
  - i. Have these symptoms ever affected your ability to work?
- e. Have you faced any difficulties reaching this clinic or hospital, such as cost, distance, or something else?
- f. How would you describe the quality of care you received at this hospital or clinic?
  - i. How long do you have to wait till you are seen by a doctor?
  - ii. How would you describe your relationship with the doctor you see there?
  - iii. How long does s/he talk to you?
    - i. Do you feel that s/he listens to your concerns?

### **12. Assistance from NGOs, CBOs or governmental organisation**

*For the following questions, I will be asking whether you have received any financial or social support from a NGO, CBO or governmental organisation.*

- a. Are you receiving any financial or any other type of assistance from the government?
  - i. What type of assistance are you receiving?
  - ii. Do you believe that this assistance has helped you?
- b. Have you ever received any help, like a loan, from a NGO, or charity?
  - i. What kind of help did they give you?
- c. Do you go to meetings held for HIV-positive people?
  - i. Do you find going to these meetings beneficial?
  - ii. Are you involved any other activities for HIV-positive people?

### **13. Activities of outreach worker**

*For the following questions, I will be asking about your activities as a peer healthcare provider*

- a. How did you become an outreach worker/peer counsellor?
- b. What does your work involve as an outreach worker/peer counsellor?
  - i. How frequently do you see clients?
  - ii. How many do you see in a week?

- iii. What kind of support do you offer?
- c. How would you describe your relationship with those you help?
  - i. How do you think your clients perceive you?
  - ii. How close are you to your clients?

#### 14. Profile of clients

*For the following questions, I will be asking for a profile of women living with HIV/AIDS (WLHA). I will be interested in knowing about their socio-economic status and their usage of healthcare services.*

- a. How would you describe WLHA, who are your clients?
  - i. Level of education
  - ii. Socio-economic status
  - iii. Do any of your clients have anyone else in their family who is HIV-positive?
- b. Do your clients ever tell you about their previous experiences using healthcare?
- c. Do your clients tell you about when they were first diagnosed with HIV?
  - i. Where are they, usually, first diagnosed?
  - ii. How do they describe their treatment by doctors at this place?
  - iii. Do they tell you about their psychological reaction to the diagnosis?
- d. Is there usually a delay between the client's diagnosis and their first entry into healthcare?
  - i. Where do they first go for treatment?
  - ii. What is their experience of this hospital/clinic?
- e. Where do most of your clients currently go for treatment?
  - i. What kind of treatment do they receive there?
  - ii. Why do they choose this place for treatment?
  - iii. How often are they expected to go there?
- f. Have any of your clients reported suffering from any side effects from the medication, such as a rash, stomach illness or any other type of symptom?
- g. Do you know if any of your clients are receiving any financial or any other type of assistance from the government?
  - i. What type of assistance are you receiving?
- h. Do you know if any of your clients receive financial or social support from a NGO or charity?
  - i. What type of support do they receive?
- i. Do you know if any of your clients go to any meetings held for HIV-positive people?
  - i. Are they involved in any other activities for HIV-positive people?

#### 15. Difficulties that WLHA experience at home

*For the following questions, I will be asking about what types of problems that WLHA, who are your clients, experience at home*

- a. Do any WLHA, who are your clients, tell you that there has been a change in their financial status since they were diagnosed?
  - i. How has their financial status changed?
- b. Do any of your clients comment that their relationship with their family has changed since their diagnosis?
  - i. Do they report any change in their relationship with their parents or brothers and sisters?
  - ii. Do they report any change in their relationship with their parent-in-laws?
  - iii. Do they report any change in their relationship to their husband or partner?
- c. Do you know if your clients receive any support from family members or in-laws when they are ill?

- i. How do they support them?
- ii. Do they assist them in caring for others who are ill in the family?

## 16. Difficulties that WLHA experience reaching healthcare facilities

*For the following questions, I will be asking you about difficulties that WLHA, who are your clients, experience in trying to reach healthcare services.*

- a. What kind of difficulties do you think your clients face in accessing treatment, such as cost, distance, or something else?
- b. How would you describe the quality of care that WLHA, who are your clients, receive at their current hospital or clinic?
  - i. Do you know how long they have to wait till they are seen by a doctor or counsellor?
  - ii. How would you describe their relationship to their doctor or counsellor?
    - i. Do you think that their doctor or counsellor listens to their concerns?
- c. Do you notice any of your clients being ill-treated by hospital staff because of their HIV-status?
  - i. How do these members of staff ill-treat them?
- d. Have you ever experienced any ill-treatment from hospital staff as part of your line of work?
  - i. How did these people ill-treat you?
  - ii. Do you think that it was because of your HIV-status?

## 17. Outcome of accessing treatment

*This is the final section of the interview. I will be asking about your current health status and how you believe access to services can be improved for other HIV-positive women.*

- a. How would you describe your current health status?
  - i. Do you suffer from HIV-related symptoms, such as tiredness, physical pain or any other types of symptoms?
  - ii. Do they interfere with your ability to work?
- b. Do you feel that there has been an improvement in your health-status since you started your current treatment?
  - i. In what ways has your health status improved?
  - ii. Has it improved your ability to work?
  - iii. Has it improved your ability to care for others?
- c. How would you describe the health status of your female HIV-positive clients?
  - i. Do they report suffering from HIV-related symptoms, such as tiredness, physical pain or any other types of symptoms?
  - ii. Do these symptoms interfere with their ability to work?
- d. Have you noticed an improvement in your clients' health-status since they started their current treatment?
  - i. In what ways has their health status improved?
- e. How do you believe you are going to use healthcare services in the future?
- f. What do you believe can be done to improve other HIV-positive women's access to services?

*Thank you so much for taking the time to participate in this interview. If you would like to give any feedback on the interview or discuss the topic with us further then you can contact us either through a member of staff at VMM or by using the contact details listed in the consent form.*

## Appendix 5: Telegu version of Peer Provider's Interview Schedule

### Interview Schedule ( Peer Provider)

#### పరిచయం :-

మీ సమయాన్ని మాకు కేటాయించినందుకు మా కృతజ్ఞతలు. మేము **HIV-positive Womens** గా వివిధంగా జీవిస్తున్నాము ఈ గ్రామీణ ప్రాంతాలలో జీవిస్తున్న మహిళలు వివిధంగా చికిత్స చేయించుకుంటున్నారు. మీ యొక్క అనుభవాలు మరియు మీ ఆరోగ్య పరిస్థితి మెరుగుపరచటానికి తీసుకుంటున్న జాగ్రత్తలు ఏలా ఉన్నాయి. (మీరు చెప్పినట్లయితే) మరియు ఒక **HIV-positive** మహిళాగా ఎలాంటి పరిస్థితులు ఎదురవుతున్నాయి. అలాంటి పరిస్థితులలో ఆరోగ్యకేంద్రానికి వెళ్ళినప్పుడు మీకు ఎదురైన సమస్యలు మరియు అడ్డంకులు మాకు చెప్పవచ్చు. మీరు 'అవును', 'కాదు' అనే సమాధానలే కాకుండా మీ బాధలు, పరిస్థితులను మాతో చెప్పుకోవచ్చు. మీకు ఇంకా ఎటువంటి ప్రశ్నలు కాని ఏమైన సందేహాలు కాని వుంటే మమ్మల్ని అడగవచ్చు. మీకు సమాధానలు ఇవ్వడానికి మేము చాలా సంతోషిస్తాము.

మీ ఇంటర్వ్యూ గంట లేదా గంటన్నర జరుగుతుంది. మీరు మాతో చెప్పినవి నేను రాసుకొంటాను. మరియు టేపు రికార్డు కూడా చేస్తారు. ఎందుకంటే ఇవి నాకు గుర్తుండటానికి మాత్రమే ఇవి మేము ఎవ్వరికి చూపించము మరియు ఎవ్వరు చూడకుండా భద్రంగా దాస్తాము. వాటిని ప్రియా, ట్రాన్స్కెండ్ టీమ్ మాత్రమే చూస్తారు. మీకు సమాధానం చెప్పడానికి ఇష్టంలేని ప్రశ్నలకు సమాధానం ఇవ్వనవసరంలేదు. ఒకవేళ టేపు రికార్డు తీసుకోవడం ఇష్టం లేకపోతే మాకు చెప్పవచ్చు.

ఈ ఇంటర్వ్యూ రెండు పద్దతులుగా ఉంటుంది. మొదటగా మీరు ఒక పేపరు మీద మీ యొక్క వివరాలు మరియు మీ వయస్సు, మీకు పెళ్ళి అయ్యిందా అని అడుగుతారు. ఇది ఒక పది నిమిషాలు జరుగుతుంది. అయితే మీయొక్క అనుభవాలు మీ **Health Services** ఇవ్వటం వలన, మొదటగా మీరు ఈ **Health Services** ఏలా ఉపయోగించుకున్నారు. తరువాత మీ **Services** ఒక **Health Care Provider** గా మరియు మీ **Clients** అనుభవాలు ఈ **Health Care Services** ఏలా వున్నాయి.

#### 1. నిర్ధారణ (Diagnosis):-

ఎ) మీరు **HIV-positive** అని తెలియకముందు దీని గురించి మీకు ఏమి తెలుసు?

- 1) HIV గురించి ఒక జబ్బుగా మీరు భావించారా?
- 2) HIV ఏలా వస్తుందో మీకు తెలుసా?
- 3) వాటి లక్షణాలు గురించి తెలుసా?

బి) మీరు **HIV-positive** అని ఏలా తెలుసుకున్నారు?

- 1) మీకు HIV అని తెలియకముందు మీరు ఎప్పుడైనా అలాంటి లక్షణాలు కనిపించాయా?
- 2) ఆ లక్షణాలు వచ్చిన తరువాత, ఎప్పటికీ మీకు HIV అని తెలిసింది?

సి) మీ HIV గురించి తెలిసిన మొదట తెలియపరచినవారు గుర్తున్నారా?

- 1) ఆయన మీకు ఏమి చెప్పారు?
- 2) మీతో చెప్పేటప్పుడు ఆ వ్యక్తి ప్రవర్తన ఏలా వుంది?
- 3) మీ అలా చెప్పిన ఏమని లేదా ఏలా భావించారు?

డి) మీకు Test ముందు లేక తర్వాత **Counselling** ఇచ్చారు?

- 1) కౌన్సిలింగ్లో ఏమి చెప్పారు?

## 2. Family Relation after Diagnosis

- ఎ) మీకు HIV వచ్చిందని తెలిసిన తరువాత మీ Family ఎవరికైనా చెప్పారా?
- 1) ఎవరితో చెప్పారు?
  - 2) ఏమని వారితో చెప్పారు?
  - 3) వాళ్ళు ఏవిధంగా స్పందిచారు, మీరు చెప్పినదానికి?
- బి) మీరు వాళ్ళకి చెప్పటం వలన మీ కుటుంబంలో మార్పులు వచ్చాయి అనుకుంటున్నారా?
- సి) మీకు బాగోనప్పుడు మీ స్నేహితులుకాని, బంధువులుకాని మీ గురించి పట్టించుకున్నారా?
- 1) ఏలా మిమ్మల్ని ఆదరించేవారు?
  - 2) మీ కుటుంబ సభ్యులకు సంరక్షణ అందించేవారా?

## 2. ప్రస్తుత చికిత్స :-

- ఎ) మీరు మొదట వెళ్ళిన ఆసుపత్రి తరువాత మరియు ఇప్పుడు తీసుకుంటున్న చికిత్స మధ్యలో ఏదైనా ఆసుపత్రిలో చూపించుకున్నారా?
- 1) వెళ్ళితే, ఎక్కడకు వెళ్ళారు?
  - 2) ఎందుకని అక్కడకు వెళ్ళారు?
  - 3) మీకు అక్కడ చూస్తారని ఎలా తెలిసింది?
  - 4) ఎలాంటి చికిత్స మీరు అక్కడ పొందారు?
- బి) ప్రస్తుతం ఎక్కడ మీరు ఈ చికిత్స తీసుకుంటున్నారు?
- 1) ఇక్కడ ఎందుకని చూపించుకుంటున్నారు?
  - 2) మీకు ఈ ఆసుపత్రి గురించి ఎలా తెలిసింది?
- సి) మీరు ఎప్పుటి నుంచి ఈ చికిత్స తీసుకుంటున్నారు?
- 1) మీరు ఎన్నిసార్లు ఆసుపత్రికి వెళ్ళారు?
  - 2) మీరు వెళ్ళినప్పుడు మీరు అక్కడ ఏమి చేస్తారు?
- డి) మీరు ఆసుపత్రికి వెళ్ళాడానికి ఏమైనా ఇబ్బందులు ఎదురొచ్చినారా? ఎలాంటివనగా ఖర్చుకాని, దూరంకాని, ఇంకేదయినా?
- ఇ) మీకు ఏదైనా Side Effects వచ్చాయా ఈ మందులు వాడటం వలన, ఎటువంటి Rashes కాని, కడుపు నొప్పికాని, ఇంకా ఏమైనా లక్షణాలు వచ్చేవా?
- యఫ్) మీకు నాణ్యమైన చికిత్సను ఇస్తున్నారని ఏవిధంగా చెప్పగలరు?
- 1) మీరు ఎంతసేపు Wait చేయవలసి వస్తుంది మీ డాక్టరుగారిని కలవడానికి?
  - 2) మీకు మరియు డాక్టరుగారికి మధ్య ఎటువంటి సంబధాలు వుండేవి?
  - 3) డాక్టరుగారు ఎంతసేపు మీతో మాట్లాడేవారు? మీరు చెప్పేది వినేవారా కాదా?
- జి) ప్రభుత్వం నుండి ఏమైనా సహాయం అందుతుందా? డబ్బుపరంగా కాని లేక ఏమైనా?
- 1) ఎలాంటి (Assitance) సహకారం మీకు అందుతుంది?
  - 2) ఇది మీకు ఏవిధంగా సహాయపడుతుంది?
- హెచ్) HIV తో జీవిస్తున్న వారి కోసం ఏర్పాటు చేసిన Meetings కు హాజరైనారా?

- 1) ఇవి మీకు ఉపయోగపడుతున్నాయా?
- 2) ఇంకా ఏదైనా HIV తో జీవిస్తున్న వారి కోసం చేసిన మీటింగ్స్ లో పాల్గొన్నారా?

#### 4. Assistance from NGO's, CBO's or Governmental Org.

- ఎ) మీకు ఆర్థికపరంగా వివిధమైనా సహాయం తీసుకుంటున్నారు లేదా అది గవర్నమెంట్ నుండి అయినా కాని చెప్పవచ్చు?
  - 1) ఏలాంటి సహాయం మీకు అందుతుంది?
  - 2) అది మీకు సరిపడేలాగా మీకు సహాయపడుతుందా?
- బి) మీకు ఏలాంటి సహాయం అందుతుంది లేదా లోన్ గాని, NGO's నుంచి కాని, విరాళాల రూపంలో కాని?
  - 1) ఎలాంటివి మీరు పొందారు?
- సి) మీరు HIV-positive వాళ్ళకోసం నిర్వహించే సమావేశాలకు వెళుతారా?
  - 1) అవి మీకు ఉపయోగపడేలా వుంటున్నాయా?
  - 2) మీ కోసం నిర్వహించే ఇతర కార్యక్రమాలలో పాల్గొన్నారా?

#### 5. Service Worker మీ యొక్క విధులు:-

- ఎ) ఒక Service provider గా ఏలా మారగలిగారు?
- బి) మీకు ఒక Service provider గా మీ పని ఏవిధంగా ఉంది?
  - 1) తరచుగా ఏలాంటి Clients ని చూస్తారు?
  - 2) ఎంతమంది వస్తారు, ఒక వారంలో?
  - 3) ఏలాంటి సహకారం వారికి మీరు అందిస్తారు?
- సి) మీరు సహాయం అందిస్తే వారికి, మీకు సంబంధం ఏలా వుంటుంది?
  - 1) మీ Clients మిమ్మల్ని ఏవిధంగా తీసుకోగలుగుతారు?
  - 2) ఎంత Close గా వారితో మీరు వుంటారు?

#### 6. Clients యొక్క వివరాలు:-

WLHA ల సామాజిక, ఆర్థిక మరియు వారు ఉపయోగించుకుంటున్న ఆరోగ్య సేవలు?

- ఎ) మీ WLHA గురించి మీరు చెప్పగలరా? మీ Clients ఎవరు?
  - 1) వారి Level of education
  - 2) వారి ఆర్థిక పరిస్థితి?
  - 3) మీ Clients బంధువులలో ఏవైనా HIV తో జీవిస్తున్న వాళ్ళు ఉన్నారా?
- బి) మీ Clients ఎప్పుడైనా వారి (Heath care using) పూర్వ అనుభవాలు మీతో చెప్పకున్నారా?
- సి) మీ Clients మీతో ఎప్పుడు HIV-positive అని మొదట నిర్ధారించుకున్న దాని గురించి చెప్పారా?
  - 1) ఎక్కడ వన్నారు, మాములుగా?

- 2) ఈ Place లో ఎలా వారి చికిత్స గురించి Doctor గారికి చెప్పగలుగుతున్నారా?
- 3) అలా వాళ్ళు Diagnosis అయిన తరువాత వారి మానసిక పరిస్థితి చెప్పుకన్నారా?

డి) Health care లో Enter అవటానికి వారికి నిర్ధారణ చేసుకోవటానికి ఏమైనా ఆలస్యం జరిగేదా?

- 1) మొదట ఎక్కడికి వెళతారు చికిత్స కోసం?
- 2) ఈ Hospital గురించి వారి అనుభవం ఏమిటి?

ఇ) మీ ప్రస్తుత Clients చికిత్స కోసం ప్రస్తుతం ఎక్కడికి వెళ్ళేవారు?

- 1) అక్కడ ఎలాంటి చికిత్స వారు పొందారు?
- 2) ఎందువల్ల అక్కడకు చికిత్సకు వెళ్ళాలని అనుకున్నారు?
- 3) ఎన్నిసార్లు వాళ్ళు చికిత్సకు వెళ్ళేవారు?

యఫ్) ఈ మెడిసిన్ వాడినందుకు మీ Clients లో ఎవరికైన Side Effects వచ్చాయా?

జి) ప్రభుత్వం నుంచి వచ్చే ఆర్థిక సహాయం పొందినవారు మీ Clients ఎవరైనా ఉన్నారా?

- 1) పొందితే ఎలాంటి సహాయం అందింది?

హెచ్) NGO's నుంచి సహాయం పొందిన Clients ఎవరైనా ఉన్నారా?

- 1) ఎలాంటి సహాయం అందింది?

ఐ) HIV Meetings చేసినప్పుడు మీ Clients ఎవరైనా వెళ్ళారా?

- 1) వాళ్ళు ఆ కార్యక్రమాలలో పాల్గొన్నారు?

## 7. Difficulties that WLHA Expreance at HOME :-

ఎలాంటి సమస్యలు వాళ్ళు ఒక WLHA గా ఉన్నందుకు ఎదుర్కొంటున్నారు, వాళ్ళు ఇంటి దగ్గర అనుభవాలు

ఎ) ఇలా HIV అని తెలిసిన తర్వాత వాళ్ళ ఆర్థిక పరిస్థితి మరిన Clients ఉన్నారా?

- 1) ఎలా వారి ఆర్థిక పరిస్థితిలో మార్పులు వచ్చాయి.

బి) అలాగే వారు Positive అని తెలిసిన తర్వాత వాళ్ళ Family తో ఏవిధమైన మార్పులు వచ్చాయి?

- 1) తల్లిదండ్రులతో గాని, అక్క తమ్ములతోగాని ఏవిధమైన మార్పులు వచ్చాయని చెప్పారా?
- 2) లేక అత్తమామలతో
- 3) లేక భర్తతో కాని

సి) వాళ్ళకు బాగోనప్పుడు అమ్మనాన్నలు గాని, అత్తమామలుగాని వారికి సహాయం చేసేవారా?

- 1) చేసినట్లయితే ఎలాంటి సహాయం?

## 8. Difficulties WLHA Expreance reaching health care favitilites :

మీరు WLHA గా ఎదుర్కొంటున్న ఇబ్బందులు, మీ Clients ఎవరు, ఆరోగ్యసేవలు తీసుకోవటానికి వెళ్ళేటప్పుడు పొందిన అనుభవాలు

ఎ) ఎలాంటి ఇబ్బందులతో మీ Clients చికిత్స పొందటానికి వస్తారు అంటే బస్సు ఖర్చు, దూరం, ఇంకా ఏమైనా?

బి) మీ Clients చికిత్స తీసుకుంటున్న Hospital లో జాగ్రత్తలు చెప్పండి.

- 1) వాళ్ళు **Doctor** గాని, కౌన్సెలర్‌ని గాని కలవటానికి ఆలస్యం అవుతుందా?
- 2) **Doctor** కి వాళ్ళకి మధ్య సంబంధాలు ఎలా వుంటాయి, వాళ్ళు చేస్తున్నవి ఏళ్ళు వింటారా?

సి) మీ **Clients** ఎవరైనా **HIV** గా వున్నందుకు **Hospital** లో ఏవరైన సరిగ్గా వాళ్ళను చూడకుండా వుండటం జరిగిందా?

- 1) ఏవిధంగా వాళ్ళు తక్కువగా చూసేవారు (**ill - treatment**)?

డి) మీరు చేస్తున్న పనిలో మీరు అలాంటివి ఎదుర్కొన్నారా?

- 1) ఎలా చేసారు?
- 2) మీరు **HIV** ఉన్నందువల్ల వాళ్ళు అలా చేసారని అనుకుంటున్నారా?

### 9. ఎలాంటి చికిత్స పొందాలని అనుకుంటున్నారు (**Outcome of Accessing Treatment**)?

మీరు ప్రస్తుతం తీసుకుంటున్న చికిత్స వల్ల మీ ఆరోగ్యం ఏలావుంది మరియు వేరే మీలాగా వున్న స్త్రీలకి ఏలాంటి సేవలు పొందితే వారి పరిస్థితి మెరుగుపడుతుంది అనుకున్నారు.

ఎ) మీ ప్రస్తుత మీ ఆరోగ్య పరిస్థితి ఏలావుందో చెప్పండి?

- 1) మీరు **HIV** కి సంబంధించిన లక్షణాలతో బాధపడ్డారా? అంటే ఆలసట, ఒళ్ళునొప్పి ఇంకా ఏమైనా?
- 2) ఇలాంటి లక్షణాల వల్ల మీరు చేస్తున్న పని కష్టంగా వుందా?

బి) మీరు ప్రస్తుత చికిత్సను మొదలుపెట్టిన తర్వాత మీ ఆరోగ్యం మెరుగుపడిందని అనుకుంటున్నారా?

- 1) ఏవిధంగా మెరుగుపడుతుందని భావిస్తున్నారు?
- 2) వారి పని సామర్థ్యం మెరుగుపడుతుందా?
- 3) వారి గురించి ఎక్కువ జాగ్రత్త పడుచున్నారా?

సి) మీ **Clients** ఆరోగ్య పరిస్థితి చెప్పగలరా?

- 1) వారు ఎప్పుడైనా **HIV Symptoms** తో బాధపడినట్లు మీకు చెప్పారా?
- 2) వాళ్ళు పనిచేస్తున్నప్పుడు మీ లక్షణాలు ఏమైనా అడ్డంగా వున్నట్లు వున్నాయా?

డి) ప్రస్తుతం చికిత్స ప్రారంభించిన తర్వాత వారి ఆరోగ్య పరిస్థితి మెరుగుపడుతుందని మీరు గమనించారా?

- 1) ఏలాంటి వాటి వలన వారి ఆరోగ్య పరిస్థితి మెరుగుపడింది?

ఇ) భవిష్యత్తులో ఏలాంటి ఆరోగ్య సదుపాయాలు వుండాలని భావిస్తున్నారు?

యఫ్) వేరే **HIV-positive** మహిళలకు ఏలాంటి సేవలు పొందగలిగితే వారి ఆరోగ్యం మెరుగుపడుతుంది?

మీకు మా కృతజ్ఞతలు, మీకు ఇంటర్వ్యూ పైన ఏవిధమైన సందేహాలు ఉంటే వాటి సమాధానాలకొరకు **VMM STAFF** ద్వారా కాని **Consent Form** లో వున్న సంప్రదించాల్సిన వాటిని మీరు ఉపయోగించవచ్చు.

## Appendix 6: Ethical Consent Form

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**HIV-POSITIVE WOMEN'S ACCESS TO HEALTHCARE SERVICES IN INDIA**  
**VASAVYA MAHILA MANDALI (VMM), ANDHRA PRADESH, INDIA**  
**Interviews with Clients of VMM's Services- Participant Information and Consent Form**

### PART I: INFORMATION SHEET

#### **PURPOSE OF RESEARCH**

Priya Lall is a doctoral student at the University of Oxford under the supervision of her advisor, Dr. Don Operario. She is conducting a study to better understand how HIV-positive women living in rural areas access medicine to improve their condition. Sharing your experiences on using traditional and/or medical treatment is very important because we do not know if HIV-positive women are able to reach facilities and what their experiences are once they use them. The information you share will help future researchers, policy makers, and those providing services to better understand your needs. This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee, VMM, Andhra Pradesh State AIDS Control Organization and the National AIDS Control Organization.

#### **SELECTION OF PARTICIPANTS AND PROTOCOL**

You are being asked to participate in this study because of your HIV-status. If you agree to volunteer for this study, a time and place to meet will be scheduled that is most convenient for you. This meeting will consist of an interview no more than two hours. I will take notes on what we talk about and also tape-record your answers to help us remember what you tell us. All of these notes and tapes will be stored in a locked file cabinet and only Ms. Lall, her translator and supervisor can look at this information.

You can ask as many questions as you like and we take the time to answer them. You don't have to decide today. You can think about it and tell me what you decide later. If you agree to participate in this survey, we may contact you to invite you to participate in an interview about your experiences using alternative and/or medical treatment. You do not have to agree to talk to us. You can choose to say no and any services that you receive from VMM will not change.

#### **RISK AND DISCOMFORTS**

This interview should not make you uncomfortable and does not pose any risks. However, if you decide not to answer some or all of the questions, just tell Ms. Lall or the interpreter at any time and I will stop the interview. You can decide not to answer some or all of the questions with no penalty. Participation in research may mean that you share private information with us, but information about you will be handled as confidentially as possible. This means that only Ms. Lall and her translator will have access to information about you. Ms Lall will protect your personal information (for example, your name, address, phone number, etc.) and comply with all applicable laws. All research records will be destroyed by Ms. Lall after 10 years.

#### **BENEFITS**

You will receive no direct benefit for participating in this research. However, the information you provide may improve the types of programmes and services provided in your community and other communities. You will not be provided with any payment to take part in the research. However, you will be given Rs. 60 for your time and travel expense.

**PART II: CERTIFICATE OF CONSENT**

I have read the foregoing information, or it has been read to me, and I have had the opportunity to ask questions about it which have been answered to my satisfaction. I understand that I can leave the interview at any time without asking for permission and can refuse to answer questions that I am not comfortable with. My personal data will be identified using only a number code, will be accessed only by the principle investigator, translator and supervisor and will be destroyed after a period of 10 years. I am aware that all the information will be kept strictly confidential except in the rare circumstances in which it is judged that I or someone else is at risk of serious harm. I also know how to raise a concern and make a complaint. Knowing all this information I agree to take part in this study.

*If Literate*

**Signature of Participant** \_\_\_\_\_

**Date** \_\_\_\_\_

**Print Name of Participant** \_\_\_\_\_

**Signature of Researcher** \_\_\_\_\_

**Date** \_\_\_\_\_

**Print Name of Researcher** \_\_\_\_\_

*If illiterate*

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

**Signature of Witness** \_\_\_\_\_

**Print name of Witness** \_\_\_\_\_

**Date** \_\_\_\_\_

**PART III: USEFUL CONTACTS**

Please ask Ms. Lall and/or her translator if you have any questions, comments, or concerns about this study. If you have more questions, comments, or concerns, please contact Ms. Lall at:

**Address:** or

Vasavya Mahila Mandali (VMM)

Benz Circle,

Vijayawada - 520 010

Andhra Pradesh

**Tel:** +91-866-2470966/2473056/2472934

**Mobile no.** +919650309587

**Fax:** +91-866-2473056

**Email:** [vasavya@vasavya.com](mailto:vasavya@vasavya.com)

**Web Address:** <http://www.vasavya.com/>

If you do not wish to speak to Ms. Lall or her translator, contact Dr. Don Operario, Ms. Lall academic supervisor at:

**Address:**

Department of Social Policy and Social Work Barnett House

32 Wellington Square

Oxford OX1 2ER, United Kingdom

**Telephone:** +44(0)1865 270325

**Fax:** +44 1865 270324.

**Email:** [don.operario@sores.ox.ac.uk](mailto:don.operario@sores.ox.ac.uk)

## Appendix 7: Telegu version of Ethical Consent Form

## HIV Positive Women's Access to Health Care Services in India

### Interviews with Clients for VMM's Services and participants Information & Consent form

#### Part - I

#### రిసెర్చి యొక్క కారణం :-

ప్రియ లాల్ అనే అమ్మాయి డాక్టరేట్ విద్యార్థిగా Oxford University లో చదువుతుంది. ఆమె అడ్వైజర్ Dr. Don Operario (డాక్టర్ డాన్), ఆమె స్టడీ చేస్తున్న అంశము ఏమనగా 'గ్రామీణా ప్రాంతంలో ఒక HIV Positive మహిళ ఏవిధంగా జీవిస్తుంది అనేది తెలుసుకుని మరియు వారు మందులు వాడటం ద్వారా వారి పరిస్థితి ఏవిధంగా మెరుగు పరచవచ్చు' అన్నది తెలుసుకొనడానికి, మీ అనుభవాలు పంచుకోవచ్చు. మీరు మందులు మరియు Traditional గా తీసుకున్న ట్రీట్‌మెంట్ బాగా అవసరం ఎందుకంటే మీరు HIV Positive మహిళగా వుండి సరైన సదుపాయాలు మరియు అవి వాడిన తరువాత మీకు అనుకూలంగా వుండేలా ఉపయోగ పడుతున్నాయా లేదా అన్నది. ఇలా సమాచారం కూడబెట్టడం వలన భవిష్యత్తులో HIV Positive బారిన పడిన వారికి కౌన్సిలింగ్ చేయడానికి సహాయపడుతుంది. ఇలా ఇంటర్వ్యూ (Interview) తీసుకోవడం వలన రిసెర్చి (Research) కి మరియు మీ యొక్క అవసరాలు తెలుసుకొని మీకు ఎక్కువ సదుపాయాలు కలుగజేయడానికి ఉపయోగపడేలా మీ దగ్గర నుంచి ఈ ఇంటర్వ్యూ తీసుకొనేది, యూనివర్సిటీ అఫ్ ఆక్స్‌ఫర్డ్, సెంట్రల్ యూనివర్సిటీ రిసెర్చి ఎత్తిక్ కమిటీ, వాసవ్య మహిళా మండలి, ఆంధ్రప్రదేశ్ రాష్ట్ర ఎయిడ్స్ కంట్రోల్ (Org.) ఆర్గనైజేషన్ మరియు జాతీయ AIDS కంట్రోల్ ఆర్గనైజేషన్.

#### పాల్గొనే వ్యక్తుల యొక్క సెలక్షన్ :-

మీరు HIV తో జీవిస్తున్నందున మీరు దీనిలో పాల్గొనవలసిందిగా అడుగుచున్నాము. మీరు దీనిలో పాల్గొనడానికి ఇష్టమైతే మీకు సరైన పద్ధతిలో అనుకూలమైన సమయం, స్థలం ఏర్పాటుచేయబడుతుంది.

ఈ ఇంటర్వ్యూ 2 గంటల కన్నా ఎక్కువ సమయం తీసుకోదు. మీరు చేప్పే అన్ని విషయాలు మాకు గుర్తు ఉండటానికి రాసుకొంటాము మరియు టేపు చేసుకొంటాము. మీరు చేప్పిన విషయాలు, టేపు అన్ని గోప్యంగా ఉంచుతాము. ఈ రిసెర్చి నందుకు విషయాలు ఒక్క ప్రియాలాల్ గారికి, ఆమె ట్రాన్స్ లేటర్ కి మరియు సూపర్ వైజర్ కి మాత్రమే తెలుస్తాయి.

మీరు అడగ వలసిన ప్రశ్నలు అన్ని అడిగిన మేము సమాధానం ఇస్తాము. మీ యొక్క నిర్ణయం ఈ రోజే చెప్పవలసినదే. బాగా ఆలోచించి తరువాత చెప్పవచ్చు.

మీరు ఈ సర్వేలో పాల్గొనటానికి ఇష్టపడితే మమ్ములను సంప్రదించవచ్చు. ఈ ఇంటర్వ్యూ నందు మీ యొక్క అనుభవాలు, మందులు వాడటం వల్ల మీయొక్క పరిస్థితి తెలుపవచ్చు. మీకు ఈ సర్వేలో పాల్గొనటం ఇష్టంలేకపోతే ఇష్టంలేదని చెప్పవచ్చు. అందువల్ల వాసవ్య మహిళా మండలి నుంచి లభించే సదుపాయాలు మారవు.

#### ఇబ్బందులు మరియు సదుపాయాలు లేకపోవడం :-

మీకు ఈ పద్ధతి ఇబ్బందిగా వుంటే మీరు ఏమి ఇబ్బంది పడవలసినదే. మీరు కొన్ని ప్రశ్నలకు సమాధానం ఇవ్వడం ఇష్టం లేకపోతే (లేదా) అన్ని ప్రశ్నలకు కూడా సమాధానం ఇవ్వడం ఇష్టం లేకపోతే మీరు ప్రియాలాల్ కి కాని ట్రాన్స్ లేటర్ కి కాని చెప్పితే ఇంటర్వ్యూని అపివేస్తారు.

మీరు కొన్ని ప్రశ్నలకు కాని అన్ని ప్రశ్నలకు సమాధానం ఇవ్వటం ఇష్టంలేనట్లయితే మీనుంచి ఎటువంటి పెనాలిటీ తీసుకోరు. ఈ ఇంటర్వ్యూలో పాల్గొనటం అనేది మీయొక్క (రహస్య) వ్యక్తిత్వాన్ని మాకు చెప్పడం. మీరు చెప్పిన విషయాలు ఎవ్వరికి తెలపకుండా నమ్ముకంగా మేము దాచిపెడతాము. మీ గురించి ప్రియాలాల్ కి, ఆమె ట్రాన్స్ లేటర్ కి మాత్రమే తెలుస్తుంది. మీయొక్క అన్ని వివరాలు అనగా మీరు, అడ్రస్, ఫోన్ నెంబర్ మొదలైనవి ప్రియాలాల్ జాగ్రత్తగా వుంచుతారు. మరియు ప్రియాలాల్ 10 సంవత్సరాల తరువాత అన్ని రికార్డులు పాడుచేస్తారు.

#### ఉపయోగాలు :-

మీరు దీనిలో పాల్గొనటం ద్వారా డైరెక్టుగా ఏమి ఉపయోగపడదు. కాని మీరు ఇచ్చే మీ పరిస్థితి సమాచారం మీయొక్క కమిటీలో ఎక్కువ పద్ధతులు కల్పించటం ద్వారా ఉపయోగపడుతుంది. మీరు ఎలాటి ఖర్చు కాని డబ్బులు కాని ఇవ్వవలసినదే. ఈ సర్వేలో పాల్గొనడానికి ప్రయోజన ఖర్చులు మరియు మీ సమయం కేటాయించినందుకు మీకు రూ॥ 60/- ఇవ్వబడుతుంది.

**Part - II****ధృవీకరణపత్రము**

నేను ఈ సమాచారాన్ని చదివాను మరియు ఈ అవకాశంతో నన్ను ప్రశ్నలు అడగవచ్చు మరియు నాకు నచ్చకపోతే నేను సమాధానం ఇవ్వనవసరంలేదు మరియు నేను అడగకుండా అక్కడనుంచి వెళ్ళిపోవచ్చును. నా వివరాలు ఒక అంకె కోడ్తో వుంటుంది. ఈ సర్వే నిర్వహించినవాళ్ళు లేక ట్రాన్స్‌లేటర్ లేక సూపర్‌వైజర్ ఈ ఇంటర్‌వ్యూని 10 సంవత్సరాల తరువాత మొత్తం పొందుచేస్తారు. నాకు తెలిసిన విధంగానే ఈ సమాచారాన్ని చాలా రహస్యంగా వుంచాలి. కాని కొన్ని అవంతరాలు వచ్చినప్పుడు తప్ప నా కూడా తెలిసిన కొన్ని సమస్యలు చెప్పటానికి నేను ఒప్పకొని ఈ సమాచారం అందిస్తున్నాను.

**If Literate :**

సంతకం(Participant) :

తేది :

మీ పేరు (Captials) :

సంతకం (Researchers) :

తేది :

మీ పేరు (Captials) :

ఈ అంగీకారపత్రాన్ని చదివి, వివరించి చెప్పినాను, దీనికి వారు సమాధానాలను చెప్పడానికి ఒప్పుకున్నారు. విముఖత / అంగీకారము

**Illiterate :**

నేను ఇచ్చిన ప్రశ్నలకు ఈ సమాచారం ఇచ్చిన వారు చాలా మృదువుగా నాకు సమాధానాలు చేప్పారు. ఖచ్చితంగా వాళ్ళ సమాధానాలు ఇష్టపూర్వకంగా ఇవ్వడం జరిగింది.

సంతకం :

మీ పేరు పూర్తిగా (పెద్ద అక్షరలతో) :

తేది :

**Part - III**

**సంప్రదించవలసిన చిరునామా**

ఈ సర్వే గురించి మీకు ఏలాంటి సందేహాలు, ప్రశ్నలు ఉన్న ఎటువంటి సహాయం కావాలన్నా దయచేసి ప్రియాలాల్ గారిని గాని అమె ట్రాన్స్ లేటర్ను గాని అడుగవచ్చు. మరిన్ని వివరాలకు ఈ క్రింది అడ్రస్సుకు సంప్రదించవచ్చు

**Address :**

**VASAVYA MAHILA MANDALI (VMM)**

BENZ CIRCLE,

VIJAYAWADA - 520 010. A.P.

Tel : 91+866-2470966 / 2473056 /2472934

**లేదా**

**St. Antony's College**

62, Woodstock Road, Oxford, OX2 65F, ENGLAND.

Tel : 44 (O) 1865 284700,

44 (O) 1865 554465

E-mail : priya.lall@sait.oxacut

## Appendix 8: Adverse Events Form

### Adverse Event Form

Date of Incident:

Date reported to Dr. Operario:

Participant ID no:

Details of Incident:

Resolution:

Referrals provided (if necessary):

Staff in VMM contacted by Researcher: Yes / No (By participant? Yes / No )

If Contacted by Researcher: Name and Address of member of staff at VMM:

Name of Researcher (Block Capitals): \_\_\_\_\_

Signed (Researcher): \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix 9:** Coverage of HIV testing by background characteristics: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to background characteristics (unweighted), India 2005-06

Coverage of HIV testing	Testing-percentages					Total	Number
	Blood tested	Not present	Refused	Other			
<b>Age</b>							
15-19	85.3	1.2	6.5	19.7	100	11844	
20-24	85.2	1.2	6.6	19	100	11260	
25-29	84.9	1.1	6.2	19.4	100	10386	
30-34	86.6	1.1	5.3	14.9	100	8918	
35-39	87	1	5.8	11.8	100	7947	
40-44	86.3	1.1	6.5	9.3	100	6466	
45-49	87.7	0.9	6.3	5.7	100	4704	
<b>Residence</b>							
Urban	83.3	1.5	8.2	7	100	30913	
Rural	88.6	0.7	4.1	6.6	100	30612	
<b>Education</b>							
No education	87.8	1.2	6.6	4.4	100	19012	
Primary	87.1	0.9	4.4	7.6	100	8563	
Secondary	85.2	1	5.3	8.5	100	27077	
Higher	82.1	1.6	10.9	5.4	100	6866	
<b>Wealth Index</b>							
Poorest	89.5	1.2	5.8	3.5	100	5912	
Poorer	87.2	0.9	5.2	6.8	100	8794	
Middle	87.1	0.8	4.3	7.9	100	12665	
Richer	85.8	1.1	4.8	8.3	100	15687	
Richest	83.5	1.5	9.3	5.8	100	18467	
<b>Marital status</b>							
Never married	82.2	1.4	6.7	9.7	100	15146	
Currently married	87.1	1	6	5.9	100	43102	
Married, but Gauna not performed	92	0.4	6.7	0.9	100	225	
Widowed	87.4	1.4	5.8	5.3	100	2023	
Divorced	79.2	0.8	3.5	16.6	100	259	
Separated	90.8	1	6	2.2	100	585	
Deserted	82.7	1.1	8.6	7.6	100	185	

**Appendix 10:** Coverage of HIV testing by state: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to state (unweighted), India 2005-06.

Coverage of HIV testing	Testing-percentages				Total	Number
	Blood taken	Not present	Refused	Other		
<b>India</b>	<b>85.9</b>	<b>1.1</b>	<b>6.2</b>	<b>0.2</b>	<b>100</b>	<b>61525</b>
<b>North</b>						
Delhi	69.9	6.4	22.6	1.1	100	645
Haryana	96.2	0	3.6	0.2	100	500
Himachal Pradesh	92.8	0.4	5.8	1.1	100	568
Jammu and Kashmir	93.8	0.7	5.4	0.2	100	592
Punjab	95.2	0.6	4	0.1	100	672
Rajasthan	98.1	0.3	1.5	0	100	646
Uttaranchal	95.1	0.2	4	0.8	100	531
<b>Central</b>						
Chhattisgarh	98.1	0	1.5	0.3	100	591
Madhya Pradesh	99.3	0.1	0.6	0	100	1120
Uttar Pradesh	88.9	1.6	9.1	0.4	100	12154
<b>East</b>						
Bihar	92.6	0.5	6.7	0.2	100	611
Jharkhand	89.9	1.2	7.5	1.4	100	517
Orissa	96.6	0.3	3.1	0.1	100	784
West Bengal	92.1	0.3	7.4	0.3	100	1194
<b>Northeast</b>						
Arunachal Pradesh	99	0	1	0	100	308
Assam	91.5	1.4	6.2	0.9	100	659
Manipur	95.7	1.7	2.2	0.4	100	4510
Meghalaya	64	0.3	32.9	2.8	100	353
Mizoram	97.4	0	2.6	0	100	344
Nagaland	0	0	0	100	100	3896
Sikkim	91	0	7.7	1.3	100	390
Tripura	98	0	0.6	1.4	100	346
<b>West</b>						
Goa	94.9	0.2	4.6	0.3	100	608
Gujarat	94.9	0.7	4.1	0.3	100	611
Maharashtra	88.4	1.4	9.8	0.5	100	8874
<b>South</b>						
Andhra Pradesh	91.3	1.8	6.4	0.5	100	7123
Karnataka	92.4	1.1	6.3	0.2	100	5807
Kerala	97.2	0.3	2.4	0.1	100	677
Tamil Nadu	96.2	0.3	2.5	1	100	5894

**Appendix 11:** Coverage of HIV testing by religion: percent distribution of women age 15-49 eligible for HIV testing by testing status, according to religion (unweighted), India 2005-06

Religion	Testing-percentages				Total	Number
	Blood taken	Not present	Refused	Other		
Hindu	91.4	1.1	5.8	1.7	100	44156
Muslim	84.8	1.8	10.6	2.9	100	8453
Christian	46.1	0.4	3.4	50.1	100	6301
Sikh	93.8	1	5.0	0.2	100	598
Buddhist/Neo-Buddhist	93.9	0.8	4.6	0.7	100	994
Jain	83.1	1.7	14.3	1	100	301
Jewish	100	0	0	0	100	10
Parsi/Zoroastrian	100	0	0	0	100	1
No religion	84.6	0	15.4	0	100	13
Donyi polo	100	0	0	0	100	61
Other	92	1.2	5.6	1.2	100	575

**Appendix 12:** Married couples' sero-status and their area of residence (weighted) (n=27810)

Area of residence	Couple's sero-status (men)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
Rural	99.4	0.28	0.04	0.08
Urban	99.6	0.4	0.14	0.12

**Appendix 13:** Female participants' sero-status and prevalence by state (weighted)

State	Female participant's sero-status		Prevalence	Number
	HIV-negative (%)	HIV-positive (%)		
<b>India</b>			<b>0.22</b>	<b>52850</b>
<b>North</b>				
Delhi	1.32	1.77	0.29	696
Haryana	1.94	0	0	1022
Himachal Pradesh	0.63	0.88	0.3	332
Jammu and Kashmir	1.04	0.88	0.18	548
Punjab	2.6	0	0	1371
Rajasthan	5.23	3.5	0.14	2764
Uttaranchal	0.8	0	0	420
<b>Central</b>				
Chhattisgarh	2.04	0.88	0.09	1075
Madhya Pradesh	5.91	4.42	0.16	3120
Uttar Pradesh	15.24	3.54	0.05	8042
<b>East</b>				
Bihar	7.14	0	0	3766
Jharkhand	2.58	0	0	1363
Orissa	4	1.77	0.09	2113
West Bengal	8.63	0	0	4552
<b>Northeast</b>				
Arunachal Pradesh	0.11	0	0	59
Assam	2.69	3.54	0.28	1424
Manipur	0.22	0.88	0.86	116
Meghalaya	0.24	0	0	128
Mizoram	0.1	0	0	52
Sikkim	0.06	0	0	34
Tripura	0.41	0	0	217
<b>West</b>				
Goa	0.15	0	0	80
Gujarat	4.76	3.54	0.16	2514
Maharashtra	9.37	21.24	0.48	4966
<b>South</b>				
Andhra Pradesh	7.8	27.43	0.75	4145
Karnataka	5.84	15.04	0.55	3097
Kerala	3.19	0	0	1680
Tamil Nadu	5.96	10.62	0.38	3154

**Appendix 14: Male participants' sero-status and prevalence by state (weighted)**

State	Male participant's sero-status		Prevalence	Number
	HIV-negative (%)	HIV-positive (%)		
<b>India</b>			<b>0.4</b>	<b>50093</b>
<b>North</b>				
Delhi	1	0	0	680
Haryana	3	3	0.2	1028
Himachal Pradesh	1	1	0.4	268
Jammu and Kashmir	1	1	0.4	491
Punjab	3	3	0.4	1462
Rajasthan	5	0	0	2641
Uttaranchal	1	0	0	374
<b>Central</b>				
Chhattisgarh	2	0	0	1150
Madhya Pradesh	7	6	3	3428
Uttar Pradesh	15	4	0.1	7458
<b>East</b>				
Bihar	6	0	0	2927
Jharkhand	3	2	0.3	1309
Orissa	4	2	0.2	1897
West Bengal	9	8	0.3	4266
<b>Northeast</b>				
Arunachal Pradesh	0.14	0	0	69
Assam	3	2	0.2	1356
Manipur	0.2	1	1.9	104
Meghalaya	0.23	0	0	113
Mizoram	0.1	0	0	49
Sikkim	0.7	0	0	37
Tripura	0.42	0	0	212
<b>West</b>				
Goa	0.15	1	1.3	75
Gujarat	5	3	0.2	2432
Maharashtra	10	21	0.8	4885
<b>South</b>				
Andhra Pradesh	8	27	1.2	4069
Karnataka	6	13	0.8	2904
Kerala	3	0	0	1451
Tamil Nadu	6	4	0.3	2958

**Appendix 15:** Couple's sero-status by state (weighted) (n= 27810)

State	Couple's sero-status (women and men)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
<b>North</b>				
Delhi	99.3	0	0.7	0
Haryana	99.7	0.3	0	0
Himachal Pradesh	98.7	0.7	0.7	0
Jammu and Kashmir	99	0.5	0	0.5
Punjab	99.4	0.6	0	0
Rajasthan	99.7	0	0.3	0
Uttaranchal	100	0	0	0
<b>Central</b>				
Chhattisgarh	100	0	0	0
Madhya Pradesh	99.6	0.4	0	0
Uttar Pradesh	99.8	0.1	0.1	0
<b>East</b>				
Bihar	100	0	0	0
Jharkhand	100	0	0	0
Orissa	99.8	0	0.2	0
West Bengal	99.4	0.6	0	0
<b>Northeast</b>				
Arunachal Pradesh	100	0	0	0
Assam	99.6	0	0	0.4
Manipur	100	0	0	0
Meghalaya	100	0	0	0
Mizoram	100	0	0	0
Sikkim	100	0	0	0
Tripura	100	0	0	0
<b>West</b>				
Goa	100	0	0	0
Gujarat	100	0	0	0
Maharashtra	99	0.6	0.1	0.3
<b>South</b>				
Andhra Pradesh	98.6	0.8	0.1	0.4
Karnataka	98.7	0.8	0.1	0.3
Kerala	100	0	0	0
Tamil Nadu	99.5	0.3	0.1	0.1
<b>Total</b>	<b>99.5</b>	<b>0.5</b>	<b>0.1</b>	<b>0.2</b>

**Appendix 16:** Multiple measurements of agricultural work and female participants' sero-status (weighted)

(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of agricultural work	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<u>Respondent works for family, others, self</u>				
For family member	9907	43	23	34
For someone else	9487	42	36	53
Self-employed	3325	15	9	13
<b>Total</b>	<b>22719</b>	<b>100</b>	<b>68</b>	<b>100</b>
<u>Respondent works at home or away*</u>				
At home	4884	22	8	12
Away	17821	78	59	88
<b>Total</b>	<b>22705</b>	<b>100</b>	<b>67</b>	<b>100</b>
<u>Respondent employed all year/seasonal</u>				
All year	1308	61	41	62
Seasonal	7792	34	20	30
Occasional	1107	5	5	8
<b>Total</b>	<b>10207</b>	<b>100</b>	<b>66</b>	<b>100</b>
<u>Respondent's type of earnings for work***</u>				
Not paid	4963	22	2	3
Cash only	12646	56	53	79
Cash and kind	2706	12	11	16
In kind only	2403	10	1	2
<b>Total</b>	<b>22718</b>	<b>100</b>	<b>67</b>	<b>100</b>

#### Appendix 17: Men's sero-status by marital status (weighted)

Marital status	Prevalence	Male participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
Never married	<b>0.2</b>	16816	34	28	16
Married	<b>0.4</b>	32318	65	141	80
Widowed	<b>0.2</b>	450	1	1	1
Divorced	<b>1.4</b>	71	0.1	1	1
Not living together	<b>2.3</b>	260	1	6	3
<b>Total</b>	<b>0.4</b>	<b>49915</b>	<b>100</b>	<b>177</b>	<b>100</b>

#### Appendix 18: Duration of female respondents' marriage in years and their sero-status (weighted)

Duration of marriage (years)	Prevalence	Female participants' sero-status			
		HIV-negative		HIV-positive	
		Count	%	Count	%
Never married	<b>0.04</b>	10743	20	4	3
0-4	<b>0.2</b>	7270	14	16	14
5-9	<b>0.2</b>	8155	15	17	15
10-14	<b>0.4</b>	7258	14	29	25
15-19	<b>0.4</b>	6858	13	28	24
20-24	<b>0.2</b>	5802	11	12	10
25-29	<b>0.2</b>	4250	8	7	6
30 or more	<b>0.1</b>	2403	5	3	3
<b>Total</b>	<b>0.2</b>	52739	100	116	100

**Appendix 19:** Multiple measures of ‘controlling behaviour’ and female participants’ sero-status (weighted)  
 (\*\*\*) <.005, (\*\*)<.01 and (\*)<.05)

Multiple measures of controlling behaviour	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<u>Husband jealous if talking with other men</u>				
Does not happen	22911	74	61	68
Does happen	7761	25	28	31
Don't know	144	0.47	1	1.22
<b>Total</b>	<b>30816</b>	<b>100</b>	<b>90</b>	<b>100</b>
<u>Husband accuses her of unfaithfulness***</u>				
Does not happen	28300	92	69	77
Does happen	2446	8	20	22
Don't know	67	0.22	11	1.22
<b>Total</b>	<b>30813</b>	<b>100</b>	<b>90</b>	<b>100</b>
<u>Does not permit her to meet her Girlfriends</u>				
Does not happen	25970	84	72	81
Does happen	4762	15	16	18
Don't know	84	0.27	1	1
<b>Total</b>	<b>30816</b>	<b>100</b>	<b>89</b>	<b>100</b>
<u>Husband tries to limit her contact with family**</u>				
Does not happen	27734	90	72	81
Does happen	3006	10	16	18
Don't know	71	0.23	1	1
<b>Total</b>	<b>30811</b>	<b>100</b>	<b>89</b>	<b>100</b>
<u>Husband insists on knowing where she is*</u>				
Does not happen	27178	88	70	79
Does happen	3515	11	18	20
Don't know	119	0	1	1
<b>Total</b>	<b>30812</b>	<b>100</b>	<b>89</b>	<b>100</b>
<u>Husband doesn't trust her with money</u>				
Does not happen	25358	82	71	79
Does happen	5328	17	18	20
Don't know	124	0.4	1	1
<b>Total</b>	<b>30810</b>	<b>100</b>	<b>90</b>	<b>100</b>

**Appendix 20:** Multiple measures of ‘controlling behaviour’ and married female participants’ sero-status within their relations (weighted)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measures on ‘controlling behaviour’	Couple's sero-status (women)				Total
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)	
	%	%	%	%	
<b>Ever experienced any controlling behaviour</b>	<b>40</b>	<b>39</b>	<b>8</b>	<b>30</b>	<b>21363</b>
Husband jealous if talking with other men	24	26	8	21	21353
Husband accuses her of unfaithfulness***	7	19	7	11	21353
Does not permit her to meet her girlfriends	15	8	7	7	21354
Husband tries to limit her contact with family**	9	19	0	4	21348
Husband insists on knowing where she is	11	16	0	11	21347
Husband doesn't trust her with money	17	16	0	4	21348

**Appendix 21:** Multiple measures of attitudes towards domestic violence and female participants' sero-status (weighted)  
 (\*\*< .005, \*\*< .01 and \*< .05)

Multiple measures on attitudes towards domestic violence	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Wife beating justified if she goes out without telling him</u></b>				
Does not agree	36715	70	74	65
Agrees	15421	29	39	34
Don't know	598	1	1	1
Total	52734	100	114	100
<b><u>Wife beating justified if she neglects the children***</u></b>				
Does not agree	33836	64	55	48
Agrees	18325	35	58	51
Don't know	568	1	1	1
Total	52729	100	114	100
<b><u>Wife beating justified if she argues with him</u></b>				
Does not agree	35942	68	70	61
Agrees	15917	30	43	38
Don't know	868	2	1	1
Total	52727	100	114	100
<b><u>Wife beating justified if she refuses to have sex with him</u></b>				
Does not agree	43080	82	87	76
Agrees	7375	14	23	20
Don't know	2253	4	4	4
Total	52708	100	114	100
<b><u>Wife beating justified if she burns the food**</u></b>				
Does not agree	41251	78	79	69
Agrees	10811	21	36	31
Don't know	655	1	0	0
Total	52717	100	115	100
<b><u>Justifies hitting or beating: wife is unfaithful*</u></b>				
Does not agree	38048	72	69	61
Agrees	13302	25	41	36
Don't know	1368	3	4	4
Total	52718	100	114	100
<b><u>Justifies hitting or beating: wife is disrespectful to in-laws**</u></b>				
Does not agree	30357	58	50	44
Agrees	21527	41	62	54
Don't know	847	2	2	2
Total	52731	100	114	100

**Appendix 22:** Multiple measures of justifications for domestic violence and couple's sero-status (men) (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Justifications for domestic violence	Couple's sero-status (men)				Total
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)	
	%	%	%	%	
Wife beating justified if she goes out without telling him**	23	34	20	38	27809
Wife beating justified if she neglects the children***	27	35	21	52	27809
Wife beating justified if she argues with him	25	32	11	37	27810
Wife beating justified if she refuses to have sex with him	15	14	16	27	27805
Wife beating justified if she burns the food	21	17	16	38	27795
Justifies hitting or beating: wife is unfaithful	23	27	32	27	27798
Justifies hitting or beating: wife is disrespectful to in-law*	35	42	21	55	27798

**Appendix 23:** Multiple measures of justifications for domestic violence and couple's sero-status (women) (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Justifications for domestic violence	Couple's sero-status (women)				Total
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)	
	%	%	%	%	
Wife beating justified if she goes out without telling him	31	31	25	47	27810
Wife beating justified if she neglects the children	36	34	32	57	27805
Wife beating justified if she argues with him	31	36	32	41	27807
Wife beating justified if she refuses to have sex with him	17	16	0	4	21348
Wife beating justified if she burns the food	21	17	16	38	27794
Justifies hitting or beating: wife is unfaithful**	27	34	20	50	27800
Justifies hitting or beating: wife is disrespectful to in-law***	42	58	37	60	27810

**Appendix 24:** Severity of violence experienced from spouse according to sero-status of female respondents (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Severity of violence experienced	Female participants' sero-status			
	HIV-negative		HIV-positive	
	% within HIV-status	Total number	% within HIV-status	Total number
Less severe violence	36	30802	45	88
Severe violence***	13	30800	26	89

**Appendix 25:** Types of injuries incurred by domestic violence and female participants' sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures on injuries incurred by IPV	Female participants' sero-status		Total number
	HIV-negative	HIV-positive	
	%	%	
<b>Any incidences of IPV caused injury***</b>	<b>15</b>	<b>26</b>	<b>30870</b>
Ever had bruises because of husband's actions	37	48	11800
Ever had injury, sprains, dislocations or burns	9	17	11795
Ever had wounds, broken bones, broken teeth or other serious***	7	19	11792
Ever had sever burns***	2	10	11795

**Appendix 26:** When domestic violence first started with spouse according to female participants' sero-status (weighted)

When domestic violence first started (years)	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Before union	83	1	0	0
0	1965	17	11	26
1-4	7487	64	16	38
5-9	1664	14	12	29
10 or more	523	4	3	7
<b>Total</b>	<b>11722</b>	<b>100</b>	<b>42</b>	<b>100</b>

**Appendix 27:** Severity of violence experienced from spouse according to sero-status of couples (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Severity of violence experienced	Couple's sero-status				Total
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)	
	%	%	%	%	
Experienced any less severe violence**	35	51	7	41	21352
Experienced any severe violence	11	21	0	14	21353

**Appendix 28:** female participant's history of sexual violence according to their sero-status (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measures on sexual violence	Female participants' sero-status		Total number
	HIV-negative	HIV-positive	
	%	%	
<b>Experienced any sexual violence***</b>	<b>10</b>	<b>22</b>	<b>30892</b>
Anyone forced respondent to perform sexual acts***	3	11	35856
Spouse ever physically forced sex when not wanted***	10	21	30892
Spouse ever forced other sexual acts when not wanted	5	9	30892

**Appendix 29:** History of sexual violence according to couples' sero-status (weighted)

Spouse ever physically forced sex when not wanted	Couple's sero-status (women)							
	Serocon (Neg)		Serodisc (Male)		Serodisc (Female)		Serocon (Pos)	
	Count	%	Count	%	Count	%	Count	%
Yes	1891	9	12	19	0	0	5	19
No	19360	91	50	81	13	100	22	81
<b>Total</b>	<b>21251</b>	<b>100</b>	<b>62</b>	<b>100</b>	<b>13</b>	<b>100</b>	<b>27</b>	<b>100</b>

**Appendix 30:** Female participants knowledge of the existence of HIV/AIDS according to their sero-status (weighted)

Ever heard of AIDS	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Yes	32621	62	91	79
No	20117	38	24	21
<b>Total</b>	<b>52738</b>	<b>100</b>	<b>115</b>	<b>100</b>

**Appendix 31:** Female participants' knowledge of the ABC method of HIV prevention methods according to their sero-status (weighted)

(\*\*\* <.005, \*\*<.01 and \*<.05)

Knowledge of ABC method of HIV prevention	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Abstinence</u></b>				
Yes	21637	66	63	70
No/ Don't know	10956	34	27	30
Total	32593	100	90	100
<b><u>Limiting sexual partners</u></b>				
Yes	23905	73	60	66
No/ Don't know	8704	27	31	34
Total	32609	100	91	100
<b><u>Use Condoms</u></b>				
Yes	19530	60	53	58
No/ Don't know	13075	40	38	42
Total	32605	100	91	100
<b><u>Count of ABC method</u></b>				
0	5407	17	14	15
1	4531	14	13	14
2	7416	23	28	31
3	15220	47	36	40
Total	32574	100	91	100

**Appendix 32:** Female participants' sero-status and their knowledge of ways to avoid HIV (weighted)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Ways to avoid HIV, spontaneously told by participant	Female participants' sero-status			
	HIV-negative		HIV-positive	
	% within Blood test result	Total number	% within Blood test result	Total number
Abstinence	9	32613	3	91
Use Condoms	22	32612	20	91
Limiting sexual partners	21	32612	14	90
Avoid sex with prostitutes	7	32613	8	90
Avoid sex with homosexuals	0.2	32613	1	91
Avoid blood transfusions	15	32613	13	91
Avoid injections	12	32613	11	91
Avoid kissing	67	32613	68	91
Avoid mosquito bites	67	32613	68	91
Avoid sexual partners with many partners	1	32613	0	91
Avoid sex with intravenous drug users	2	32613	1	91
Avoid sharing razor blades with AIDS patient	3	32613	2	91
Avoid IV drip	1	32613	1	91
Use blood only from relatives	64	32613	62	91
Use only new/sterilized needles	18	32612	14	91
Other responses	2	32613	1	91
<b><u>Knows of ways to avoid HIV</u></b>				
Knows ways	49		55	
Does not know ways	51	32618	45	91

**Appendix 33:** Multiple measures of mobility of married female participants and their sero-status within their partnership (weighted) (N= 27786)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measurements of mobility	Couple's sero-status (women)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
<b><u>Ever moved residence*</u></b>				
Moved Residence	86	83	89	66
Always lived in residence	14	17	11	34
<b><u>Years lived in residence*</u></b>				
Always lived in residence	14	17	11	33
0-9	38	42	26	33
10 or more	48	41	63	33

**Appendix 34:** Multiple measures of mobility of married male participants and their sero-status within their partnership (weighted) (N= 27786)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measurements of mobility	Couple's sero-status (men)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
<b>Ever moved residence***</b>				
Moved Residence	26	40	40	37
Always lived in residence	74	60	60	63
<b>Years lived in residence***</b>				
Always lived in residence	74	60	60	63
0-9	12	13	5	27
10 or more	14	27	350	10

**Appendix 35:** Male participants' previous sexual history and their HIV-status (weighted)

Sexual History	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Never had intercourse	14600	29	20	11
Had sexual intercourse at first union	11713	23	50	28
Had intercourse prior to marriage	23577	48	108	61
<b>Total</b>	<b>49890</b>	<b>100</b>	<b>178</b>	<b>100</b>

**Appendix 36:** The total lifetime number of sexual partners that married women had and their sero-status (weighted)

Total lifetime number of sexual partners	Couple's sero-status (women)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
1	99	91	95	97
2 or more	1	9	5	3

**Appendix 37:** The total lifetime number of sexual partners that married men had and their sero-status (weighted)

Total lifetime number of sexual partners	Couple's sero-status (men)			
	Serocon (Neg)	Serodisc (Male)	Serodisc (Female)	Serocon (Pos)
	%	%	%	%
1	82	78	85	55
2 or more	18	22	15	45

**Appendix 38:** Female and male participants' relationship to their last sexual partner and their sero-status (weighted)

Relationship to last sexual partner	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Spouse	37742	99.8	77	95
Someone other than spouse	86	0.2	4	5
<b>Total</b>	<b>37828</b>	<b>100</b>	<b>81</b>	<b>100</b>

Relationship to last sexual partner	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Spouse	31116	96	134	97
Someone other than spouse	1295	4	4	3
<b>Total</b>	<b>32411</b>	<b>100</b>	<b>138</b>	<b>100</b>

**Appendix 39:** Female participants' recent sexual activity and their sero-status (weighted)

Recent sexual activity	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Never had intercourse	10712	20	4	3
Active in last 4 weeks	29059	55	55	49
Not active in last 4 weeks - postpartum abst.	1429	3	4	3
Not active in last 4 weeks - not postpartum abst.	11497	22	52	45
<b>Total</b>	<b>52697</b>	<b>100</b>	<b>115</b>	<b>100</b>

**Appendix 40:** Male participants' recent sexual activity and their sero-status (weighted)

Recent sexual activity	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Never had intercourse	14600	29	20	11
Active in last 4 weeks	25619	52	114	64
Not active in last 4 weeks	9578	19	43	25
<b>Total</b>	<b>49797</b>	<b>100</b>	<b>177</b>	<b>100</b>

**Appendix 41:** Female and male participants used condom last sexual intercourse and sero-status (weighted)

Last intercourse used condom	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Yes	2310	6	2	2
No	35519	94	79	98
<b>Total</b>	<b>37829</b>	<b>100</b>	<b>81</b>	<b>100</b>

Last intercourse used condom	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
Yes	2841	9	10	7
No	29563	91	128	93
<b>Total</b>	<b>32404</b>	<b>100</b>	<b>138</b>	<b>100</b>

**Appendix 42:** The amount of wives male participants had according to their sero-status (weighted)

Number of wives	Male participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
1	32044	99.2	138	97.2
2 or more	274	0.8	4	2.8
<b>Total</b>	<b>32318</b>	<b>100</b>	<b>142</b>	<b>100</b>

**Appendix 43:** Multiple measures of food consumption and female participants' sero-status

(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of food consumption	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Consumption of milk or curd*</u></b>				
Never	6010	11	7	6
Daily	20965	40	48	42
Weekly	8357	16	27	23
Occasionally	17400	33	33	29
Total	52732	100	115	100
<b><u>Consumption of pulses or beans</u></b>				
Never	476	1	1	1
Daily	27349	52	60	53
Weekly	19681	37	45	39
Occasionally	5224	10	8	7
Total	52730	100	114	100
<b><u>Consumption of dark green leafy veggies</u></b>				
Never	142	0.3	0	0
Daily	33619	64	70	61
Weekly	15387	29	42	37
Occasionally	3569	7	3	3
Total	52717	100	115	100
<b><u>Consumption of fruits*</u></b>				
Never	1739	3	2	2
Daily	6683	13	11	10
Weekly	14303	27	44	38
Occasionally	29959	57	58	50
Total	52684	100	115	100
<b><u>Consumption of eggs**</u></b>				
Never	18196	35	29	25
Daily	1913	4	10	9
Weekly	15082	29	39	34
Occasionally	17530	33	36	32
Total	52721	100	114	100
<b><u>Consumption of fish</u></b>				
Never	19654	37	39	34
Daily	3426	6	2	2
Weekly	11551	22	29	25

Occasionally	18087	34	44	39
Total	52718	100	114	100
<b><u>Consumption of chicken or meat**</u></b>				
Never	18389	35	33	29
Daily	447	1	1	1
Weekly	11468	22	40	35
Occasionally	22413	43	41	36
Total	52717	100	115	100

**Appendix 44:** Multiple measures of gendered barriers to healthcare and female participants' sero-status (weighted)  
 (\*\*< .005, \*\*<.01 and \*<.05)

Multiple measures of gendered barriers to healthcare	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Getting permission to go</u></b>				
No problem	41423	79	87	76
Not a big problem	7843	15	18	16
Big problem	3460	7	9	8
<b><u>Getting money needed for treatment</u></b>				
No problem	32037	61	63	55
Not a big problem	11646	22	25	22
Big problem	9045	17	26	23
<b><u>Distance to health facility</u></b>				
No problem	26374	50	59	52
Not a big problem	13030	25	25	22
Big problem	13326	25	30	26
<b><u>Having to take transport</u></b>				
No problem	28478	54	54	47
Not a big problem	12270	23	35	31
Big problem	11978	23	25	22
<b><u>Not wanting to go alone</u></b>				
No problem	33935	64	69	61
Not a big problem	12792	24	29	25
Big problem	5993	11	16	14
<b><u>Concern no female health provider</u></b>				
No problem	30967	59	66	58
Not a big problem	12005	23	23	20
Big problem	9749	18	25	22
<b><u>Concern no provider</u></b>				
No problem	29642	56	64	56
Not a big problem	11290	21	20	18
Big problem	11793	22	30	26
<b><u>Concern no drugs available</u></b>				
No problem	29717	56	70	61
Not a big problem	11148	21	21	18
Big problem	11865	23	23	20

**Appendix 45:** Multiple measures of female respondents' control over their financial resources and their sero-status (weighted)  
(\*\*\* <.005, \*\*<.01 and \*<.05)

Multiple measures of respondents' control over their finances	Female participants' sero-status			
	HIV-negative		HIV-positive	
	Count	%	Count	%
<b><u>Has money for her own use</u></b>				
Yes	23627	45	57	50
No	29100	55	57	50
Total	52727	100	114	100
<b><u>Who decides how to spend money</u></b>				
Respondent alone	2615	24	8	22
Respondent and husband/partner	6238	57	23	62
Other	2039	19	6	16
Total	10892	100	37	100
<b><u>Final say on deciding what to do with money husband earns</u></b>				
Respondent alone	2556	7	7	9
Respondent and husband/partner	23748	61	48	65
Other	12848	33	19	26
Total	39152	100	74	100
<b><u>Earns more than partner</u></b>				
More than him/About the same	2191	20	6	16
Less than him	8205	75	29	76
Not Applicable	497	5	3	8
Total	10893	100	38	100

**Appendix 46:** Region of India which female HIV-positive participants' lived in and whether they undertook a HIV test (unweighted)

Region of India	Ever been tested for AIDS	
	Yes (count)	No (count)
North/North Eastern States	10	33
Central/Western states	4	53
Southern states	7	84
<b>Total</b>	<b>21</b>	<b>170</b>

**Appendix 47:** Religion of female HIV-infected participants religion and whether they undertook a HIV test (unweighted)

Religion	Ever been tested for AIDS	
	Yes (count)	No (count)
Hindu	14	144
Non-Hindu	7	26
<b>Total</b>	21	170

**Appendix 48:** Household ownership of a BPL card and whether female HIV-infected participants undertook an HIV test (unweighted)

Household ownership of a BPL card	Ever been tested for AIDS	
	Yes (count)	No (count)
Yes	3	57
No	18	104
<b>Total</b>	21	161

**Appendix 49:** Years of coverage by AWC and female HIV-positive respondents' propensity to undertake an HIV test

Years of coverage by AWC	Ever been tested for AIDS	
	Yes (count)	No (count)
0-9	2	40
10-19	14	50
20 or more	3	36
<b>Total</b>	19	126

**Appendix 50:** Multiple measures of female HIV-positive respondents' decision making capabilities and if they have ever been tested (weighted)

(\*\*\* <.005, \*\*<.01 and \*<.05)

<b>Multiple measures of decision making capabilities</b>	<b>Ever been tested for AIDS</b>	
	Yes (count)	No (count)
<b><u>Final say on own health care</u></b>		
Respondent alone	1	29
Other	3	43
Total	4	72
<b><u>Final say on making large household purchases</u></b>		
Respondent alone	1	11
Other	2	60
Total	3	71
<b><u>Final say on making household purchases for daily needs</u></b>		
Respondent alone	2	28
Other	1	44
Total	3	72
<b><u>Final say on visits to family or relatives</u></b>		
Respondent alone	1	12
Other	2	60
Total	3	72

**Appendix 51:** Multiple measures of female HIV-positive respondents freedom of movement and if they have ever been tested (weighted)  
 (\*\*> .005, \*\*>.01 and \*>.05)

<b>Multiple measures of respondents' freedom of movement</b>	<b>Ever been tested for AIDS</b>	
	Yes (count)	No (count)
<b><u>Allowed to go to: market</u></b>		
Alone	7	86
With someone else only	1	21
<b>Total</b>	<b>8</b>	<b>107</b>
<b><u>Allowed to go to: health facility</u></b>		
Alone	7	79
With someone else only	1	28
<b>Total</b>	<b>8</b>	<b>107</b>
<b><u>Allowed to go to: places outside this village/community</u></b>		
Alone	6	72
With someone else only	2	34
<b>Total</b>	<b>8</b>	<b>106</b>

**Appendix 52:** Multiple measures of gendered barriers to healthcare and female HIV-infected propensity to undertake a HIV test (weighted)  
 (\*\*\*) <.005, \*\*<.01 and \*<.05)

Multiple measures of gendered barriers to healthcare	Ever been tested for AIDS	
	Yes (count)	No (count)
<u>Getting permission to go</u>		
No problem	6	81
It is a problem	2	25
<b>Total</b>	<b>8</b>	<b>106</b>
<u>Getting money needed for treatment</u>		
No problem	3	60
It is a problem	5	47
<b>Total</b>	<b>8</b>	<b>107</b>
<u>Distance to health facility</u>		
No problem	5	54
It is a problem	3	52
<b>Total</b>	<b>8</b>	<b>106</b>
<u>Having to take transport</u>		
No problem	6	48
It is a problem	2	59
<b>Total</b>	<b>8</b>	<b>107</b>
<u>Not wanting to go alone</u>		
No problem	5	64
It is a problem	3	42
<b>Total</b>	<b>8</b>	<b>106</b>
<u>Concern no female health provider</u>		
No problem	5	61
It is a problem	3	46
<b>Total</b>	<b>8</b>	<b>107</b>
<u>Concern no provider</u>		
No problem	4	60
It is a problem	4	47
<b>Total</b>	<b>8</b>	<b>107</b>
<u>Concern no drugs available</u>		
No problem	4	66
It is a problem	4	41
<b>Total</b>	<b>8</b>	<b>107</b>

