

Centre for International Health

**Stigma and discrimination of Indian women living with HIV/AIDS:
Perceptions and experiences of women in Mumbai, India**

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**This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University of Technology**

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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signed:

Pamela O'Connor

4th August 2008

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DEDICATION

To the Indian women I met in the community slums,

I dedicate my time and labour with the hope that change may come.

They have my great admiration for their resilience,

despite their difficult and challenging lives.

They deserve the best.

ABSTRACT

Stigma and discrimination are now recognised as major factors in the spread of Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS). To date, research has focused on how to change individual responses to stigma and discrimination without exploring the social and structural dimensions. Complex community and societal dimensions, such as culture, power and difference need to be explored if progress is to be made in coping with stigma and discrimination. India now has HIV/AIDS prevalence figures to rival sub Saharan Africa. The disease has spread from high-risk populations such as intravenous drug users and commercial sex workers into the general population. Married, monogamous, heterosexual women in slum communities are highly vulnerable. Factors such as caste, class, ethnic group, poverty and social expectations present formidable layers of stigma for these women. They have also faced discrimination since before their birth. HIV/AIDS imposes yet another layer of stigma and discrimination upon their shoulders.

The aims of the study were firstly to investigate whether stigma and discrimination existed for these women by documenting and analysing literature on the individual, societal and cultural situation of Indian women living with HIV/AIDS (IWLWHAs). Secondly, the study aimed to identify, evaluate and explore the psychosocial needs and coping strategies of IWLHAs, to determine the barriers to accessing health services, and describe community perceptions as they were experienced by the participants.

This qualitative research study examined the multiple layers of stigma and discrimination experienced by women infected and affected by HIV/AIDS in a low socio-economic area of Mumbai, India. This was achieved by interviewing women who were benefiting from a home-based service – *Positive Living – An integrated home-based care programme for people living with HIV/AIDS* under the auspices of the KJ Somaiya Hospital in Mumbai. This programme provides a nutrition and home-based service to the nearby community slums. The conceptual framework used for this study was developed to evaluate the effects of natural disasters such as

tsunamis, floods and earthquakes. HIV/AIDS is no less of a tragedy for individuals, families and communities. Within this framework, human capacity or the ability of individuals to cope is linked to social ecology - the relationship between individuals and their community. This dimension overlaps with culture and values. Three other dimensions affect humans – economic status, the environment and living conditions, and physical health.

I have developed this framework further to examine threats and strengths which arise from these dimensions, and which affect human resilience. An exploratory case study was considered the most suitable approach to explore these areas, as it permits more sensitivity and richer data, and enhances rigour. In-depth interviews of 45 women in three different age groups, home visits and observations, focus group discussion, key informants, narratives, vignettes and photographs were supported by documentary data collection in triangulation of the data. A reflective journal recorded observations and perceptions in the field during three months in India.

Results from the combined data indicated that IWLWHAs experienced discrimination in their families, communities and health care settings. Fear of future discrimination ensured secrecy which, in turn, prevented them accessing community services which would provide emotional and physical support. A range of reactions was demonstrated by the affected women, half of whom were also infected which added to their burden. Women who could not disclose their condition were extremely isolated, lacked family and community support, feared the future and felt hopeless.

Despite their appalling living conditions of poverty, overcrowding, prevalence of disease and pollution, the women displayed a sense of pride, dignity and resilience. Culturally appropriate strategies are necessary to address the lack of education and awareness as only two of the 45 women had any knowledge of HIV/AIDS before their own diagnosis which often followed their husbands' positive status. In addition, the social and cultural dimensions which affect these women have to be explored and examined in order to strengthen the 'shock absorbers' of the family. The community health workers and co-ordinator of the home-based service were vital in providing emotional support and health information to the women. Finally, no change is possible unless men take responsibility for their sexual mores. Policy

makers and programmes have to look further for strategies which would engage men in the process to change their attitudes and thus protect vulnerable women and children.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AusAID	Australian Agency for International Development
ANC	Antenatal Clinic
ART	Anti Retroviral Therapy
CHARCA	Co-ordinated HIV/AIDS and STD Response through Capacity Building and Awareness
CIDA	Canadian International Development Agency
CSW	Commercial Sex Worker
DOTS	Directly Observed Treatment, Short Course
FGD	Focus Group Discussion
GIPA	Greater Involvement of People Living with AIDS
HIV	Human Immunodeficiency Virus
ICHAP	India Canada Collaboration HIV/AIDS Project
IDU	Intravenous Drug User
ILO	International Labor Organisation
INP+	Indian Network for People Living with AIDS
IWLWHA	Indian Women Living With HIV/AIDS
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Policy
NGO	Non-Government Organisation
PLWHA	People Living With HIV/AIDS
PPTCT	Prevention of Parent to Child Transmission
SACS	State AIDS Control Society
SAHAS	Somaiya Action for HIV/AIDS Support
SIDA	Swedish International Development Cooperation
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Program

UNICEF	United Nations International Children’s Education Fund
UNIFEM	United Nations Fund for Women
USAID	United States Agency for International Development
VCCTC	Voluntary Confidential Counselling and Testing Centre
WHO	World Health Organization

LIST OF CONFERENCE AND POSTER PRESENTATIONS

- O'Connor, P (2006, July 3).
From woe to go in my field research in India. Paper presented at the 2006 Centre for International Health Research Colloquium, Curtin University, Perth Awarded "Best Presentation"

- O'Connor, P (2006, August 3).
My research in India: Experiences of women with HIV/AIDS in Mumbai, India. Paper presented at Women's Healthworks, Perth.

- O'Connor, P (2006, September 12).
Field research in India. Paper presented to a meeting of psychologists, Perth.

- O'Connor, P (2006, September 25).
Stigma and discrimination in India: Women living with HIV/AIDS in Mumbai, India. Paper presented at 37th Public Health Association of Australia Annual Conference, Sydney, New South Wales.

- O'Connor, P (2006, November 6).
Stigma and discrimination of women with HIV/AIDS: Perceptions and experiences of women in Mumbai, India. Poster presented at Mark Liveris Health Sciences Research Student Seminar, Curtin University, Perth.

- O'Connor, P (2006, November 16).
Stigma and discrimination in Mumbai, India. Poster presented at 2nd WA Transcultural Mental Health Conference, Perth.

- O'Connor, P (2007, May 15).
Facing up to stigma and discrimination Paper presented at Psychosocial Perspectives on HIV/AIDS – Emerging Themes Conference, Melbourne.

- O'Connor, P (2007, October 8).

Facing up to stigma and discrimination. Paper presented at, Centre for International Health, Doctoral Forum, Curtin University, Perth.

- O'Connor, P (2008, July 7).

Psycho-social and cultural dimensions in stigma and discrimination research
Paper presented at the 2008 Population Health Congress 2008, Brisbane.

GLOSSARY OF INDIAN TERMS

Amla	Gooseberry
Alta	Red dye used for staining feet
Ashram	Spiritual community or retreat
Bhakti	Faith, surrendering to the gods
Bindi	Mark on forehead, often dot shaped, worn by married Hindu women
Brahmin	Member of the priest/scholar caste, the highest Hindu caste
Cabin	Office
Chai	Spiced tea made with milk
Chappals	Sandals, thongs (Aus)
Chudhyaan	Bangles
Dalit	Preferred name for lowest caste, formerly “untouchables”
Dharma	Word used by Hindus and Buddhists to describe their moral codes
Dobi wallah	Man who does the washing
Dobi ghat	Public place where washing is done
Dowry	Money and goods given by bride’s parents on marriage to son-in-law’s family; the practice is now outlawed, but still exists
Dravidian	Cultures and languages of the south
Dupatta	Long scarf often worn with salwar-kameez
Eve-teasing	Sexual harassment of women and girls
Firangi	Foreigner
Ganesh	Hindu god of good fortune
Guru	Holy teacher
Haldi kum-kum	A celebration of women held on festival days
Gujarat	A state in Western India
Jain	Follower of religion called Jainism
Karma	Hindu, Buddhist and Sikh principle of retributive justice for past deeds
Kacha katori	Temporary dwelling or household item
Kholi	Dwelling or room

Kshatriya	Hindu warrior and ruler caste
Kum-kum	Red powder used to make the round mark denoting a married Hindu woman
Kurta pajama	Long shirt and pants worn by men
One Lakh	Rupees 100,000
Lathi	Truncheon or stick
Maidan	Open area, parade ground
Mangalsutra	Wedding necklace worn by Hindu women that carries religious significance and is regarded as sacred
Mehndi	Henna, ornate designs on women's hands and feet for festivals, marriages and occasions
Memsahib	Madam
Nagnika	Engagement
Namaz	Muslim prayer
Nirvana	Buddhist ultimate release from the cycle of existence
Panchayats	Village council of five people (Panch=5)
Parsis	Follower of the Zoroastrian faith
Partition	The division of British India into India and Pakistan in 1947
Patrivata	Devoted wife
Peon	Lowest grade clerical worker
Puja	Religious offering, prayers
Purdah	Custom of keeping women in seclusion
Rajput	Hindu warrior caste, former rulers of north-west India
Rangoli	Elaborate flower patterns on floor made of chalk, rice-paste
Roza	Practice of fasting among Muslims
Saree	Traditional woman's attire that is popular in many parts of India
Salwar kameez	Women's traditional dress (long tunic over pants) popular in many parts of India
Sati	The act of immolation, or a widow sacrificing herself
Scheduled caste	Dalits
Shastric	<i>Shastras</i> are the sacred Hindu law books
Sikh	A religion in India where the men wear turbans
Sindoor	Red powder Hindu women put in their hair parting

Tambula	A type of musical instrument
Tikka	Mark Hindus put on their foreheads
Untouchables	Now referred to as 'dalits'
Vedas	Collection of scriptures composed in 2 nd millennium BC
Veni	Braided hair or a garland of flowers
Wallah	A man, often combined with occupation as in Carpet wallah
Zenana	Area in an upper-class home where women are seclude

PROLOGUE

What is it that I want? I am comfortable in my job. I love where I work, and the challenges it presents. My children are ‘well settled’ as the Indians say, and I earn enough to travel and socialise. I am in my sixties, and supposed to be contemplating retirement in a few years. What am I searching for? I dig out my favourite poem marked by my grandmother in 1892.

I am a part of all I have met;
Yet all experience is an arch where thro'
Gleams that untravell'd world, whose margin fades
For ever and for ever when I move

How dull it is to pause, to make an end,
To rust unburnish'd, not to shine in use!
As tho' to breathe were life.....” (Tennyson, 1892, p. 51)

It describes exactly how I feel, but does not give me answers. I take myself to the sea, and sit in the sand, listening to the sea, and asking for guidance. I have returned to university studies – anthropology, this time. I think that, given the opportunity in my youth, I could have enjoyed the life that I imagine of those early anthropologists and Victorian women travellers, who visited exotic places in their heavy long dresses, noting botanical specimens, or the ways of the indigenous people.

Out of the blue, my lecturer gives me the opportunity to do my PhD, and travel to India. What a powerful combination! I have already visited India twice: once briefly on the way to England, with my husband. The second time was a fantastic journey with two women. “The three Mas”, the Indians called us, as we floated from one exotic location to another, staying in fantastic hotels and palaces, with meals you could die for. This was a pilgrimage for my friend to revisit where she had gone to

school in the Nilgiri hills, in Southern India, after being ousted from Singapore during World War II.

But what would I study? My lecturer was looking for someone to evaluate a community service in India. I start reading about Indian women and HIV/AIDS, and it leaps out at me. Stigma and discrimination are as old as the hills and a recurring source of indignation for me. The interplay of power, and the powerless, is a continuing theme. It propels me into the work that I do every day with women in our society. I think, like I have always thought: “Just begin, and see where it takes you.....”

At times I feel overwhelmed - more than that – a feeling of inadequacy beyond words. How could I think that I could do this? As I read, the stigma of Indian women affects me, and I know that is what I can do. But will my study be useful – it has to go beyond describing what we all know. Indian women may learn and have coping strategies beyond ours. I like the idea of looking at the societal and community factors.

My supervisor puts me at ease, which is very important to me. She has such an incisive mind which steadies me and even if I have to be taken on baby steps, I know I can take off. And there is the joy of research, leading me into other reading. We went to the Writers Festival, and heard Greg Roberts talking about his book “Shantaram”, and his experiences in India. I bumped into Peggy Holroyde, an Indiophile with a fantastic store of knowledge of the culture, so I will get in touch with her later. Today is a start, and a way of getting into the day of reading, writing and getting my head around the first part. I think I can write the abstract now – another leap ahead! So here goes.....

CHAPTER 1

INTRODUCTION AND OVERVIEW

“The greatest single international failure in the response to HIV/AIDS, is the failure to intervene, dramatically, on behalf of women.” (Lewis, UN Envoy on HIV/AIDS in Africa, 2005, p. 3).

1.0 Introduction to the chapter

This thesis examines, discusses and analyses stigma and discrimination, and its relationship to Indian women, living in community slums in Mumbai, India. The study is one of the few qualitative studies which examine the complex factors underpinning stigma and discrimination of lower socio-economic status Indian women, infected or affected by HIV/AIDS. The findings provide valuable data on the perceptions and experiences of women, within their families and community, and the presence of stigma and discrimination. The thesis reports the threats and strengths which affect women’s resilience. The first chapter introduces the thesis, by providing the background and rationale for the study, explains the conceptual and theoretical framework, the aims, objectives and significance, and finally, gives an overview of the study, chapter by chapter.

1.1 Background to the study

1.1.1 The personal and professional background of the researcher

My interest in the area of stigma and discrimination evolves from a lifelong interest in the inequalities of human systems, and man’s inhumanity to man. I have a working history of over 50 years. Initially, the early training of nursing and midwifery in Perth gave me a basic knowledge of the physical and biomedical self. I was always interested in the mind-body connection, but nursing at that time was focused only on the physical dimension. I travelled to Europe, and spent six years working and living in southern Africa, where I was able to experience the poverty in the country.

On my return to Perth, I studied psychology and counselling. I found psychology to be very focused on behaviour and quantitative methods, and there was little opportunity for qualitative research at that time. My interest in the unconscious mind resulted in a postgraduate diploma in Clinical Hypnosis. After some experience in a home-based community service for veterans, I set up the first dementia-specific home respite service in Australia, training and supporting 30 home care workers (Kingsley and O'Connor, 1991).

I then set up a counselling service in a women's health centre, where I have worked for eleven years. I then obtained a Masters in Philosophy in the field of women's studies. Women's health centres address women's issues from a psycho-social model of health, acknowledging socio-economic and cultural influences on individuals. For example, media, culture and society are complex influences on the formation of female body esteem and body image. Counselling, for me, consists of never-ending circles composed of a person's personality, background, culture and socio-economic circumstances.

Recently, I have studied in the areas of anthropology, development and indigenous issues. This blend of different disciplines leads to a rich theoretical and experiential context embodying cultural, social, psychological and developmental domains. Gender issues, particularly in the areas of power and discrimination, are the factors which have motivated me to conduct this research. My experience as a woman is both useful and a potential source of bias; however, every effort has been made to maintain standards of objectivity and faithful reportage as (Creswell, 1994) suggests. A part of the process of research is the effect on the researcher, and this is explored in my reflective diary, in Chapter 13.

By examining the social, cultural and other influences inherent in the Indian situation, we may be able to learn strategies to combat stigma and discrimination, both in India and Australia. In Chapter 3, I have discussed the existence of stigma and discrimination, globally, in areas such as mental health and HIV/AIDS. Australia is no exception. Despite laws related to racism and the rights of indigenous people, and people from culturally and linguistically diverse backgrounds, there are examples of stigmatising a group or a person. I have purposely used the first person

singular in the analysis, in agreement with Berg and Pearson, (2004), who acknowledge the presence of the researcher in qualitative research, unlike some disciplines where the researcher's voice is discouraged.

1.1.2 HIV/AIDS in the world and India

The number of people living with HIV/AIDS in the world was estimated at 33.2 million people in 2007, 15.4 million being women and 2.5 million children (UNAIDS, 2007). Previously, the figures were greater, especially for India. The reduction in numbers is attributed not to a lowering of infections, but to better survival rates, and more accurate data collection methods (UNAIDS/WHO, 2007).

India's figures have also been revised downwards to 2.45 million people living with HIV/AIDS, because of more accurate data collection methods (World Bank, 2007). The epidemic in India is highly heterogenous and concentrated in six states, of which Maharashtra is one. Until now, the epidemic has been concentrated in high-risk populations such as men who have sex with men (MSM), injecting drug users (IDU) and commercial sex workers (CSW). Low use of condoms and safe sex, migrant and highly mobile populations, the low status of women, and stigma and discrimination are additional factors in the spread of HIV/AIDS (World Bank, 2007). These factors, which make India very vulnerable to the epidemic, are discussed in Chapter 2.

Three of the most disturbing facts about the existence of HIV/AIDS are, firstly, that an increase in the prevalence rate of merely 0.1% in a country like India would increase the number of people living with HIV/AIDS (PLWHA) by over half a million people (World Bank, 2007). Secondly, the incidence amongst married monogamous women is also growing (D'Cruz, 2004). This denotes the changing face of the epidemic, as it moves into the general population. Thirdly, it is recognised that stigma is driving the third phase of the HIV pandemic. The fear of stigma prevents people from accessing services, and there is a lack of treatment and care, both in the community and health care settings (Mawar, Sahay, Pandit and Mahajan, 2005). Despite all the efforts to curb the epidemic, it is reported that more adult women than ever before are living with HIV/AIDS. Between 2004 and 2006, the increase of one million raised the number to 17.7 million women in the world. In sub-Saharan Africa, 60% of the people infected are women, and in India, a large

proportion of women have acquired the disease through their husbands (UNAIDS, 2006a).

1.1.3 Stigma and discrimination and HIV/AIDS

Stigma and discrimination in association with HIV/AIDS are well documented. These areas have been examined from an individual, and psychological point of view, but not from a social perspective until recently. Factors such as caste, ethnic group, poverty, and social expectations, present formidable layers of stigma for women in India. HIV/AIDS places yet another layer of stigma onto females, and the resulting discrimination may prevent women from being diagnosed, accessing services, and receiving familial and community support. Primary prevention policies and interventions aimed at controlling the spread of AIDS in India are “totally inadequate in content, volume and orientation” according to D’Cruz (2003, p.255). Research is now focusing on more complex community and societal factors such as culture, power and difference, in order to understand the mechanisms of stigma and discrimination.

The individual perception of stigma and discrimination is important, but only part of the jigsaw. Society’s reaction of HIV/AIDS is perceived through laws, rules, policies and procedures which further stigmatise people living with HIV/AIDS (PLWHA) as seen by the compulsory screening and testing of groups and individuals, and the prohibition of PLWHA from certain occupations or employment (Aggleton, 2000). The role of governments is crucial in the prevention, protection, treatment and care of PLWHA. Through denial or apathy, governments can fail to protect individuals from discrimination; or neglect to respond to those living with the infection. Legislation to ensure the right to employment, education, privacy and confidentiality are essential so that further stigmatisation does not take place (Aggleton, 2000). On the community level, stigmatisation and harassing of PLWHA has been widely reported throughout the world. Acts of violence, murder and abuse have resulted from people revealing their status (Aggleton, 2000). Children have been turned out of schools (Slater, 2004), discriminated against at play (discussed in Chapter 9), and at risk of being put out on the street, with the resulting exploitation and child labour (Martin, 2005).

Women are particularly susceptible to such stigma and discrimination in countries where they are already in a disadvantaged position, because of their gender. Cultural norms which prevent control of their bodies and sexual relations, combined with lack of power, decision-making processes, lack of economic independence and domestic violence, add to their vulnerability. Traditional beliefs and attitudes may give rise to erroneous assumptions of pollution by women because of their natural body functions. India is a country where women with low socio-economic status experience these inequalities of power, status and identity. In order to address this gap in the literature, I have explored the perceptions and experiences of women directly infected or affected by HIV/AIDS, living in community slum conditions in Mumbai, India. Usually, these women would have little voice or have any power to make a difference in their lives.

1.2 Aims and objectives of the study

This qualitative research study examined and evaluated the multiple layers of stigma and discrimination experienced by women living with HIV/AIDS in a low socio-economic area of Mumbai, India.

The first aim was to investigate and evaluate stigma and discrimination faced by Indian women living with HIV/AIDS (IWLWHAs) living in Mumbai, and to examine their perceptions and experiences. Previous research indicated that despite the efforts of the government, stigma and discrimination still exist for Indian women. The study aimed to achieve this objective by in-depth interviews of individual women who were infected and/or affected by HIV/AIDS. Additional data was to be collected from interviews with key informants working in research, or in the field, and group discussions. This interview data was to be analysed using a psychosocial framework, and thematic analysis.

The second aim was to identify and explore the psychosocial needs and coping strategies of IWLWHAs. A life-threatening illness such as HIV/AIDS has obvious effects on the health and wellbeing of those people affected. I wanted to explore the individual's perception of her own needs at this time of crisis, juxtaposed against the needs of the family, and whether these needs were met. Understanding these needs

leads to better ways of strengthening human capacity. The strategies women use in crisis can be healthy and active coping skills resulting in high resilience. If there are poor coping skills, further problems would be anticipated. The in-depth interviews and home visits and observation of conditions were major sources of data collection in this area.

The third aim was to consider the barriers to accessing health services of IWLWHA. Previous research indicated that Indian women are low on the priority list of accessing treatment if they are infected with HIV. Stigma and discrimination, secrecy and shame, lack of awareness, low priority, lack of decision-making and economic difficulty are some of the reasons for women presenting at hospitals late in the progress of the disease. The interviews with the participants and key informants were aimed at providing such data.

The fourth aim of this research was to explore community perceptions as experienced by the participants. The presence of stigma and discrimination and the fear of same would be revealed by the interviews, in addition to documentary data collection and national and international reports.

The final aim of this study was to review and analyse literature and research on the situation of Indian women living with HIV/AIDS from the individual, societal and cultural aspects. The instruments of data collection ranged from peer-reviewed research, documentary data including newspapers, other media such as magazines and electronic sources, and government reports.

1.3 The study design and methodology

The decision to use a particular research design is guided by considerations of the nature of the aims, the amount of control of the researcher and the desired end-product (Yin, 1994). In this study, a predominantly qualitative design made use of both the data, and a methodological triangulation approach. Thus, the study used multiple data sources to examine the problem, and multiple methods to study the data from different viewpoints (Patton, 2002). Examination of the situation from multiple viewpoints strengthens a study according to Patton (2002, p.247).

For example, the qualitative data from the interviews, combined with quantitative data of the demographics of the participants, provides a detailed and comprehensive picture of IWLWHAs, and the findings are supported by data in the literature and documentary data collection. The participant and key informant interviews and focus group discussion were subjected to thematic analysis and the psychosocial framework, which is described fully in Chapter 4. Frame analysis was used with the documentary data to explore themes and meanings.

1.3.1 The conceptual framework used for the study

The theoretical framework used for this study is based on the concept that the psychosocial well-being of an individual is defined with respect to three core domains: human capacity, social ecology and cultural values. Human capacity refers to the physical and mental health of a person, including his/her knowledge and skills. Social ecology includes the social connections and support that people share, and which impacts on their psycho-social wellbeing. Cultural values impart a sense of unity and identity to individuals and communities.

This framework has been drawn and modified from the Psychosocial Framework developed by a group of five academic departments and five humanitarian agencies operating from Queen Margaret University, Edinburgh in 2000. The group was drawn from organisations and academic institutions working in development. They sought to develop a framework which would provide a structure for interventions in complex emergencies such as conflict, mass displacement or natural disasters. Because of its holistic approach, it permits detailed examination of the impact in various domains. For example, the culture and values domain explores how people perceive and understand experiences and events in their lives (The Psychosocial Working Group, 2003). There are other influences such as the availability of economic, physical and environmental resources, which have a significant impact on psycho-social wellbeing. All these areas are interconnected, and overlap; and changes in one area will affect the other areas.

Poverty is a force on its own, and exacerbates the effect of other areas when they are combined (The Psychosocial Working Group, 2003). I modified the psycho-social framework further to explore the negative impacts of the six dimensions, identifying

these as threats; and applied the same methodology to identify strengths which affect resilience. This can be seen in the modified figure presented in Chapter 4. By analysing in this manner, a clearer picture emerged of interventions which will strengthen the women's resilience.

The many layers of stigma and discrimination of Indian women with lower socio-economic status were examined to provide a background. HIV/AIDS attracted another layer which added to their considerable burden.

1.3.2 The qualitative design

The research used a case-study approach, combining multiple qualitative research methods. A qualitative approach, considered to be more sensitive to the context, included in-depth interviews, home visits to the participants of the *Positive Living Project*, community mapping and observations, focus group discussions, interviews with key informants, an accumulation of documentary data, reflective diary, and narratives.

1.3.3 Study participants

The participants in the study consisted of women who were infected, or affected by HIV/AIDS. They lived in the community slums around the hospital. There were three groups – the first group were aged 18-25 years, the second group 26-45 years, and the third group 46 years and more. The groups were constructed to give as wide an overview of the participants as possible. One of the inclusion criteria of the Somaiya Action for HIV/AIDS Support programme was an income below Rs 4000 (AUD \$107) per month, so these women were vulnerable to malnutrition, and lacked the necessities for life; especially as floods two months previously had added to their desperate circumstances. There were young women who had been left widowed with children to raise without sustainable incomes; and older women were called upon to provide sustenance at a time of their lives when, traditionally, they would have expected help from their children.

Despite the poor, sparse and unhealthy living conditions, I was constantly impressed by the women's appearance. The infected women were thin and gaunt, but always clean and well dressed in saris, and their homes tidy and as clean as possible. This

took enormous effort, under the circumstances, as they battled with the symptoms of TB or other infections. They were always welcoming and hospitable, and talked openly about their circumstances, resulting in a diversity of opinions. The younger women showed resilience and strength beyond their years, and a remarkable capacity for duty of care, assuming responsibilities for the remaining members of their households.

1.4 The research site

1.4.1 The K J Somaiya Trust and the home-based care programme

The K J Somaiya Trust and the Centre for International Health, at Curtin University in Perth, developed a collaboration which resulted in several students being invited to Mumbai to implement research studies.

The K J Somaiya Trust is an organisation founded by Padmabhushan Pujya Shri K J Somaiya, to promote social service activities in Mumbai and around India under the guiding principles of the Bhagavad Gita: “To remove the suffering of all beings afflicted by pain”. In 1992, a medical college and free hospital were built to serve the large slum communities in Mumbai of Qureshi Nagar (population 69,222), Pratikshanagar (25,000), Chunabhatti (56,000), and Antop Hill (62,253), in all 212,425 people (Somaiya Medical Trust, 2005).

It was realised by the K J Somaiya Trust in 2003 that there was a massive need to provide health care for the growing numbers of people suffering from HIV/AIDS, in the form of holistic care that would include diagnosis, symptomatic treatment, comfort, psychological education and rehabilitation. The burden on women and young girls and children was acknowledged as significantly worse. As well as the training and sensitisation of all hospital staff, a home-based programme was set up for the holistic management of the disease and to reduce vulnerability of women and children. This programme was called *Positive Living - Integrated Community and Home-based Care Program for People living with HIV/AIDS (PLWHAs)*, renamed (SAHAS). It was set up with the support of Catholic Relief Services in 2004. By April 2005, the hospital had catered for more than 400 persons for pre and post-test counselling. More than 3,000 expectant mothers had been enrolled in the Prevention

of Parent to Child Transmission programme, and 275 people living with HIV/AIDS had been in-patients at the hospital (Somaiya Medical Trust, 2005).

In recognition of the poverty of most of the patients, a nutritional scheme was then set up. Because of funding, the number of participants is small – 26 persons compared to the growing need (Somaiya Medical Trust, 2005). During the flooding in August 2005, the programme was able to provide some clothes, mats and food. These were still being distributed in November 2005, when I was at the hospital.

1.4.2 The Positive Living Program (now renamed SAHAS)

The home-based care program recruited and employed community health workers from the slum communities to survey the needs of the families visited, and to provide information about the Somaiya Hospital services. The team set about building rapport, and sensitisation of the communities by means of street plays. To date, more than 550 people have accessed the services. They have developed pamphlets and posters in Hindi, Marathi, Gujarati and Bengali, which have been distributed in the target communities as well as the hospital departments. A phone counselling service has been set up for people outside the target areas. Counselling was also provided by a psychologist who is the Co-ordinator of the programme. The project has developed a wide network of other agencies concerned with HIV/AIDS, in order to study best practice, referrals, advocacy and sustain project outcomes (Somaiya Medical Trust, 2005).

In addition, an innovative course has been set up to help infected and affected women to become economically self-reliant, and manage the nutritional inputs to their families. The first course started with tailoring and embroidery, with seven sewing machines and 15 trainees in November 2005. It is planned to expand the training to book binding, envelope and file-making in the future (Somaiya Medical Trust, 2005). *Positive Living - Integrated Community and Home-based Care Program for People living with HIV/AIDS (PLWHAs)* in Mumbai, India, provided me with the opportunity to conduct a study in the slum communities surrounding the K J Somaiya Hospital, within the auspices of the SAHAS programme.

1.5 Findings of the research

The presence of stigma and discrimination was confirmed by the in-depth interviews with the IWLWHA. More specifically, there was an added layer of stigma and discrimination, contributed by the disease itself. This finding was supported by evidence from research articles, documentary data collection, and key informant interviews. Stigma and discrimination occurred in families, communities and healthcare. Fear was a dominant feature, and this led to secrecy, and, in turn, to restriction of access to healthcare and other services for IWLWHA.

The study also confirmed that men are a pivotal reason for these women contracting HIV/AIDS because of ignorance, fear, promiscuity, irresponsibility and high mobility. Cultural factors such as religious ordinance, and traditional mores, are still strong in these communities, and affect women significantly. Research literature, interviews with IWLWHA and key informants were in agreement with this finding. IWLWHA were shown to be resilient despite their difficult circumstances, and positive interventions can be made, which will strengthen their human capacity. The interviews were a major source of this data.

1.6 Significance and contribution of the study

The study has significance for several groups, the most important of which are the beneficiaries of the service who were women who participated in the study. These are women who traditionally do not have a voice, no opportunity to make decisions about expenditure in the family nor priority in health care. At least they were able to describe how it feels to be doing their best to support the family and to have contracted AIDS through no fault of their own and yet to be discriminated against, sometimes in their own families, and in the community. From my understanding of counselling, the encouragement and opportunity to express their feelings and perceptions is worthwhile. Additionally, their perceptions and experience become part of a larger contribution in understanding the role and capacities of women in India. Through the process of acknowledging their strengths, despite incredible hardship, empowerment should take place.

The second group for which the study is significant, are organisations which provide home-based care. The study gives them the opportunity to observe the success of a home-based care service which was initially set up from a community survey. Responding to perceived needs in a particular community is most important, if a service is to succeed. For example, the service was able to respond to the community after flooding because of their established contacts. The employment of health workers from the community is a major factor in the success of this service. Specialised and ongoing training are important if the workers are to make the most of their entrée into the community. Secure funding is vital to maintenance and expansion of this service.

The third group are healthcare-managers. Evidence was given of discrimination in hospitals by the women participants. Documentary data collection showed the need for further training and allaying of fears of workers. The KJ Somaiya Hospital's training and awareness of discrimination is shown to be working by the interviews.

The fourth group are the community health workers. As in the case of the women participants, empowerment is observed to have taken place. The women recruited from the community had little previous experience of home-based care apart from their own families. They have provided a worthwhile service, and, in the process, have been empowered in their own lives.

The next group are policy-makers. It has been shown in this study that it is crucial to support the role of women in the family and community. The opposite has been taking place in India for centuries. There are real obstacles for women in the structures of religion, politics, power and dominance. Unless these are addressed, families will continue to crumble under the strain of poverty and HIV/AIDS.

Men are an important group for whom the study is significant. Men are integral, and, in fact, the main pivot of change in this dilemma. Unless they learn to treat women differently, nothing will change. Religious, political and community leaders have to be encouraged to take responsibility for their actions and the effect on women. India is a strongly patriarchal society, where women's essential needs have been neglected

over centuries of male power in all facets of life from family, through communities, government instrumentalities, and religion.

This study has significance in research, as it supports evidence that stigma and discrimination of PLWHA still exists in India. Piot, in his capacity as Executive Director of UNAIDS, asserts that “attacking stigma, mobilizing the whole of society, championing effective solutions and fully resourcing the response” are the four priorities in winning the AIDS fight in India (Chatterjee, 2004, p. 7). By reviewing the literature on stigma and discrimination, it can be seen that these reactions are not only individual, but part of complex structural and environmental responses which are also culturally and socially determined. Stigma and discrimination are demonstrated by the women’s personal experiences in their own families, in the community, and in healthcare settings. Although Indian women from lower socio-economic backgrounds have suffered from stigma and discrimination all their lives, the discrimination attached to HIV/AIDS was felt keenly by them. This is discussed further in Chapter 9.

Lastly, the study was significant for me. I sought to understand the complex cultural and social factors which influence power and, ultimately, stigma and discrimination. Coming from the outside is sometimes an advantage. I brought to the area all of my diverse experience in understanding women, healthcare, community-based service co-ordination, and training. I find now that the experiences in this field research inform my counselling work, emphasising the need for women to be able to access other women in all times of their lives.

This study examined stigma and discrimination faced by Indian women with HIV/AIDS, and provides urgently needed data on their perceptions and experience. The epidemic has existed in India for 20 years, and it is important to examine what progress has been made, particularly for women. Research by Pradhan, Sundar and Singh (2006) has shown that Indian women with lower socio-economic status are neglected in regard to prevention, treatment and healthcare. The study highlights those areas which still exist and increases knowledge of interventions for women living with HIV and AIDS especially in a heavily populated developing country context. The views and perceptions of the participants are vital in planning

interventions which are responsive to their needs, by sustaining and strengthening their capacity. The role of stigma and discrimination in forming barriers to health care and treatment has been explored. It is hoped that recommendations arising from the study will impact on policy-makers and strengthen those existing programmes which are providing good service.

1.7 Recommendations from the research

The following are some recommendations based on the study and the analysis. They have been described more fully in Chapter 15.

- Supporting the IWLWHA by counselling, facilitating sharing with other women and by consulting the IWLWHA community regarding their perception of their needs
- Including reproductive health, sex education and awareness of HIV/AIDS in school curriculum, particularly for girls and deliver HIV/AIDS material in culturally sensitive and appropriate formats through the media and in the community
- Providing sensitisation and awareness programmes for all hospital and community service providers, especially nurses - to have a more significant role in the care of IWLWHA
- Seeking to understand cultural and social mores and work towards changing male attitudes by peer education, understanding cultural and religious practices, gender equity programmes in schools.
- Examining mental health initiatives regarding stigma and discrimination and providing appropriate and emotional counselling
- Using the media to judiciously to promote female equality – i.e. educating journalists and responsible reporting
- Including traditional and complementary practitioners in HIV/AIDS education and encouraging and supporting the work of community health workers
- To roll-out antiretroviral therapy more efficiently, especially to vulnerable women
- Improving women's economic position by education, skills training and micro-credit schemes
- Continuing to support human rights organisations, i.e the Lawyers Collective

- Lobbying on behalf of women by encouraging high-profile women to take an active role in improving conditions for IWLWHA and encouraging more research of women by women.

1.7 Some limitations of the research

There are limitations to any field research, and in this study it is acknowledged that there were the following difficulties, which need to be taken into consideration. I could not speak the languages, and therefore depended on the interpreter, and the community health workers, who were important in establishing rapport and contact with the participants. Language and cultural differences are acknowledged to be barriers. These difficulties are part of field research, and were tempered by the willingness and co-operation of the Somaiya staff and the interpreter.

Financial considerations limited the period of fieldwork to three months. The time allotted in the field was necessarily short, and did not allow for deep immersion in the culture, social milieu, or the lives of the participants. The required number of interviews was completed in the time span, but there was little extra time to engage in focus group discussions, or key informant interviews.

I was dependent on the judgement of the Somaiya staff, as to the suitability and availability of the participants, whose health, family and working commitments had to be respected. The women were not always available to be interviewed, even though appointments were arranged, and this resulted in delays. The limitations are further expanded upon, in Chapter 4.

1.8 Overview of the thesis

The design, methodology, development of this research study, and its findings, are presented in fifteen chapters. This chapter has provided the background for the study, including the professional context of the researcher, the prevalence of HIV/AIDS globally, and in India, and the setting for the field research. The aims and objectives of the study, its theoretical and conceptual framework, and the significance and contribution in various areas are included.

Chapter 2 examines the global prevalence of HIV/AIDS and interventions undertaken such as increased condom use, treatment of sexually transmitted infections, reducing the number of sexual partners, harm minimisation with injecting drug users, education of commercial sex workers, and prevention of mother-to-child transmission. Interventions in various countries are described. The history of HIV/AIDS in India is outlined, with its particular vulnerabilities and responses, both nationally and internationally. Finally, the situation regarding HIV/AIDS in the state of Maharashtra, and particularly Mumbai, is described.

In Chapter 3, stigma and discrimination and prejudice are examined. The historical and cultural antecedents, characteristics and functions of these areas are important for interventions to be effective. Theoretical approaches such as Goffman's work, (Goffman, 1963) and mental illness are outlined, as well as the psychological effects. Lastly, interventions, both international and Indian, are described. HIV/AIDS brings with it another layer of stigma and discrimination. The discussion of gender issues is commenced and continues in Chapter 5.

Chapter 4 is concerned with the design and methodology of the study. Firstly, the rationale, aims and conceptual framework are discussed. The site of the field research is explained, as well as the sample and recruitment methods. The methodology described includes focus group discussion, in-depth interviews, observation and community mapping, and the use of cultural interpreters, key informant interviews, reflective journaling, narratives and vignettes. The data analysis includes ethical considerations, the dilemmas encountered, and determination of rigour in the study.

In Chapter 5, I have briefly explored Indian history, particularly regarding women, and the contribution of Manu, who is described fully in Chapter 5 (p.113). His influence on the status and identity of women has been considerable. The effect of British colonisation and the role of women in the Independence movement are examined. Feminism, the rise of the middle class, and occupations such as nursing and teaching offered promise to women, but have failed to deliver real change to women in poorer classes. The interactions between women and society are examined. The impacts of culture through class, caste and religion, community and family are

interlinked and affect each other. The structural obstacles facing women are also outlined.

Chapter 6 continues the contextualising of Indian women in regard to HIV/AIDS. The factors which make Indian women particularly vulnerable are discussed. These include general factors such as female biology and sexual violence. There are other factors which affect Indian women such as poverty and the deficiencies in nutrition, education and awareness and decision-making. Lifelong stigma and discrimination and gender inequality are major factors which make women vulnerable and which increase the burdens when they contract HIV/AIDS. Children are especially vulnerable, and mothers worry about their future when their own is compromised. The position for widows is serious and difficult.

Chapter 7 commences the data analysis of the study. The socio-demographic profile of the participants revealed the close links between lower caste and socio-economic status. The data showed low levels of education, and lack of awareness regarding HIV/AIDS, before their own diagnosis, or a family member, in a great majority of women. Half of the women were both infected and affected by HIV/AIDS, and there were young women widowed and struggling to make ends meet. The number of children in the households reflected the decimation of family members due to HIV/AIDS.

In Chapter 8, the data analysis of the interviews commences. Environmental factors which impinge on women's wellbeing such as overcrowding, poor sanitation and disease, are discussed. Economic threats such as poverty and finances, and the increases in workload, brought about through HIV/AIDS, are examined. The threats and strengths arising from culture and values, are evaluated from the data collected from the participants of the study.

Chapter 9 continues analysis of the data collected from the in-depth interviews. The area of social ecology is derived from the Psychosocial Framework. The data is analysed through the threats and strengths perceived by the participants, in areas such as awareness of the community, disruption of family structures, and changing roles and responsibilities, as HIV/AIDS affects families.

Human capacity is analysed in Chapter 10. The threats which have been discussed in the previous chapters are understandably overwhelming, and yet the women participants showed resilience and flexibility in adjusting to the rigours of HIV/AIDS, both for themselves and their families.

In Chapter 11, the documentary data collected during the time of the field research in the form of newspaper articles, as well as government reports, and news articles from various media are examined, and evaluated. Six themes including HIV/AIDS and research, stigma and discrimination, gender and cultural issues and social condition in Mumbai are elicited and discussed.

Chapter 12 discusses the themes from the focus group discussion and key informant interviews in the following key areas: stigma and discrimination, lack of awareness, mode of transmission, discrimination in healthcare, discrimination and empowerment of women, and effective strategies.

Chapters 13 and 14 contain Part I and II of *The Power of Voice*. Chapter 13 reflects the voice of the researcher as it details the daily difficulties and frustrations of field research. Chapter 14 contains four narratives derived from the interviews, and represent certain aspects of HIV/AIDS. For example, Narratives 1 and 4 are the stories of women affected by HIV/AIDS. Veena's narrative is of a woman infected by HIV/AIDS and Neela is a woman who has been affected by discrimination. The other two narratives are derived from my observations of the social conditions of Mumbai.

In the final and concluding Chapter 15, I present an overview of the research design and process. The key threats and strengths which affect women coping with HIV/AIDS are discussed. These include stigma and discrimination, women's vulnerability and status, family cohesion and support, community understanding, healthcare, policy-makers and human rights.

Recommendations include areas such as education and awareness, men's responsibilities, changing attitudes and beliefs, community and employment

initiatives, and human rights. The significance of the study is discussed from the point of view of clients, K J Somaiya Hospital, policy-makers and myself. Finally the limitations of the study such as generalisability, language and interpretation, duration of the study, health of the participants, dependence on the SAHAS team, financial costs and the position of the researcher. A final statement concludes the thesis.

CHAPTER 2

GLOBAL DIMENSIONS OF HIV/AIDS & THE CONTEXT OF HIV/AIDS IN INDIA

“Mumbai is a major partner in global development. It has all the various features that have made the city a breeding ground for drug peddlers, traders of flesh and people indulging in high risk behaviour, bearing serious consequences for the spread of the HIV epidemic.”

(Bharat, cited in D’Cruz 2002, p.2).

2.0 Introduction to the review of literature

In this Chapter I review the literature related to HIV/AIDS in an interpretive manner, including the international context of the incidence of the disease, and effective interventions to prevent its spread. These interventions address areas such as condom use, sexually transmitted infections (STIs), reducing the number of sexual partners, safe injecting behaviour, mother-to-child transmission, community and medical interventions.

India is considered particularly vulnerable because of the socio-economic conditions and poverty, the difficulties of providing information and awareness, gender inequality, corruption, and the judiciary process. Interventions are necessary in community and health care, workplace and legal structures. These interventions are implemented by the national government and also international programmes. The state of Maharashtra and its capital, Mumbai, are considered high-risk areas for HIV/AIDS because of the huge migrant population, socio-economic conditions, and the number of commercial sex workers in the largest brothel-based industry in India.

2.1 International context

HIV/AIDS has reached pandemic proportions in the world. People suffering from these conditions were estimated at 33.2 million adults, and 2.5 million children in 2007 (UNAIDS, 2007). In 2004, an estimated 2.5 million people became infected, and there were 2.1 million deaths (UNAIDS, 2007). The overwhelming majority of people with HIV/AIDS (i.e. 95%), live in the developing world, with the worst affected being sub-Saharan Africa, with just over 60% of the world's total sufferers (AVERT, 2005). There are now 16 countries in Africa where more than one-tenth of the population have HIV/AIDS; and in Botswana, 37.5% of the population is affected (AVERT, 2005).

In Asia and the Pacific there are an estimated 8.2 million people with HIV/AIDS. The AIDS epidemic is also increasing in Eastern Europe and Central Asia, with 1.4 million sufferers, and worrying figures from the Caribbean show worse epidemics than anywhere else in the world except Africa (AVERT, 2005). In some countries such as Sweden, where the reported number of new cases had dropped, authorities were disappointed to find that numbers have inexplicably increased again (AVERT, 2005). Since 2002, more funding has been made available for anti-retroviral medication (ART); however the number of people newly infected continues to increase; and the number of people in developing countries receiving ART remains a small proportion of those who could benefit from the treatment (UNAIDS, 2004a; 2004b, p.2).

2.2 International interventions to reduce HIV

Several researchers (Ainsworth and Teokul, 2000; World Bank, 2007) argue that now there are proven successful strategies to combat AIDS by increasing condom use, treating sexually transmitted infections (STIs), reducing number of sexual partners, safe injecting behaviour and drugs to prevent mother-to-child transmission.

2.2.1 Condom use

The ABC strategy is one of the Abstinence, Being faithful, Condom Usage (ABC) strategies which have proved successful in Uganda and Thailand to reduce HIV. This approach needs national co-operation and male education to succeed. In Uganda,

there has been a fall of adult prevalence of HIV from 15% to 5% in ten years. Thailand set an objective of 100% condom use, and used many sectors of national and local government to achieve it (Shelton et al., 2004). Ensuring that the individuals most likely to spread HIV adopt safer behaviour through whatever combination of direct or indirect interventions, by the use of non-government organisations or others, is a responsibility that governments cannot afford to ignore. UNAIDS reported in 2006 that in 11 sub-Saharan African countries, eight reported increased use of condoms, but the actual use remains below 50%. In a survey of five cities in India, it was found that by implementing education by male peer educators, the use of condoms in Mumbai was increased significantly (UNAIDS, 2006c). In Kolkata, commercial sex workers have banded together to refuse clients who will not wear condoms. Condom usage has increased from 3% in 1992 to 90% in 1998 (Solomon et al., 2004).

2.2.2 STIs and their treatment

Sexually transmitted infections are a source of major concern, especially in poorer countries, because they are a co-factor in HIV transmission. AVERT (2005a) claims that an untreated STI can increase the acquisition and transmission of HIV tenfold. Furthermore, a person who is HIV positive, and has an untreated STI, has the potential to progress to AIDS quicker. In order to maintain health of HIV positive people, it is therefore important to treat STIs. The 2006 UNAIDS/WHO report claims that data on STIs is extremely scarce. One of the reasons for the lack of data is the social stigma attached to these infections. No single organization reports STD statistics globally, and the last estimates of STIs in the world were completed by the World Health Organisation in 2001. In 1999, it was estimated that there were 340 million new cases in men and women aged 15-49 years, mostly in South and South-East Asia, sub-Saharan Africa and Latin America and the Caribbean.

2.2.4 Reducing number of sexual partners

The joint United Nations and World Health Organisation report on the international situation of HIV/AIDS notes that many young people continue to engage in high risk behaviour where HIV/AIDS is concerned. The rates vary greatly from one country to another. For example, the numbers of young women who are infected by HIV/AIDS between the age of 15 and 24 years range from 7% in Chad to 50% in

Ghana, whilst the figures of young men range from 72% in Madagascar to 91% in Cameroon. The rates for men are twice as many as women in Asia. In eight countries which have submitted regular reports to the UNAIDS/WHO survey, three reported little or no change in prevalence, whilst three reported an increase, and two countries were able to report that there had been a decrease (UNAIDS/WHO, 2006).

The spread of HIV/AIDS is also influenced by men having sex with men, and those who have sex with both men and women, particularly in mobile populations such as truck drivers or commercial sex workers. Forty four per cent of men reported buying sex in 2004 in the countries responding to the UNAIDS/WHO report. In Andhra Pradesh in India, 42% men having sex with men were married, and 50% having extra-marital sex with women, and just under half of those men did not use condoms (UNAIDS/WHO, 2006).

2.2.5 Safe injecting behaviour

HIV spreads quickly in intravenous drug user communities, however there is only 5% coverage of ART medication for this population across the world. The use of contaminated equipment accounts for 80% of all HIV infections. There is a growing epidemic of intravenous drug use in sub-Saharan Africa. In the Russian Federation, the provision of safe needle exchanges and drug substitution therapy is known to be effective, and yet funding has been cut in recent years. Harm-reduction strategies have been endorsed by UNAIDS, and have proved efficient in countries like Australia, Sweden, China, Hong Kong, Thailand and the United States; and yet some countries such as the Russian Federation prohibit the use of methadone or buprenorphine. India has no harm-minimisation policy, which leads to a lack of co-ordination in designing and implementing interventions (UNAIDS/WHO, 2006).

2.2.6 Commercial sex workers

Commercial sex workers (CSWs) and injecting drug users (IDU) are linked together, and further associated with increases in HIV. Manipur in India has a well-established HIV epidemic where 20% of the sex workers were found to be injecting drugs. In Ho Chi Minh City in 2002, 49% commercial sex workers who were injecting drugs were found to be HIV positive, whilst 19% commercial sex workers who were taking drugs orally, rather than injecting, were found to be HIV positive.

The rate was much lower for those CSWs not on drugs (8%) (UNAIDS/WHO, 2006).

2.2.7 Drugs to prevent mother-to-child transmission

Mother-to-child transmission (MTCT) is also known as *vertical transmission* and *perinatal transmission*, as it mainly occurs around the time of delivery. If there are no medical interventions for the mother, the rate rises to 25-40% in sub-Saharan Africa, owing to the likelihood of breastfeeding. Several antiretroviral (ART) courses have shown to be effective. These include zidovudine alone, zidovudine and lamivudine, and nevirapine. They have been shown to be effective long term up to 24 months, protecting the infant even while the mother is breastfeeding (UNDP/UNFA/WHO/World Bank Special Program of Research & Development and Research Training in Human Reproduction, 2003). The limiting factors of success are therefore not the efficacy of the medication, but cost and availability to women. The United Nations agencies recommend a four-pronged approach to prevent MTCT of HIV. This includes 1) the prevention of HIV infection in the parents, 2) the prevention of unwanted pregnancies in HIV-infected women, 3) the prevention of HIV transmission from mother to child, and 4) the treatment of HIV infected women, their infants, and young children, partners and families (UNDP/UNFA/WHO/World Bank Special Program of Research and Development and Research Training in Human Reproduction, 2003).

2.3 Interventions to reduce stigma and discrimination in communities and schools

2.3.1 South Asia

In a UNAIDS report on stigma and discrimination, the following successful programmes are noted. In Nepal, volunteers are drawn from local communities to effectively spread messages of care and support to infected people. In Bangladesh, a human rights framework is used by voluntary organisations to initiate discussion with a view to changing legislation to minimise stigma. In Sri Lanka, PLWA support groups are holding workshops to desensitise the public and challenge discriminatory attitudes (UNAIDS, 2004a). This work is very valuable as well as the importance of education for women and girls. UNAIDS/UNFPA and UNIFEM (2004) conducted a

32-country study which found that women with post-primary education were five times more likely to know facts about HIV/AIDS than illiterate women.

2.3.2 Africa

In 2002, Uys outlined the difficulties of community caregivers and collaboration with hospital staff at seven sites in South Africa (Uys, 2002). In Zambia, studies have shown that more educated young people have less likelihood of having casual partners, and use condoms more readily. Despite the overwhelming facts that education helps, 40% countries still have not introduced HIV/AIDS education into schools. Uganda is a success story in reaching 10 million children via the classroom, and reducing the figures of sexual activity from 60% in 1994 to 5% in 2001 (UNFPA UNAIDS, UNIFEM 2004c). In Botswana, a home-based care programme explores the significance of caring in young and old, the role of stigma and the need for psychosocial support (Hirschfeld and Lindsey, 2002; Lindsey, Hirschfeld, Tlou and Ncube, 2003). In this country, where girls are four times more likely than boys to be HIV positive, innovative programmes using peer groups have been introduced. There are a number of studies on various dimensions of HIV/AIDS that cannot be included due to space constraints.

2.3.3 Medical interventions

Throughout the world, 64 million female condoms have been distributed. The uptake rates differ – in Brazil, the acceptance rate is 41-95% (Royce, Sena, Cates and Cohen, 1997; UNAIDS, 2006b). There have been promising microbicide trials in India, Brazil and Zimbabwe, but the costs may be prohibitive, and therefore limiting. These products can kill, neutralize or block HIV and other STDs. Theoretically, this gives women more decision-making power, and less reliance on their partners and the male condom. In India, the Council of Medical Research has a task force on microbicides; however research is progressing very slowly because of underfunding and political marginalisation, because it is a female issue (Krishnakumar, 2005).

The World Health Organisation and UNAIDS implemented the 3 x 5 initiative to provide 3 million people with antiretroviral treatment (ART) by the end of 2005 in 50 developing countries. These medications not only extend survival rates, but also increase quality of life for people living with HIV/AIDS (PLWHA). The Global

Coalition on Women and AIDS asked for half that allocation to be made to women. The programme concentrated on five areas: simplified, standardised tools to deliver ART, new services to ensure effective reliable supply of medicines, rapid identification, dissemination and application of research and successful strategies, urgent and sustained support for countries, and a global leadership, strong partnership and advocacy (UNAIDS/WHO, 2006).

By 2006, 700,000 people or 28% of 7.1 million people were receiving ART in low-middle income countries. The coverage in sub-Saharan Africa had increased from 2% to 28%, and in East, South-east and South Asia, the figures had increased fourfold to 19%. There was increased survival on ART, but data was from small research studies. In June 2006, 81% of patients started in 2004 were still on first line regimens, whilst 8% had died and 9% were lost to the research. Thailand not only had the distinction of success in condom use but increased survival of 90% after four years, and the largest percentage of people on ART. There were similar increased survival rates in Botswana, Cameroon, Ethiopia, Peru, Trinidad and Tobago, and Uganda. In addition, increased quality of life was reported in Kenya and Thailand (UNAIDS/WHO, 2006).

Ninety countries had provided target data at least. Ninety per cent had a national AIDS policy and 85% had a national body to co-ordinate strategy. Financial resources globally had increased with an annual average increase of US\$1.7 billion. Some countries had increased coverage for prevention services, but the goal of 25% reduction in HIV prevalence in young people remained elusive. Only five countries met that target. HIV/AIDS continues to affect women and young people, with half of new infections being in the 15-24 year old range. Stigma and discrimination was reported in 30 countries and remain key barriers in implementing successful prevention programmes.

Governments continue to fail to care for the 15 million children orphaned by AIDS (UNAIDS 2006b). The goal posts then moved to the aim of universal access of ART drugs by 2010. In order for that to happen, the same problems of inequality of access, IDUs, children, financial resources, and drug-resistant tuberculosis need to be addressed (WHO/UNAIDS/UNICEF, 2007).

2.4 The context of HIV/AIDS in India

2.4.1 History of HIV/AIDS in India

The first AIDS case was reported in Chennai in 1986. The Indian Government set up a National AIDS Control Program managed by the Ministry of Health and Family Welfare in 1992. At this time, the main activity was to monitor the HIV infection rates amongst populations at risk in selected urban areas, and there was a four-year plan aimed at prevention (World Bank, 2005). The period of 1986-1992 was characterised by denial of the threat of AIDS, and it was left to the states to implement progress without guidance. 1992-1999 saw the first acceleration of the programme with World Bank funding of \$US84 million interest free credit to implement the programme. Some 25 states set up AIDS organisations (SACS) with differing levels of commitment. For example Tamil Nadu, Andhra Pradesh, and Manipur showed a strong response whilst Bihar and Uttar Pradesh are still lagging behind (The World Bank Group, 2005; YOUANDAIDS, 2005).

In 1991, India developed a National AIDS Control Organisation (NACO), which focused on blood safety, prevention among high risk populations, awareness-raising and improving surveillance (World Bank, 2007). The World Bank at this time estimated the numbers of PLWHA would reach 1 million by 2000 (World Bank, 2005). Policy discussions between the World Bank and the government encouraged the removal of discriminatory public health practices, and the adoption of internationally agreed policies and ethical standards for the treatment of PLWHA. New legislation amended India's Drugs and Cosmetics Act, the quality of condoms sold, improvements to blood banks, closure of unlicensed blood banks and prohibition of paid donations (World Bank, 2005).

By 1999, the National AIDS Control Program had achieved a reduction in risk behaviour, increased condom use, near 100% blood safety, (compared to 30% previously), increased knowledge of prevention, a network of 140 blood surveillance and 180 sentinel sites, and legislatively appropriate policies, regarding the humane treatment of PLWHA (World Bank, 2005). Injecting drug users in India are a high-risk group, who use heroin as the drug of choice. This was a factor in the rapid spread of the infection. Following the first reported cases in Chennai in 1986, later

IDUs were found to be infected in Manipur (Gaitonde, 2001). The dominant mode of transmission is heterosexual sex in India, except in the north-eastern states where injecting drug use is the principal mode (WHO/UNAIDS/UNICEF, 2007). Another factor which hastened the spread of HIV/AIDS, was the rapid expansion of economic growth which led to more slums, more migrant populations, more casual workers, child labourers and poverty. Poor people could not afford condoms. Prostitution and the lack of treatment of STIs led to easier transmission of HIV/AIDS.

At first the population of PLWA was seen as deviant, and not “our” problem, and seems still to be tainted with that stigma. Changing patterns in India led to more nuclear families, women working outside the home, and poorer children. Virginity in women is still valued in the community, but promiscuity in men, which involves risky behaviour, is widely tolerated (Gaitonde, 2001). India had the second highest incidence of HIV/AIDS in the world after South Africa, according to some authors (Chatterjee 2004; Lal 2003; NACO, 2004b). The National AIDS Control Organisation of India (NACO) assessed the number to be 5.134 million (NACO, 2002-2004), rising to 5.21 million in 2005. However, UNAIDS revised the figures in 2007 to less than half that number (2.5 million). The new estimates are derived from a population-based survey, expanded sentinel surveillance, and revised methodology. The figures are currently disputed, and show the difficulty in assessing India’s prevalence Solomon, Chakraborty and Yepthomi (2004) noted the significant underreporting of data because of stigma and discrimination problems. NACO also states that the predominant mode of transmission is through heterosexual contact (85.7%). Other modes include mother-to-child transmission (2.7%), blood transfusions (2.6%) and injecting drug use (2.2%) (NACO, 2004). The spread of HIV/AIDS in India has been accentuated, because people do not present at hospitals until they have recurrent opportunistic infections such as tuberculosis (Mehta and Gupta, 2007). Indian women, in particular, do not seek medical assistance until late stages of the infection for reasons that are later discussed. In turn, the infections of HIV/AIDS and tuberculosis are amongst the health related ‘shocks’ which can drive people into poverty (Mehta and Gupta, 2007).

Each year, a national HIV sero-surveillance survey attempts to identify the numbers of people who have HIV/AIDS. The year 2002 showed an increase of 600, 000 new

cases from 2001 (Chatterjee, 2004). The National AIDS Prevention and Control Policy of India clearly states that there is a moral and humanitarian obligation to provide appropriate care and support to people living with HIV/AIDS in the areas of clinical management, nursing care, infection control, education, counselling and psycho-social support through home-based services (NACO, 2004). This follows closely the United Nations General Assembly Special Session on AIDS's Declaration of Commitment in 2002, which aims at the highest possible treatment of people living with HIV/AIDS (Piot and Seck, 2001).

Although the prevalence in India is considered low (0.5-1.5% population), comparable to less than 0.2% in Australia and 0.4% to 1.00% in the United States, it is a serious epidemic in a number of areas (UNAIDS/WHO, 2006). The population of India is estimated at 1.7 billion (Ekstrand, Garbus and Marseille, 2003), and even a small increase in the percentage points increases the number of PLWHA to millions (Mehta and Gupta, 2007). The low prevalence is itself a problem as it makes it harder to raise sensitivity, according to Chatterjee (2004). There is considerable regional difference in prevalence. For example, the states of Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland have generalised epidemics, whereas other states have low level epidemics. In high prevalence states such as Maharashtra, the epidemic is spreading from urban to rural areas, and from high-risk groups to the general population (Chatterjee, 2004). High mobility of the population, and lack of information are two reasons why it is difficult to track (Chatterjee, 2004). Social reactions to the disease are overwhelmingly negative, as shown in 36% of respondents in one study who felt it would be better if infected individuals killed themselves (Ambati, Ambati and Rao, 1997).

2.5 India's vulnerability to HIV/AIDS

India has particular vulnerability to HIV/AIDS because of poverty, and because it is a vast country with high socio-economic disparities, and very low levels of literacy in certain parts. There are huge migrant populations, untreated STIs, and the particular vulnerability of women because of low levels of awareness and education, low status and limited access to resources (Chatterjee, 2004). The high-risk groups

are injecting drug users, men who have sex with men, and women who are unable to negotiate safe sex (World Bank, 2007).

2.5.1 Economy

In the early 1990s, India faced a severe financial crisis, the gross fiscal deficits reached 10% of GDP, and the annual inflation rate was nearly 17%. Therefore, India put emergency measures into place and embarked on a structural adjustment programme which included liberalising foreign investment and exchange, reducing tariffs and trade barriers, reforming and modernising the financial sector. These measures had beneficial effects on the economy, although progress has been uneven, and foreign investment remains lower than in other developing countries. There were corruption scandals in 2001 related to defence procurement, stock market manipulation and mismanagement of the largest state-owned mutual fund. Richer states appear to be increasing incomes faster, and therefore poverty has been increasingly concentrated in the slower growing states (Ekstrand, Garbus and Marseille, 2003).

The structural adjustments aimed at shifting spending on health to the private sector. Consequently the private sector now provides 81.6% of all health spending. The government has the responsibility to spread literacy and access to primary health care, and to undertake public health campaigns in the areas of HIV/AIDS and major infectious diseases, but these have been compromised by lack of budgeting (Ekstrand, Garbus and Marseille, 2003).

2.5.2 Poverty

There has been a decline in poverty in India in the 1990s, but the actual decrease remains debatable. Some states have been more successful in reducing the poverty rate. There are more than 200 million people with malnutrition, or chronic food shortage, even though India has one of the largest targeted food assistance programmes in the world (Ekstrand, Garbus and Marseille, 2003). The anti-poverty programmes provide employment, productive assets such as land or animals, training, credit and food security to the poor. However, these programmes are criticised for being inefficiently managed, badly targeted, and fragmented (Ekstrand, Garbus and Marseille, 2003).

The World Health Organisation states that poverty is the main reason babies are not vaccinated, clean water and sanitation are not provided, drugs and treatment are not available, and mothers die in childbirth in India (Mehta and Gupta, 2007). The large numbers of people living below the poverty line in India - 320 million, (UNAIDS, 2004b) pose enormous challenges in the detection and treatment of HIV/AIDS. Poor sanitation, overcrowding and sub-standard living conditions, lead to lowered resistance to co-morbid conditions such as tuberculosis, and contribute to the spread of disease. HIV/AIDS is only one of many conditions that people in slum communities face every day.

2.5.3 Socio-economic factors

The diversity in levels of society and employment make it difficult to implement programmes across the board. People in slum communities are not able to afford proper health and medical care, and this is particularly applicable to women. HIV/AIDS places even more financial burdens on those least likely to afford them. The effects of living in a slum community in Mumbai have been documented by (Parkar, Fernandes and Weiss, 2003). They found that the overcrowding, pollution and limited social supports, because of the breakdown of families, disrupted social networks affecting individuals and communities.

2.5.4 Education and awareness of HIV/AIDS

Chatterjee (2006), and Population Foundation of India (2007), both estimate the number of illiterate women in India to be nearly 245 million (over 50%). Education provides a conduit for accurate information, whilst a lack of education means more dependency on unreliable sources. There is a lack of empowerment to make decisions, and to act independently without health information. This is a major problem for women in poor circumstances in India. Figures for literacy vary greatly from state to state in India. For example, the literacy rate is highest in Mizoram i.e.90%, and lowest in Uttar Pradesh i.e. 30% (YOUANDAIDS, 2007).

Whatever the numeracy and literacy levels, education about HIV/AIDS and sexual matters in general is still limited, particularly amongst women, because of sexual taboos. In Maharashtra, 82% of people had heard of HIV/AIDS, but only 6.5%

married women had heard about the disease from a health worker. Their information was mostly from media sources, family or friends, which indicates the information may be incorrect or incomplete (Population Foundation of India, 2007).

2.5.5 Lack of awareness about HIV/AIDS and STIs

India has a very high rate of STIs. Unlike HIV, STIs can be treated and cured relatively easily if treated properly and early (AVERT, 2007). The current estimates are that approximately 6-9% of the population in India suffer from STIs, with more than 40 million new infections reported per year. Those on low incomes cannot always afford to buy condoms, or access treatment (Solomon, Chakraborty and Yepthomi, 2004). Women with STIs are considered to be two to four times more at risk of contracting HIV than women without such infections (Royce et al., 1997). Researchers in Mumbai found that men attending public STI clinics had a high prevalence of HIV, associated with HSV-2 infection, and visiting female sex workers (CSWs). Of the married men, 46% had visited a CSW in the past three months (YOUANDAIDS, 2007).

2.5.6 Gender inequality

Sen (2006) states that there are seven kinds of gender inequality in India - firstly, *mortality* is unusually high for women in India, given that more male babies are born. Compared to Africa, (1.022) one would expect a higher ratio of women, but in India, the figures show 0.93 ratio, which is a difference of 9% or 36 million. Sen (2006, p.1) calculated this number in 1986, and called this population: “the missing women who should have been born”. Secondly, there is *natality inequality* – the preference for boys, leads to sex-selective abortion. Thirdly, Sen describes *basic facility inequality*. Girl children may not receive equal education but also are not encouraged to develop natural talents. Lack of opportunities for higher learning creates *professional inequality*. Females are not equally represented in property *ownership*. The last inequality is *household*, which refers to the lack of decision-making by women in families and households (Sen, 2006).

Although the status of women in India is changing, particularly in the upper and middle classes, there are still large numbers of women who have little say in many facets of their lives, from economic decisions, to negotiating safe sex. Cultural and

religious beliefs relegate women to a lower level than men, with resulting disempowerment and difficulties, despite the fact that Indian women work hard, and shoulder the caregiver burden for the family. Female children receive less education and less nourishment, and are discriminated against from birth onwards. These factors are major contributors to stigma and discrimination, and are further discussed in Chapter 5.

2.5.7 Corruption and crime

Corruption pervades all areas of economic and political life in India. The corporate sector contributes to both public and private sector problems. The high levels of corruption lead to leakage of funds from those allocated to HIV/AIDS programmes, as well as the common practice of paying bribes to expedite action on projects. With decentralisation, the states are being made responsible for corruption; however they may lack the will or the resources to tackle it (Ekstrand, Garbus and Marseille, 2003). There is significant organised and random violence. The dislocation of population from ethnic violence and human trafficking has particular significance for women, and makes targeting programmes more difficult (Ekstrand, Garbus and Marseille, 2003).

2.5.8 Judiciary

The Indian judicial system is another area affected by corruption at the state level. Added to this is the enormous backlog of cases (estimated to be 28 million), extremely slow processing (5-10 years), low levels of knowledge about new legislation, and weak enforcement of decisions (Ekstrand, Garbus and Marseille, 2003). These factors have implications for the human rights of PLWHA, as well as police harassment of certain groups such as sex workers, men having sex with men, and even the workers in HIV/AIDS programmes. In addition, there is no national legislation in India to protect PLWHA (Ekstrand, Garbus and Marseille, 2003).

2.6 Interventions in HIV/AIDS in India

2.6.1 Responses to HIV/AIDS in India

A review of interventions in 2003 revealed that interventions have targeted high-risk groups such as sex workers, intravenous drug users, men having sex with men,

truckers, migrant labourers and street children (Chatterjee, 2004). The United Nations Office of Drugs and Crime (UNODC) worked at the national level with the Ministry of Social Justice and Empowerment, as well as the Ministry of Health and Family Welfare, to include HIV/AIDS in ongoing programmes. Peer networks were started in the North Eastern states and metropolitan cities, mainly in the area of drug users, and detoxification camps were held (Chatterjee, 2004).

The United Kingdom Department of International Development (DFID) has been working in partnership with the NACO, and with centres in Gujarat, Orissa, Andhra Pradesh, West Bengal and Kerala, to reduce the spread of HIV, targeting commercial sex workers (CSWs), injecting drug users (IDU) and men having sex with men (MSM). In West Bengal, 100,000 people have been reached through non-government organizations (NGOs). State AIDS Control Societies (SACS) have designed targeted programmes according to prior needs assessments. The United States Agency for International Development (USAID) have ongoing focused intervention programmes in Tamil Nadu and Maharashtra, helping NGOs to design strategies to high-risk groups especially in the sex industry (Chatterjee, 2004).

2.6.2 Prevention of HIV transmission in the general population

Acknowledgement of monogamous married women as a group has brought about a partnership of the United Nations Development Fund for Women (UNIFEM), the United Nations Development Program (UNDP), the Indian Railways and NGOs to use peer counsellors in the railways, schools, hospitals and training colleges, working towards a gender-sensitive approach on HIV/AIDS care and prevention. Three main areas were emphasised: skill-building internships for PLWHA, psycho-social support, and provision of micro-credit. To date, peer counsellors have reached 70,000 people in the five entry points of the railway community. A Railway Women's Empowerment and AIDS Prevention Society (REAPS) has been set up to mobilise, and strengthen community responses to HIV/AIDS, and gender-related issues. Gender and HIV education has been introduced into all the Indian Railway Schools, from the ninth grade, encouraging young people to question gender stereotypes, and for women to negotiate safer sex and promote male sexual responsibility (Chatterjee, 2004).

2.6.3 Interventions focusing on children and young people

With UNICEF funding, 291 Prevention of Parent-to-Child Transmission (PPTCT) teams are providing services across high and low prevalence states in India. The overall intervention uptake rate is 87.6% of HIV positive women receiving Nevirapine as well as their newborn babies. The United Nations Children's Fund (UNICEF) and the National AIDS Control Organisation (NACO) are developing a plan to reach young people who have finished school; and have also implemented a programme of prevention and education in four high-prevalence states including Maharashtra. This involves using peer education (Chatterjee, 2004). In addition, the World Bank, the Ministry of Health and the Ministry of Home Affairs are providing education in schools and universities and colleges. The United Nations Development Program (UNDP) and National Indian IT Programme (NIIT), a premier IT education institute, have collaborated to raise HIV/AIDS awareness in young people by using peer educators. After the initial awareness session, the students themselves have designed screen savers, posters, power point presentations and street plays (Chatterjee, 2004; WHO, 2004).

2.6.4 Community-based care model

The India-Canada Collaborative HIV/AIDS Project (ICHAP) has developed a community based care model for HIV prevention and care for rural migrant men and their families, in 133 villages in Rajasthan. In Karnataka, ICHAP works with the state AIDS Prevention Society to help establish sustainable systems. In 2003, VCTCs were increased from 6 to 31. Model voluntary counselling and testing centres have been set up in Chennai, Mumbai and Imphal, with the help of the World Health Organisation (WHO, 2004).

2.6.5 Community interventions

D'Cruz (2002, 2004) claims that primary prevention activities, aimed at controlling the spread of HIV/AIDS, are totally inadequate in content, volume and orientation, and leave much to be desired in terms of the effectiveness of programmes and policies. The development of secondary and tertiary health interventions has burdened populations with the responsibility of providing home-based care for ill members. Community care has become the watchword for secondary and tertiary care. In India, community care is a euphemism for family care. These community

care models were supposed to be an ideal model, however in India, families have to provide the community care services.

HIV/AIDS families deserve special attention because the family members are also stigmatized and isolated, and infection in one member points to another member being infected. The enormous upheaval and change in the family structure has not been the subject of research. D'Cruz (2004) reports that the women were angry, resentful and bitter, but still provided care to their husbands, and said there was no change in their respect for their husbands. Changes in family life affected children, although they had limited understanding of the problems.

2.6.6 Workplace interventions

A collaboration of the International Labor Organization (ILO) and the CBWE (Ministry of Labour) have provided HIV/AIDS education to workers in the organised and unorganised sector throughout India, as well as encouraging trade union leaders, labour inspectors to be more aware of difficulties for their labour force. A national workshop was organised to highlight stigma and discrimination issues in the workplace. The United Nations Country Team has initiated a project to ensure that all UN officials in India are trained, and aware about HIV/AIDS. In Gujarat, the Reliance Group, India's largest private company, has agreed to sponsor one workshop a month on HIV/AIDS for its own staff, and set up an STD and DOTS (TB treatment) centre. The State Bank has pledged that loans will only be given to those units which have HIV/AIDS prevention, care, and support activities (Chatterjee, 2004).

2.6.7 Care, support and treatment

NACO, ICHAP, CIDA and UNAIDS organized a national consultation on community-based care and support for HIV/AIDS. The recommendations were to expand focus to low-prevalence states, explore models of comprehensive care, endeavour to keep people in their communities, train physicians, particularly in the private sector, and increase the capacity of families to care for the infected and affected (Chatterjee, 2004). The provision of free antiretroviral therapy (ART) was introduced through government hospitals in 2003 (Tarakeshwar, Krishnan, Johnson, Solomon, Sikkema and Merson, 2006) although it had been available in the private

sector beforehand. However, NACO's ART initiative reported difficulties in the lack of government infrastructure, lack of finances to access treatment, and lack of access for women. Certainly, the distribution of ART has not been taken up to the full (UNAIDS/WHO/UNICEF, 2007).

2.6.8 Legal and ethical issues

The Lawyers Collective has prepared draft legislation to protect the rights of PLWHA. They provide ongoing advocacy in this area. In 2004, UNIFEM supported a consultation with women's groups to see if gender issues were being addressed in the bill. The Swedish International Development Organization (SIDA) has been working in the area of advocacy of vulnerable populations such as women, MSM, CSW and IDU. Namakkal, Tamil Nadu, has a Positive Living Project aimed at improving access to quality care and support to PLWHA and their families, including home-based care, and outreach services (UNIFEM, 2007).

2.6.9 Healthcare interventions

The World Health Organisation, in 2007, noted that access to treatment for HIV/AIDS has increased gradually in India since 2004. The provision of ART to children has started with a goal of 40,000 children by 2011. Prevention of mother-to-child transmission programmes began in 2002, and were being offered in 2433 health centres by 2006. Voluntary HIV counselling and testing started in 1997, and between 2002 and 2005, 3.03 million people had been tested (WHO/UNAIDS/UNICEF, 2007).

2.7 The national AIDS prevention and control policy

In 1987, the Indian government adopted a national AIDS prevention and control policy which included programmes of condom promotion, behavioural change, community information and education, targeting special groups, blood safety and treatment for sexually transmitted infections (UNAIDS, 2007). Education and awareness of HIV/AIDS has been undertaken in all states of India through the Department of Education and non-government organisations (NGOs). Film stars and celebrities have spread the messages as well as street plays, songs and dramas. A toll-free national telephone help-line has been established. Community Popular

Opinion Leaders are trained to educate peer groups, and schools have AIDS education programmes (Solomon, Chakraborty and Yephthomi, 2004).

As a result of these and other methods, awareness of AIDS has risen from 54% to 78% in urban populations, and 13% to 64% in rural areas since 1987 (Solomon, Chakraborty and Yephthomi, 2004). However, when the figures for women are separated, NACO reports 15% urban women and 35% rural women lack AIDS awareness (NACO, 2004). Television is rated as the most effective medium for imparting knowledge, and radio and print have a low effective rate according to Pallikadavath, Sreedharan and Stones (2006). They suggest using health workers, community level activities such as adult education programmes, and networks of friends and family. In South India, the Positive Women's Network is seeking to address stigma, fear and paranoia of other individuals (UNAIDS, UNFPA and UNIFEM, 2004).

Discrimination is addressed within the national HIV/AIDS policy, although various states' policies may differ. Despite the policies, there is no legislation to implement change, although some authors have said that there is an urgent need for such legislation (Arunkumar, Sankar, Archana and Kochumuttom, 2002). Although all hospitals in Mumbai are expected to provide care for people living with HIV/AIDS (PLWAS), people with HIV report harassment when they try to access health care (UNAIDS, 2007b). HIV prevalence varies widely according to geographical areas and risk groups. There are two different situations – lack of support and care for PLWHA, and also the fear of stigma prevents many people getting tested.

Some examples of programmes to offset the effects of stigma and discrimination are The Society for Positive Atmosphere and Related Support to HIV/AIDS in Kolkata, in which women learn to sew and sell handicrafts. In Manipur, the Social Awareness Service Organisation helps HIV-infected widows, and The Institute of Health Management employs social workers to intervene in family disputes. PRAYAS is a non-profit organisation which researches the effects of HIV/AIDS stigma on women and their coping abilities (Cohen, 2004). UNAIDS supported a partnership between the Nagaland SACS, NGOs, Nagaland Network of Positive People and Naga People's Movement for Human Rights to address stigma and discrimination. At a

state workshop, representatives from the government, tribal hierarchy, students, church, media and lawyers joined to address stigma and discrimination through community involvement and partnerships (Chatterjee, 2004).

There are other examples of the use of positive people to spread the message. For example, the Gujarat State AIDS Control Society has undertaken a comprehensive needs assessment in six urban settings with the help of people who are HIV positive. This has resulted in building networks, research capacities and a morale boost for the researchers. UNIFEM has supported the participation of three HIV positive women in a national consultation on Domestic Violence Bill organised by Action India and the Lawyers Collective. The Indian Network for People living with HIV/AIDS (INP+) launched the Positive Speakers Bureau. This is designed to empower PLWHA to tell their stories, in order to reduce stigma and discrimination (Chatterjee, 2004).

2.8 International responses to HIV/AIDS in India

The World Bank has worked with the Government of India through NACO to ensure collaboration with overseas partners such as UNAIDS, WHO, USAID, DFID and CIDA. Overseas funding for HIV/AIDS projects totalled US\$328 million in 2005 (World Bank, 2005). The World Bank stresses that India must move quickly to target high-risk groups such as CSWs, MSM, migrant labourers, and IDUs to contain the spread of the epidemic. Strategies promoted are peer counselling, condom promotion, treatment of STDs, and patient programmes.

Prevention strategies, which have proved successful, are information and awareness campaigns with an emphasis on behaviour change, voluntary testing and counselling through blood banks and STD clinics, and the reduction of transmission through blood transfusions and exposure through occupations. Funding through the World Bank provides low cost treatment for PLWHA, home and community-based care and treatment of opportunistic infections. Another facet is the strengthening of the effectiveness of programmes across the country, and improving surveillance and data collection (World Bank, 2005). It is important to focus on the state of Maharashtra, because different states in India have made varying responses, as seen above. The

following section details the pertinent issues and challenges facing the state, and, in particular, the city of Mumbai, its capital.



Figure 1: Location of Maharashtra in India (Source: www.mapsofindia.com)

2.8.1 The state of Maharashtra

Maharashtra is the third largest state of India, and leads the country in industry, contributing 13% of the national output, producing chemical and allied products, electrical and non-electrical machinery, textiles and petroleum (Chatterjee, 2004). However, over 64% of the state's population are employed in agricultural areas. Maharashtra is one of six states with a high prevalence rate of HIV/AIDS - over 5% among groups with high-risk behaviour, and 1% among women attending antenatal clinics in public hospitals (Chatterjee, 2004).

2.8.2 The mega city of Mumbai

Maharashtra's main city, Mumbai, has a prevalence of over 2% of the population (Solomon, Chakraborty and Yepthomi, 2004). Situated on the western seaboard of India, Mumbai is the financial capital of India. It has also been named the AIDS

capital of India. The bustling, thriving metropolis attracts migrant workers, and truck drivers from all over the country (Bharat and Aggleton, 1999). Mumbai is located on a peninsular with little space to expand, resulting in overcrowding, with over 15 million inhabitants living in an area of 440 square km (Mumbaispace, 2005), and poor socio-economic conditions for a majority of the inhabitants (Eliot, 1998).

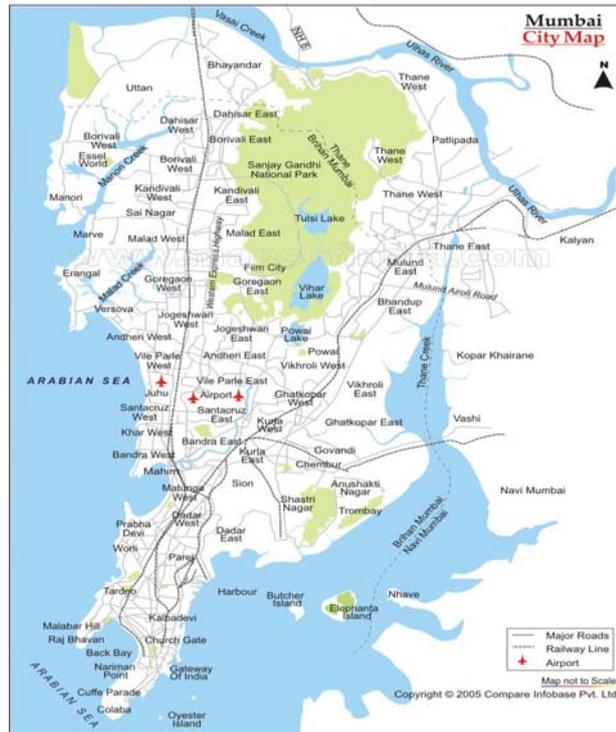


Figure 2: Map of Mumbai (Source: www.mapsofindia.com)

2.8.3 The unique place of migrants in Mumbai

The female population living in rural areas has declined from 70% to 50% because of migration away from rural areas and villages. Thus, female migration to the cities is rarely voluntary, but as a result of decreasing rural viability, according to Feldman (1998). The factors contributing to the increasing poverty amongst rural women include a decrease in per capita food availability. This has occurred in rural areas because of animals slaughtered to feed the cities. In turn, this has meant losses in the traditional employment of women in their subsistence occupations of sheep rearing, dairying, wool-making and weaving. Tribes such as the Halkars, who are sheep rearers, have disappeared in 19 districts in Maharashtra (Mishra, 1999). Singh (1999, p.21) terms this migration the “feminization of poverty,” and claims that the centrally sponsored poverty eradication programmes have also meant that women

have become more impoverished, and moved to the cities as programmes may not have favoured or reached them.

The exchange of rural hardship for urban squalor is the reality for many women instead of dreams of economic liberation, and employment in the city. Poverty and low status make women especially vulnerable, and despite the gains made by middle to upper class women in India, tradition and poverty are still major obstacles for most women (Schaffer and Mitra, 2004). In addition to the migration from rural to urban areas, poverty and its attendant overcrowding among the male population in Mumbai has contributed to men seeking work outside the crowded city. This has resulted in a vast army of truck drivers traversing the whole country (Stansbury and Sierra, 2004). They are away from home for prolonged periods of time, and are known to be major carriers of HIV/AIDS, as they are reported to have up to 200 sexual encounters in one year, although these figures are said to be reducing, for example, 48% to 27% from 1996 to 2002 (Solomon, Chakraborty and Yepthomi, 2004). 70% of male migrant workers are reported to have STIs and 30% to have AIDS. The men return to urban and rural households where they pass on the infection to their wives and, ultimately, children, through mother-to-child transmission.

2.8.4 The sex worker industry in Mumbai

The migration to big cities such as Mumbai is especially hard on women. Uprooted from their families and village traditions, they become embroiled in the traumas of cash-commodity-flesh-trading in order to survive. This results in criminal activities such as prostitution, bootlegging, and trade in contraband. Since the first AIDS case was detected in Chennai, Tamil Nadu, in 1986, there has been an alarming growth in the number of HIV positive people in Mumbai, which has the largest brothel-based sex industry in India, with an estimated 15,000 sex workers, 62-70% of whom are HIV positive. The number of HIV positive sex workers increased from 1% to 51%, in 5 years (1993-1998) (Ekstrand, Garbus and Marseille, 2003). India's cultural diversity, regional differences and taboos may hinder the collection of exact data, so the figures may be even higher, according to several researchers (Solomon, Chakraborty and Yepthomi, 2004; Chatterjee, 2004).

2.9 Summary of chapter

The literature regarding HIV/AIDS in India is now extensive. There are national government departments and organisations, state societies for the prevention of HIV/AIDS, and many internationally funded organisations. The research, however, tends to focus on perceived high-risk groups such as CSWs, MSM and IDU. These groups will have higher profiles in different states and cities. For example, the size of the brothel-based sex industry in Mumbai will attract more attention. Married women have not been a focus of attention until recently, and because of the low status of women in the slums, are unlikely to attract attention. Although India's HIV/AIDS epidemic is small in prevalence, the huge population means that even a small increment leads to millions of people being affected. Recently, the incidence is said to have been halved, because of more accurate surveillance methods. India has implemented successful interventions and strategies, however, structural problems in the allocation of funds, corruption and mismanagement, mean that even the distribution of lifesaving medication is delayed. Where peer education and community responses are implemented, there is significant success. Stigma and discrimination play an important role in the epidemic because of structural and cultural factors. Chapter 3 discusses the ubiquity of stigma, discrimination and prejudice; and how understanding of the concepts is necessary in order to strategise responses in the area of HIV/AIDS. Chapter 5 provides a historical and social background to the stigma and discrimination of Indian women.

CHAPTER 3

ASPECTS OF STIGMA AND DISCRIMINATION IN RELATION TO HIV/AIDS

“HIV-related stigma and discrimination are more difficult to address than the actual virus, and tend to be an afterthought. We can no longer claim that stigma and discrimination are abstract and intangible concepts.” (Eka Esu Williams, Horizons/Population Council, South Africa, cited in Health & Development Networks, 2007, p.48).

3.0 Introduction to the chapter

In this chapter, the cultural and social aspects of stigma, discrimination and prejudice are explored. The stigma which accompanies HIV/AIDS globally, and in India, are described, with particular reference to Indian women. Strategies which have been implemented successfully, and approaches in the mental health area are discussed.

3.1 Stigma

Stigma occurs in all societies, and it is created by individuals and communities in a response to their own fears (Brimlow, Cook and Seaton, 2003). It is remarkably consistent across all cultural contexts (Ogden and Nyblade, 2005). We see it in Australia in areas such as mental health. There is still a stigma attached to a mental illness and attending a psychologist. Responses to stigma may vary in different cultures, thus understanding local values and beliefs are essential, when designing programmes (Weiss, 2001).

Stigma is a Greek word which means a brand or mark on the body. These marks identified people to be avoided by others in their society - for example, criminals, or slaves (Goffman, 1963). Before modern medical miracles, people with diseases such as syphilis, known as the ‘grand pox’, exhibited visible signs such as great pustules.

No-one wanted to claim this disease. The British called it the 'French disease', the Japanese named it the 'Chinese disease', the Turks the 'Christian disease', the Persians the 'Turkish disease', and the French the 'Spanish disease' (Gaitonde, 2001).

In medieval times, lepers were treated as if highly contagious, and made to wear bells (Gaitonde, 2001). In recent history, the Nazis branded Jewish people with numbers in concentration camps, which remain forever etched on their arms. Falk (cited in Weiss and Ramakrishna, 2001, p.2) identifies groups which are singled out to be stigmatised as women, people with cognitive deficits, homosexuals, single people, prostitutes, African-Americans, the overweight and even successful people. A group which he has missed are the physically disabled, particularly women. "*Stigma kills*" according to Sam Friedman from the National Development and Research Institute, United States (Health & Development Networks, 2006). It is as simple as that.

Nicola Brennan from IrishAid, Ireland says:

"Stigma continues to be one of the great barriers in effectively addressing HIV/AIDS. Its impact is far-ranging – discouraging decision makers from pursuing sound public health policies, deterring individuals from finding out about HIV status, inhibiting those infected from being open and taking action."

David, a patient with 'Empowering Concepts', Mozambique says:

"Stigma begins internally with me, and then becomes external, based on my own perceptions of good and bad, right and wrong."

This statement is from Paul Toh, Thailand:

"Self stigma is more deadly than the HIV living within our bodies. It infects your mental state, resulting in behaviours beyond your own ability to comprehend."

These voices were recorded in a continuing eforum – “*Living on the outside*” reveal the seriousness and trauma of experiencing HIV/AIDS (Health & Development Networks, 2006).

3.1.1 Meanings of stigma

There are two general meanings of stigma. One is used in the religious sense, where a person receives a stigma or stigmata as a sign of religious fervour, such as Saint Francis of Assisi. Even more recently, a Catholic churchgoer in Western Australia has developed the stigmata for years (Gibson, 2006). The wounds of the crucified Christ appear as real on a person’s hands and feet and side, and may be observed to bleed. Kostermanis (2006, p.27) says:

“For all Christians, the stigmata of Christ should provide inspiration and guidance to reach out and care for the stigmatised and to fight it where stigmatisation occurs. It seems to me, in Christianity, there is simply no place for stigmatisation.”

Stigma is also used to describe a person not marked physically, but in a social sense, with a sign of disgrace, or discredit or infamy (Gilmore and Somerville, 1994). For example, a paedophile may be stigmatised in our society, even if he has served his time in prison. Stigmatisation places people in a separate group where they feel different, devalued and discriminated against – an “undesired differentness” according to Goffman (1963). Sometimes the results can be productive. For example, a woman may feel stigmatised by her gender and inequality, and make extra efforts to succeed in life.

We learn stigmatisation from childhood, and use it in many forms. Pryor, Reeder and Landau (1999) carried out studies with children, and found that their reactions towards interacting with a PLWHA were closely correlated to their parents’ reactions, so these attitudes are learned early, and fit into a social contamination model. This means that people are afraid of catching the disease just by being near someone who is infected. Fear is uppermost in the production of stigma. This fear may arise from the stigma-bearer reminding others of their own vulnerability.

‘Normal’ people may fear contamination, or acquiring a disease such as HIV/AIDS, or that they may be tempted to indulge in some perceived deviant behaviour. There may also be a fear of having to help, or a fear of being powerless (Pryor and Reeder, 1993).

Some societies may not be able to distinguish between scientific explanations and superstitious beliefs, and may perceive HIV/AIDS as a retribution for moral transgressions, or punishment for having deviated from the mores of their particular society. Stigmatisation increases if the individual is seen to have caused the infection, such as injecting drug users, men having sex with men, and commercial sex workers (Quam, 1990; Mak, Mo, Cheung, Woo, Cheung and Lee, 2006).

The negative emotions which result from fear can be projected onto a person or group, instead of dealing with disturbing emotions. Societies, in general, will react strongly to a perceived threat to their values, and work to reduce difference, strengthen conformity, and define the boundaries by exclusion of ‘different’ people. As described above, throughout history, groups of people have been identified and scapegoated. Certain illnesses have attracted stigmatisation because they are related to sexual transmission, i.e. syphilis. It is not surprising; therefore, that HIV/AIDS has attracted its own stigmatising perceptions and attitudes. Herek (1999) suggests that HIV/AIDS has at least four of the characteristics likely to attract stigma. It is a disease perceived to be the bearer’s responsibility, it is life-threatening, contagious, and, lastly, it is seen to be repellent, ugly or upsetting.

3.1.2 Fear of stigma

Darak (2004) carried out a study in Pune, Maharashtra, exploring the fear of stigma. He found that there were three major categories of fear – the effect on one’s image in society, social and/or physical isolation, and ostracism. Women suffered from *courtesy stigma* (being associated with the HIV/AIDS positive person), even if they were not infected themselves. Secrecy associated with the disease affected women’s ability to access resources, care and treatment, their efficiency at work, interpersonal relations, expression of their feelings and emotions.

In addition, secrecy leads to social isolation, one of the greatest punishments known to mankind (Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo, 2007). We all suffer when we are not accepted socially. This, in turn, leads to loneliness (Williams, 1997). Lonely individuals are more likely to approach stressors as threats rather than challenges, and to cope with these threats in a passive way. They do not seek out help, as they have low self-esteem. There is evidence that unless the need for belonging, control, self-esteem and meaningful existence are met, humans suffer mental and physical illness (Williams and Zadro, 2005).

3.1.3 Characteristics of stigma

Gilmore and Somerville (1994) define four characteristics of stigma: a) The problem or condition which triggers the stigmatising reaction; b) Identifying the person or group targeted for stigmatisation; c) Identifying the stigma and d) The reaction to the stigmatised person. Differences in disease attributions and stigma depend on factors such as whether the disease creates physical limitations to the infected, whether the disease poses serious consequences to others, and whether the disease is associated with symbolic meaning and negative images (Pryor, Reeder and Landau, 1999). According to Novick (cited in Lee, Kochman and Sikkema, 2002, p. 210), the condition of HIV/AIDS provides another layer on top of the existing stigma which is associated with perceived deviant behaviour. For example, homosexuals may already be stigmatised in society, and even more so if they contract HIV/AIDS.

Stigma can be directed at different people in different cultures (Pryor, Reeder and Landau, 1999). In the United States, the ratio of AIDS infection of men to women is about 16:1, which leads to the perception that HIV/AIDS is a disease which is more associated with homosexuals or injecting-drug-users. In Africa, the ratio is more 1:1, and the dominant means of transmission is through heterosexual intercourse, leading people to associate HIV/AIDS with migratory labour, and/or breaking sexual taboos. Different health beliefs have their role also. In Africa, the wasting away in AIDS is associated with the power of witches to attack the life force, and may be attributed to sorcery (Pryor, Reeder and Landau, 1999). Shame leads to secrecy, in order to protect one's reputation (Menadue, 2006). Chatterjee (2002) found in his research, that TARSHI's telephone helpline in India helps to deal with this aspect.

3.1.4 Functions of stigmatisation

Pryor and Reeder (1993) identify the purposes of stigmatisation. Firstly, it can be individually protective – one may avoid having sex with people known to have HIV/AIDS. Secondly, stigmatisation can have a role in collectively strengthening or homogenising a community, since it gets rid of socially unwanted people. For example, asylums were used in the past to house the mentally ill or depressed, thus separating these people from the community. As people age in our society, they are increasingly separated into progressive stages of aged care. Thirdly, stigmatisation can be used as a means of social control. South Africa successfully segregated the Africans, who were perceived as less desirable members of society from the ruling class through the system of apartheid. The exercise of power and domination is inherent in this area. By stigmatising, one group gains more power or control over another. Mak et al. (2006) use Weiner's attribution theory to explain that individuals assess whether a person has been responsible for their illness, and whether it is controllable. They then blame and exclude people, especially with HIV/AIDS.

3.1.5 The influence of Goffman in understanding stigma

The theoretical understanding of stigma has been shaped by Goffman (1963). He was a social science theorist, and his approach refers primarily to the way people manage themselves in social interactions. He theorised that the stigmatised individual was a person who possesses a difference which is not valued in society. When individuals fail to meet the norms of society, they are reduced from being acceptable, to being discounted. The discrepancy between what is desired, and what is acceptable, creates the "spoiled identity" (Goffman, cited in Parker and Aggleton, 2003, p.14). This change is not created by the individual, but comes from what that particular society's perception of 'normal' is. Unfortunately, the stigmatised take on society's perspective which leads to internalised negative feelings, such as shame, dejection, self-doubt, guilt, self-blame (Health and Development Networks, 2006). Alonzo and Reynolds (1995) remind us that people who are stigmatised are not inherently pathological, immoral or deviant, only different.

Parker and Aggleton (2003) argue that approaches based on Goffman's work view stigma as a static, unchanging characteristic; and that definitions of stigma have been vague and varied. Interventions have focused on the perceptions and attitudes of

individuals, and the implications for social interaction. For example, programmes which aim at changing anxiety and fear of PLWHA, or endeavouring to increase altruism or empathy by individuals or groups. Weiss and Ramakrishna (2003) agree that, although Goffman's work is still relevant, there are limits to its applicability to managers and policymakers. Policy-makers in the disability area have turned from this approach to structural notions of discrimination and oppression (Sayce, 1998).

3.2 Types of stigma

Researchers such as Inzlicht, McKay, & Aronson (2006) and Aggleton, Wood, & Malcolm (2004) have endeavoured to identify different categories of stigma in order to understand the phenomenon; and to guide interventions to reduce its effects.

3.2.1 Individual stigma

Self stigma is stigma that is accepted and internalised by a person so that he/she takes on the attitudes and perceptions of others, which become the belief system. The person can then restrict his/her behaviour, and develop self-blame and self-pity (UNAIDS, 2001). This leads to *attributional ambiguity*, whereby the person is uncertain whether s/he is being judged because s/he deserves it, or because of prejudices held against one's group (Inzlicht, McKay and Aronson, 2006). Thus, even before society can reject, the person already rejects him/herself, and feels dirty, ashamed, and marked (Health and Development Networks, 2006). This *internalized stigma* means that the person may not seek medical attention. It can have a profound psychological effect, and leads to depression, and isolation (Aggleton, Wood and Malcolm, 2005); Bharat terms this personal stigma *enacted* (Bharat, 2004). *Felt* stigma is that which is perceived to be in the surrounding atmosphere affecting the person, and can result in violation of the person's rights. It can be *overt* or *subtle* (Pryor and Reeder, 1993).

3.2.2 Dyadic stigma

In addition to the stigma which affects the individual, there is *dyadic stigma*, described by (Wight, Aneshensel, Murphy, Miller-Martinez and Beals, 2006) which may include the stigma felt by the person who has HIV/AIDS, combined with caregiver stigma, (being associated with someone who has HIV/AIDS), plus the

overlap in stigma which represents the individual perceptions of the person with HIV/AIDS and the caregiver.

3.2.3 Instrumental and symbolic stigma

Herek (1999) uses the term *instrumental stigma* to describe the fear and apprehension that are likely to accompany any deadly or transmissible disease. Because HIV/AIDS is a potentially fatal condition, this stigma is another facet of the layers of stigma felt by a person with this disease. *Symbolic stigma* may be used as a vehicle to express hostility towards already marginalised groups (Herek, 1999). Groups such as commercial sex workers, men who have sex with men or injecting drug users endure such stigma.

3.2.4 Courtesy stigma

Bharat, Aggleton and Tyrer (2004) use the term *courtesy stigma* which arises from the association of family members or medical workers, whereby they are branded for working or helping PLWHA (Health and Development Networks, 2006). This stigma was expressed by the community health workers in the SAHAS programme during this research study. Objects also may be associated with stigma, and become 'tainted'. Thus, family members may isolate cooking and eating utensils used by the person with HIV/AIDS (Pryor and Reeder, 1993), even though there is no risk of contamination.

3.2.5 Structural stigma

Structural stigma derives from institutions such as the media when they spread stigmatising messages (Corrigan, Watson, Gracia, Slopen, Rasinski and Hale, 2005). Reporting can be responsible, but is often sensational and insensitive. Mak et al. (2006) use the term *public stigma* in examining institutions and funding. They argue that this affects public policy and resource allocation.

3.2.6 Restigmatisation

This can occur when one group is singled out already, such as homosexuals (Herdt, 2001). It is important to understand this type of stigma, as it may lead to covering up, or passing as normal. There is always the possibility in publicising situations of stigma and discrimination, that the person is restigmatised. Bharat and Aggleton

(1999) assert that stigma leads to loss of social status and prestige, and affects a person's self-worth.

3.3 Prejudice

Prejudice, according to Chambers Dictionary, is “a biased opinion based on insufficient knowledge” (www.chambersharrap.co.uk). Prejudice serves a purpose for the individual, according to Katz (1960). Firstly, there is an *instrumental* function – i.e holding a particular prejudice has a reward. A sense of personal security can be gained by stigmatising a group. Therefore, by avoiding such a group, there is a perception that one is protecting one's health. Secondly, there is an ego-defensive function – where a person projects unacceptable views onto another person, in order to defend him/herself. Thirdly, a value-expressive function – this acts to distance oneself from the group by expressing views of the dominant ideology. Lastly, there is a knowledge function, which enables a person to make sense of the world, and give structure to his/her experiences.

People who have more prejudice may believe that PLWHA should be placed under control of the State, in order to prevent spread of the disease; or that compulsory testing from high-risk groups may ensure control and prevention of further spread in the community (Kippax, Tiller, Crawford and Cregan, 1991). The expression of such views establishes the prejudiced person as being firmly against the deviant or different; and helps the prejudiced person to understand, and make sense of AIDS. Punishment and retribution may be enacted at an institutional and individual level, in the form of refusal of treatment, incarceration, isolation and avoidance of people suspected of having AIDS (Kippax et al., 1991).

There is also a natural, rational fear of a deadly illness which provides a protective function for the person. However, it must be remembered that one can avoid HIV/AIDS by adhering to safe sexual practices without resorting to prejudice. Irrational fears arise from exaggerated risks of contagion (Kippax et al., 1991). In the beginning, ‘deviant’ groups such as CSWs, IDUs and homosexuals were targets, but now prejudice is extended to any person with HIV/AIDS, whatever their sexual

orientation. A further rational fear can arise as people learn of discriminatory practices. This is the fear of being rejected and stigmatised if infected.

3.4 Discrimination

Discrimination is based on fears such as those described in the previous section. Because the person is seen as undesirable, isolation and rejection arise. From the point of view of the discredited person, he/she accepts the norms of the community/society and internalises the negative values as shame, repressed anger, self-hatred from the discrimination in addition to his/her already existing *self stigma* (Bharat, Aggleton and Tyrer, 2004). Discrimination is a product of existing institutions and power differences, and can be used by one group against another for power acquisition (Kippax et al., 1991). Individuals may, however, fight against that rejection, and develop theories which dispute their imputed inferiority, and expose the fallacies of the dominant perspective. Alonzo and Reynolds (1995) and Goffman (1963) suggest that the group of stigmatised individuals develops an awareness of their difference through the media sensationalising their plight. This can work for or against them. Thus, Alonzo and Reynolds (1995, p.314) have developed the following definition:

“The stigmatized are a category of people who are pejoratively regarded by the broader society, and are shunned, devalued or otherwise lessened in their life chances, and in access to the humanizing benefit of free and unfettered social intercourse.”

This results in social exclusion, violence, blaming, labelling, neglect and denial of resources and services which should be rightfully for all. The stronger the shame in a society, the greater is the discrimination. Burns (1996), writing in the New York Times, called PLWHA in India the “*wretched new class of infected untouchables*”, an example of restigmatisation. Isolationist practices are widespread in India, where HIV/AIDS persons are hospitalised in ill-equipped wards of hospitals (Bharat, 2004; Bharat, Aggleton and Tyrer, 2004). Another definition comes from Weiss and Ramakrishna (2001, p.3):

“Stigma is a social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgement about a person or group. The judgement is based on an enduring feature of identity attributable to a health problem or health-related condition, and this judgement is in some essential way, unwarranted. In addition to its application to persons or a group, the discriminatory social judgement may also be applied to the disease or designated health problem with repercussions in social and health policy.”

Discrimination is even less defined than stigma. Commonly, it is taken to mean being treated unfairly through “*dislike of the unlike*” (Marshall, 1998; Parker and Aggleton, 2002, p.9). Parker and Aggleton have extended the theories beyond the individual reaction to social processes which must be analysed in terms of power and domination and control mechanisms in order to understand how discrimination occurs. Examination of the struggle for power goes beyond the individual, and is better understood by the combination of the individual, culture and community. Scapegoating, blame and punishment are methods used by the community to display discrimination (Parker and Aggleton, 2002).

Stigma and discrimination are not concepts set in concrete. In fact, there are periods when the person living with HIV/AIDS may not be discriminated against. According to Alonzo and Reynolds (1995), there are four stages of the stigma trajectory where the person will exhibit different reactions to the stigma – at risk, diagnosis, latent, and manifest. The role of culture in the adjustment to HIV/AIDS in a family is discussed later in Chapter 8.

3.5 Psychological aspects of stigma

3.5.1 Stresses for men and women living with HIV/AIDS

There is no doubt that HIV/AIDS places an enormous burden on the individual. I examined research on the psychological aspects of resilience, to examine the threats and strengths which either help people to cope, or further threaten their ability. We know that stressful life circumstances have the potential to generate additional stress and feelings of being overwhelmed or overloaded for the caregiver (Wright and Martin, 2003).

People with HIV/AIDS experience more depression (Gore-Felton, Koopman, Spiegel, Vosvick, Brondino and Winningham, 2006) and more psychological distress (Catz, Gore-Felton and McClure, 2002). Penzak, Reddy and Grimsley (2000) estimated lifetime prevalence of major depression of PLWHA at 22-45%, whereas general population incidence of depression is 17%. The high levels of anxiety and depression experienced by PLWHAS lead to poor compliance to treatment and acceleration of progression of disease, physical decline and decreased purpose in life. Social and contextual factors including minority status, isolation and limitations in supportive resources make them even more vulnerable to negative psychological effects. On the other hand, quality social roles mediate the effect of health problems, particularly psychological wellbeing. Coping with prejudice involves making trade-offs in which some of the goals of the individual may be sacrificed to achieve those which are most important to the stigmatised individual in a particular situation. For example, a person may not even attempt to find work because he/she is afraid of stigma (Wight et al., 2006). Inzlicht, McKay and Aronson (2006) proposed that the effort required to cope with devalued social identity drains the person, leaving him/her less able to engage in self-control for other things.

Chronic uncertainty is another source of stress experienced by the stigmatised. This is caused by the person being unable to distinguish whether they are being singled out, because of prejudice against their group, or because of personal attributes (attributional ambiguity). "Stigma increases a person's stress, uncertainty and vigilance, and can lead to intellectual underperformance" (Inzlicht et al., 2006, p.2). When faced with prejudice, individuals have to choose to respond by confronting the perpetrator, or ignoring the situation (Shelton, Richeson, Salvatore and Hill, 2006). Thus, a person may use avoidance, or wish that the situation would go away. For example, a person may not even attempt to find work because he/she is afraid of stigma (Wight et al., 2006).

Rogers, Hansen, Levy, Tate and Sikkema's (2005) study on loss in bereaved HIV-positive men and women found that optimism was associated with active coping. Social support has an important role in lowering depression. If a person uses maladaptive coping (i.e. denial or avoidance) this leads to more depression.

Depression gets worse if not treated. Sikkema, Kochman, Di Franceisco, Kelly and Hoffmann (2003) returned to their research into grieving three years after the initial research, and found that higher levels of grieving were associated with maladaptive escape and avoidance strategies; and additionally, self-controlling coping strategies were associated with higher levels of depression.

3.6 Stigma related to HIV/AIDS

In the mid 1980s, researchers began reporting public attitudes towards AIDS, and found that the disease attracted more stigma than other conditions. Three factors have been cited by numerous authors as being influential – personal contact with PLWHA, attitudes towards homosexuality, and knowledge about HIV transmission. Strategies to counteract stigma have focused on education, primarily, and also social cognition theories (Hayes, Vaughan, Medeiros and Dubuque, 2002). Social cognition theories assert that associations are made in the brain between HIV and memory nodes, of ideas like promiscuity, death, homosexuality and threat. Over time, these associations become more entrenched. In order to break these associations, it is necessary to challenge these automatic network associations. For example, if a member of the family is affected, this may cause cognitive dissonance, as it challenges previously held ideas of homosexuality. This may explain why personal experience with a PLWHA changes attitudes from discrimination to positive (Hayes et al., 2002).

Sexual prejudice (formerly termed homophobia) may help maintain stigmatized beliefs about PLWHA in spite of educational campaigns. Hayes et al. (2002) found that AIDS was not perceived as being more debilitating than cancer. They used an interesting technique of imaginal exposure. By imagining a loved one to have HIV/AIDS, it was found that the relative or friend would be rated more favourably than an unknown person. Sexual prejudice remains an enduring obstacle. Stigma and discrimination are common to all PLWHA. These factors still persist despite education, awareness building, and worldwide efforts to stamp them out (de Bruyn, 1998) and remains one of the most poorly understood facets of the disease (Parker and Aggleton, 2003). Many authors describe stigma and discrimination as major problems in the prevention, disclosure, testing and access to services and care of

PLWHA (Population Council, 2005; Asia Pacific Network of People Living with HIV/AIDS, 2004; Brown, Macintyre and Trujillo, 2003).

ICRW's research in Tanzania found that 56% of PLWHA had experienced at least one form of stigma or discrimination, and nearly 30% knew of someone who had experienced this. In their research in Ethiopia, Tanzania, Vietnam and Zambia, study participants expressed deeply-held fears about the disease. Women are more prone to be stigmatised, and this is a barrier to health treatment (ICRW 2006; Population Council, 2005). Family and community stigma creates barriers to people being able to discuss safe sex practices, use condoms, disclose HIV status, use services and receive treatment (Nyblade, Pande, Banteyerga, Bond, Kilonzo, Mbwambo, and Kidanu, 2004). In recent studies, Mak et al. (2006); Mak, Poon, Pun and Cheung (2007) found that public stigma towards HIV/AIDS was higher than that directed towards other diseases such as SARS and tuberculosis in Hong Kong. They consider that individual stigma is broadened into public policy, and therefore provides institutional discrimination, resulting in less resource allocation, public education, research into the area of HIV/AIDS, and less civil protection of infected people.

3.7 International approaches to stigma and discrimination

Herek (1999) notes that ever since the first cases were detected in the United States, in 1981, PLWHA have been the target of stigma. Early surveys of public opinion showed widespread fear of the disease, lack of knowledge, and willingness to support draconian policies aimed at restricting such people. Despite 20 years of education and awareness programmes regarding HIV/AIDS, stigma still exists. In 1997, the general public still overestimated the risks of HIV transmission through casual contacts, and perceived PLWHA as deserving of their fate. A survey of 1800 people in 1992 reported that they had experienced violence in their communities because of their HIV status. In South Africa, an HIV-infected volunteer who revealed her status was beaten to death by neighbours (Herek, 1999; Piot, 2000). Studies in the US have found that African-Americans face higher risks of physical attack, and have reduced access to housing, employment and education due to their marginalized status (Inzlicht, McKay and Aronson, 2006).

The presence of stigma and discrimination leads to a loss of livelihood, marriage and child bearing, poor care, withdrawal of care giving, a loss of hope and future, and one's reputation, a sense of worthlessness, and a loss to the family and society according to Ogden and Nyblade (2005). Thomas, Rehman, Suryanarayanan, Josephine, Dilip, Dorairaj, and Swaminathan (2005) also agree that stigma needs to be discussed in its cultural context, but do not suggest how that might be achieved. They encourage HIV-infected individuals to leave the stigma behind, avoid internalising their stigmatising feelings, and work toward a better quality of life. Chesney and Smith (1999, p.1170) issue an imperative that steps be taken to address the serious problem of stigma associated with HIV – a second epidemic which must be stopped. Political leaders and health care professionals must make a strong commitment to stop it:

“They must confront their own prejudices and address any ambivalence, fear, hostility towards PLWHA that they harbour so that they can openly demonstrate or model compassion and caring for PLWHA.”

3.8 Stigma and discrimination in India

The situation regarding stigma and discrimination and people infected and affected by HIV/AIDS is even more difficult in India. Bharat, Aggleton and Tyrer (2004) report that, in India, stigma towards PLWHA permeates all facets of society including the family, community, different settings and health care, employment and education. Peter Piot, in his capacity as Executive Director of the Co-ordinating Board of the joint United Nations Programme on AIDS, described stigma as “a continuing challenge which prevents concerted action at a community, national and global levels” (cited in Parker and Aggleton, 2002, p.1) PLWHA are stigmatised with a “dirty disease” and “a disgrace to their family (Bharat, cited in Tarakeshwar et al., 2006, p.9) and both infected and affected people face ostracism, isolation and stigma. In a GIPA study in Delhi, 70% of the participants said they had faced stigma and discrimination – 74% of women and 68% of men (Chatterjee, 2004) Kumar, Ananthan and Saravanan (2000) surveyed hospital workers, medical professionals, heads of personnel and social welfare departments in industry and commerce in

2000. They found that stigma, discrimination and denial existed in all these areas, and that women are blamed for the transmission of STIs.

From the perspective of a person living with HIV/AIDS, stigma adds to the suffering of what is already a terrible disease (Weiss and Ramakrishna, 2001). They point out that sometimes hearing the diagnosis is more troubling than the symptoms of the disease, because of the associations. Stigma can be seen as common to mental illness, disability, and HIV/AIDS. PLWHA in 38 states in India acknowledged the burden of stigma and discrimination and how these factors add to their distress (Chatterjee, 2004).

3.8.1 Indian healthcare and discrimination of PLWHA

Unfortunately, it is in the healthcare domain in India that much discrimination exists for the person who has HIV/AIDS. One would expect that health care personnel would be trained in this area, but, in reality, health-care workers have their own fears and prejudices. Numerous authors point to evidence of denial of treatment in private hospitals in India (Aggleton, 2000), lack of confidentiality, general neglect, isolation and shunting patients from one facility to another (Bharat, Aggleton and Tyrer, 2004; YRG Care, 2004).

An APN (Asia Pacific Network) report in 2004 suggests that AIDS discrimination in Asia results from disclosure. Negative experiences in the health sector may influence disclosure elsewhere, i.e. within the family or workplace (Bharat, Aggleton and Tyrer, 2004). There appears to be a discrepancy between how the staff of hospitals regard the treatment of PLWHA, and the families and other patients. Some doctors refuse to treat patients, based on their assumptions of how the person became infected (Elamon, 2005). Widespread discrimination exists in all areas of healthcare including government and private hospitals, religious organisations and NGOs. In addition, policy does not always translate into practice, despite education programmes. Fear has a different base to knowledge, and can be rational or irrational (Vati, Walia and Sharma, 2003). There is no difference if the person with HIV/AIDS is being treated in the mental health area, where stigmatising attitudes to mental illness already exist. Wright and Martin (2003) found no improvement in

individual staff members' readiness to provide HIV care in a public mental health setting.

Aggleton (2000) found in Mumbai, evidence of stigmatising in the form of tubs of disinfectant under the beds of HIV positive patients, and hospital records marked in big letters **HIV**, or in specially designated beds in a ward. Confidentiality may not be observed in the hospital setting, and is much more likely not to be observed in places of employment where there is a threat of instant dismissal. Previous instances of stigma and discrimination are effective barriers to disclosure. In businesses which Aggleton (2000, p.26) surveyed, employers used denial, by saying their employees

“Do not have behaviour which makes them suspect for HIV. They are very well educated andso cannot fall easily for such things”.

These attitudes are strengthened by people and laws which should protect the worker but also deny their status and condition (Aggleton, 2003).

3.9 Gendered dimensions of stigma and discrimination for IWLWHA

Stigma and discrimination have particular relevance for women, and are inextricably woven into the texture of gender issues in India. Women are more affected by stigma (Asia Pacific Network of People Living with HIV/AIDS, 2004), and it can be said that the disease status adds to vulnerability, especially in women. Mawar et al. (2005); Chatterjee (1999); Population Services International India (2003) all agree that gender inequality is driving the epidemic, and therefore, a specific policy needs to be developed. This is particularly important in a patriarchal society. Very little has been developed for women. For example, the Saadhan HIV/AIDS Helpline developed in Mumbai has only 10% female callers, despite the numbers of women suffering from HIV/AIDS (Population Services International India, 2003).

Discrimination and violence towards women (i.e. rape) are conduits for the infection. Throughout the world, sexual abuse by caretakers with HIV/AIDS, and intercourse with irresponsible partners expose women. Poverty drives women into prostitution,

and trafficking is rife. Yet laws, policies and programmes to protect women are sadly lacking (Human Rights Watch, 2004). Overall, there is neglect of women's health, nutrition, education, literacy and property rights (Ekstrand, Garbus and Marseille, 2003). Even with the knowledge that women's needs are different, and largely unmet, there are very few gender-just programmes which address this problem. Sudha, Vijay and Lakshmi (2005) state the need for appropriate education for illiterate females.

Joseph and Bhatti (2004) interviewed Indian wives of men with HIV/AIDS and found that the women's concerns were as follows: increased financial difficulties, childcare, compromised help-seeking due to stigma, sexual interactions, communication, caregivers' role, inadequate care and increased concern about parenting. Escape avoidance was the most preferred coping strategy. Women with HIV/AIDS in India are faced with multifarious predicaments, which compromise their adaptation to the disease. These included concerns with financial issues, housing, health issues, death and dying, and children. Women who shared the diagnosis risked stigma and isolation and loss of self esteem.

The effect of HIV/AIDS was to complicate family caregiving responsibilities, cause anger and frustration, and add the risk of losing children. Bharat and Aggleton (1999) showed that household responses were not as supportive if a woman had HIV. Women could be burdened with a sick partner. Returning to their parental home was not always easy because of stigma, isolation and societal labelling as promiscuous. There is very little data post HIV infection about women as wives, mothers and daughters; as well as well as the havoc HIV/AIDS brings in marital relationships, childcare, social support, and the future. Coping patterns include escape avoidance seeking social support, self-control, distancing, positive reappraisal, painful problem solving, confrontative coping and accepting responsibilities. The researchers suggest that services need to be family oriented, community-based, using existing formal and informal networks. Interventions should assist with parenting skills, support groups and individual therapy sessions, cognitive behavioural therapy, psycho-educational approaches on safe sex, skills building, and assertiveness training, in order to negotiate safe sex. In addition, relaxation therapy, supportive services, improvement

of women's economic status, subsidised medical care, shelter and care for children were also suggested improvements (Bharat and Aggleton, 1999).

3.10 Strategies to overcome stigma and discrimination

Very few psychosocial studies focus on women with HIV, especially minority and low income women (Gillman and Newman, 1996). There are suggestions that women may experience even more distress, because of poverty, childcare, responsibilities of caring for others, and existing stigma and social isolation. In one study, Sikkema et al. (2003) used scales for depression, anxiety, stress, social support, coping, time since HIV diagnosis, CD4 counts and demographics, and reported that $\frac{3}{4}$ of the women participants had significant psychological distress - mild to severe depression, raised anxiety and a wide range of stresses. Gielen, MacDonnell, Wu, O'Campo and Faden (2001) emphasised the importance of quality of life among women living with HIV/AIDS, including self-care. Certain psychosocial factors could be expected to have a negative impact on quality of life, such as high rates of sexual and physical violence. Women often have inadequate social supports, and express concerns about stigma and discrimination and hopelessness.

For women, higher levels of social support mediate against the effect of the illness. A larger social network is associated with better mental health and overall quality of life. Social support is seen as a means of buffering oneself in the presence of stress. Practising more health-promoting behaviours i.e. taking vitamins, eating and sleeping well, exercising, managing stress, and self-care behaviours provide possible opportunities to improve quality of life. Penzak et al. (2000) found that women who had full-time work had lower levels of depression. Social support is seen as a means of buffering oneself in the presence of stress. Even in the face of a stigmatizing disease, women were able to identify positive things such as motivation to change positively, in addition to the negative experiences such as physical symptoms, limited life-span, alienation and stigma. Gore-Felton (2006) found higher levels of depression in life-threatening illness, and symptomatology.

A long list of researchers have found depression in PLWHA in the United States. Hackl, Kalichman and Sonlai (1996) examined women's responses, and found they had five main concerns: the impact of stigma, child care, caretaking roles, social support needs, death, dying and despair. In this study, women talked about the losses of their future, relationships, family and friends, ability to have children, ability to work, and fears about disclosing their status. Telling their children was one of the worst things they experienced, fear of rejection, coping with symptoms, daily hassles, guilt, depression anxiety and anger, fears of death, pain and suffering, and guilt over having an HIV positive baby. Women suggested having a positive attitude, creating a support system, educating and taking care of oneself. Researchers added providing social networks to buffer against stress.

Indian researchers have found similar emotional distress in PLWHA. For example, Chandra, Ravi, Desai and Subbakrishna (1998) found that depression was present in 40% of their sample of 51 HIV-positive men and women. Anxiety was found in 36% of the sample, and 14% had serious suicidal ideation. *Mama Jaja* describes the strengths of Ugandan grandmothers but the researchers are reluctant to talk of resilience of these women because "it will serve to excuse the world's apathy and neglect... People do not just bounce back, but over time they exhibit fortitude, endurance, and refuse to despair" (Poindexter, 2005, p.13). Gillman and Newman (1996) conducted a study in the United States on the psychosocial concerns and strengths of women with HIV. The women's concerns included finances, drugs, housing, health, death and dying and their children. They expressed fear over loss of control of their lives, possible loss of their children and housing, so many women kept their HIV status secret. Family, partners and friends were supportive. Children were a source of support. These women showed an uncanny will to live – resilience, flexibility, endurance, courage and compassion. HIV was just one of many problems, as the women were more concerned about where to eat and sleep.

3.11 Mental illness approaches to stigma

Stigma and discrimination have long been associated with people who have mental illness, so I examined literature to see if there were answers to these issues. Some authors feel that the labelling of mental disorders is in itself stigmatisin, probably

because of associations which go back centuries (Chamberlin cited in Sayce 1998, p.331). Angermeyer and Matschinger (2005) found that labelling of mental illness such as schizophrenia led to social distancing, because of the fear of the perceived unpredictability of such persons. Sayce (1998) found that discrimination in mental illness has not lessened but increased, in Britain in the 1990s. It may be important to develop more than one term to describe the very different facets of an individual's sense of shame, and a pattern of victims being refused jobs on account of their psychiatric diagnosis. There is a danger that the word stigma meaning a mark of disgrace will keep pulling us back to an individual perception. If we have to use one word, probably discrimination is better, because we are not compounding the stigma, and it remains 'structural', or social in origin, taking into account cultural beliefs (Sayce 1998).

Byrne (1999) feels that for any improvement in discrimination change must involve carers, other health care professionals, employers, schoolchildren and teachers, media, and the general public. Weiss and Ramakrishna (2001) assert that research into stigma has to include particular social and cultural contexts, variance between individuals and health care providers, and social policy in relation to human rights, access to health care and social services. Rosen (2006) says that western societies could learn from developing countries in combating stigma and discrimination. Other countries may provide better results by not isolating people, involving PLWHA in traditional healing, helping them to have valued work, and not isolating families. Corrigan and Penn (1999) claim, that strategies which have been tried in order to reduce stigmatization include *protest, education and contact*. *Protest* does not work because it is reactive – it diminishes negative attitudes about mental illness, but does not promote more positive ones.

Education provides information so that the public can make more informed decisions about mental illness, and contact diminishes stigma. *Education* may also lead to diminished discrimination, even if dramatic changes in stereotypes and stigma are not observed. However, there has not been enough research into the effect of education on behaviour change, or the impact over time. *Contact* has the best effect when people with a mental illness are presented as competent, and work together with members of the community on a task. Contact seems to work by a person's

natural stereotype of a group being superseded by another positive image. The possibilities of education and attitude change are reflected in the following statement from an Australian man suffering from HIV/AIDS, and gives hope for the future:

“Being diagnosed with HIV in the 80s involved a strong sense of stigma as I learned to live with the ‘gay plague’, the ‘new leprosy’ or the other shameful descriptors of the media. I no longer have these feelings about being HIV positive. Society has changed its attitudes towards us (to a large degree) and my family and friends have supported me all the way. I have learned to be open about my status, to feel OK about being positive without any real fear of repercussions” (Menadue, 2006).

The examination of stigma, discrimination and prejudice are necessary in order to firstly understand how they arise. This background informs this research study by exploring the individual and societal responses. Pryor and Reeder (1989) describe the immediate feelings and reactions to someone with HIV/AIDS, which is based on many different negative associations. They claim that the second process takes place as people use reason and cognitive rules which reduce stigma. This means that in time, people can learn to change their opinion regarding HIV.

3.12 Summary of chapter

This chapter has explored the history and characteristics of stigma, discrimination and prejudice. It is becoming clearer that education and awareness programmes lack the ability to change attitudes and beliefs in any significant way. More effective strategies need to be developed and the mental illness field has history and understanding to give. Cross-disciplinary research may uncover shared patterns which would be more useful than addressing the stigma and discrimination of PLWHA in isolation. Chapter 4 outlines the research design and Chapter 5 addresses the gender base of stigma and discrimination for Indian women.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

“An omnibus field strategy is one that simultaneously combines document analysis, interviewing of respondents and informants, direct participation, and introspection.” (Denzin, cited in Patton, 2002, p.265).

4.0 Introduction to the chapter

This chapter describes the background and the reasons for the study, the conceptual framework, and the research process. In addition, data collection and analysis, ethical considerations, and rigour of the study are discussed.

4.1 The rationale for studying stigma and discrimination

I was drawn to this area because of my work with women as a psychologist in a women’s health center. In Australia, I experienced the growth of feminism which has stalled to some degree, contributing to present inequalities of gender. For example, it was reported in *The West Australian* (4 October 2007, p.12) that the proportion of women in senior executive positions in Australia is actually falling, despite the fact that women now fill 64.9% of the public service. The issues that I see every day in counselling such as depression, domestic violence, financial strain and anxiety have a social and cultural underpinning. When I read of Indian women who are not prostitutes or injecting-drug-users but simply married women infected by their husbands, I wanted to know how they could be stigmatised and discriminated against.

4.2 Aims of the study

The first aim of the study was to determine whether stigma and discrimination exist for the target group of women affected and infected by HIV/AIDS. Their perceptions and experience were paramount, hence the qualitative approach. The second aim

was to document and analyse literature on the individual, societal and cultural situation of IWLWAs. A comprehensive and wide range of research and expertise was analysed to determine the extent of the problems of stigma and discrimination. Thirdly, the study aimed to identify and explore the psychosocial needs and coping strategies of IWLWAs. The fourth aim was to explore the barriers to accessing the health services. This was based on the knowledge that HIV/AIDS is accompanied by secrecy. The extent of non-disclosure will determine PLWHAs' ability to access health services. Additionally, stigma and discrimination will impact on peoples' decision to maintain secrecy. The health services in India are notable for their lack of training in stigma and discrimination, and women are particularly vulnerable. The last aim was to explore the community perceptions as IWLWAs experienced them.

4.3 The conceptual framework

The conceptual framework used for this study proposes that the psychosocial wellbeing of an individual is defined with respect to three core domains: human capacity, social ecology, culture and values. This framework may be used to map the vulnerability and resilience of individuals when faced with overwhelming events such as war or tsunamis. HIV/AIDS is no less a catastrophe for the individual, family and community. Psychosocial wellbeing is a broader term than mental health, and takes into consideration social and cultural factors which impinge on the individual. The individual's human capacity is composed not only of his/her physical and mental health, knowledge and skills; but also education and training which can enhance that capacity (The Psychosocial Working Group, 2003). Resilience as a concept has the advantage of examining coping from an assets base rather than deficits, thus building positive and hopeful foundations. The resilience of survivors can be strengthened by interventions where cultural and social issues are acknowledged, and respected. Additionally, these domains represent pools of resources which can be mobilized (The Psychosocial Working Group, 2003).

This framework resonates with Parker and Aggleton (2003), who have positioned stigma at the intersection of culture, power and difference. Stigma feeds on the existing inequalities of class, race, gender and sexuality. Bhattacharya (2004) explains why individual-based interventions may not work for Indians. He argues

that family norms and traditions, illness beliefs, spiritual views, socio-economic factors and community trust are vital in comprehending and planning interventions, particularly for Indians. It is also important to move away from a medical model which approaches the problem of HIV/AIDS as a disease which needs healing, rather than the wider approach which takes into account social factors such as the disruption to a community. At the same time, the community has resources which can be mobilized with support (Strang and Ager, 2007). The following figure represents the six important areas which either strengthen or reduce individual's ability to cope under difficult circumstances.

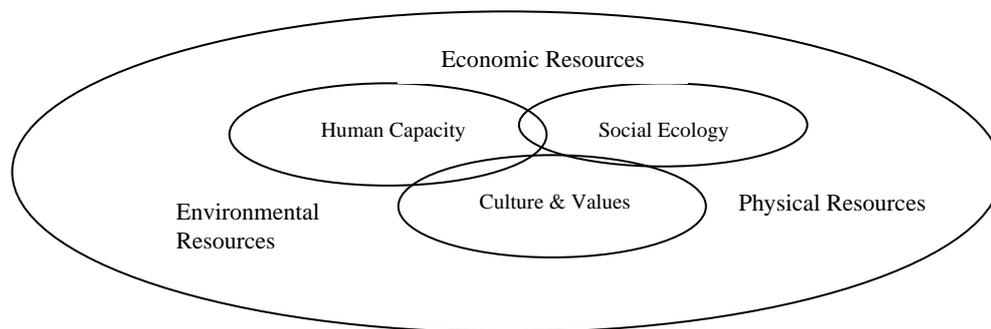


Figure 3: The interlocking circles of human capacity, social ecology and values (Psychosocial Working Group, 2003)

The psycho-social framework encourages evaluation of the goals, focus and priorities of existing programmes. Understanding the interdependency between the domains enables barriers to be identified and should promote better planning and implementation. The above framework guided the research process and methodology. The interlocking domains of human capacity, social ecology and culture and values were explored, as well as the influences from physical, environmental and economic spheres in relation to the stigma and discrimination faced by IWLWHAs.

I modified this framework further to explore the threats and strengths posed by the domains to the women in this study. This exploration was carried out in order to explore the positive and negative effects on the resilience of Indian women living with HIV/AIDS and the impacts on stigma and discrimination. Resilience is a broad term which describes the process of “withstanding the negative effects of risk exposure, and demonstrating positive adjustment in the face of trauma or adversity”

(Bartley 2007). Social deprivation and poverty will affect individuals' prospects throughout the course of their lives to succeed at school and obtain well paid, secure employment. However, there are always individuals who manage to lead healthy and rewarding lives despite the shortcomings of their situations. Bartley (2007) claims that social relationships, community ties and relationship skills are the key buffers which help offset the extremes of deprivation. This study explores the influences which impact on the women participants, but more importantly, highlights the assets which the participants draw on in their daily lives to help them cope. Strategies can then be implemented which would minimise the threats and enhance the coping abilities of the women. Broad topics and themes included in the interviews were as follows: the socio-cultural contexts of the lives of IWLWHA; the sense of security and community cohesion experienced as the illness unfolds; cultural and social factors, and how these link to perceptions and anxieties about the future; and the mediating influence of family, community and services.

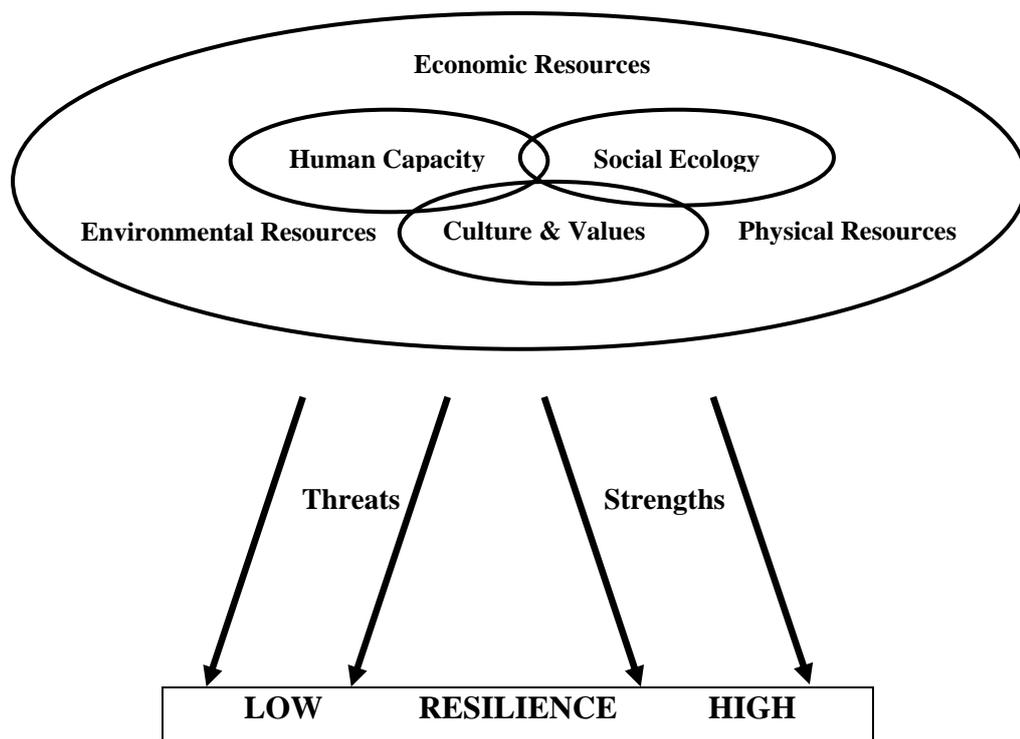


Figure 4: Modified Psychosocial Framework

4.4 The research approach

4.4.1 Qualitative design

This methodology was selected as it was most suitable for this kind of naturalistic and exploratory field research, because of its ability to provide valuable and rich data from the respondents themselves. Detailed data was collected from open-ended questions, providing direct quotations. The subjective data gathered seeks to understand people's perceptions, feelings and understanding of the reality of their world within a holistic framework. The researcher and interpreter were considered integral parts of the investigation. In addition to interviews, the researcher's observations and perceptions were used to describe the context of the variables being investigated.

A variety of different methodologies may be used within the umbrella of qualitative research, such as natural inquiry, interpretive research, hermeneutical research, post-positivism, critical theory and constructivism (Bailey, 1997; Guba and Lincoln, 1994). The philosophies which underpin this type of research are many and diverse, and may lead to different expressions. Social reality is not easily pinned down or absolute, so no one design is the "gold standard" (Gilgun, 2006, p. 436), nor is there one single truth or reality (Mays and Pope, 2000). In this study, different methods have been used to analyse the data. For example, frame analysis was used with the documentary data collection. The interviews were partly analysed with the use of graphs and quantitative measures, as well as content analysis underpinned by the psychosocial framework described in Figure 3. This resulted in the same conclusions being reached from different sets of data. The presence of stigma and discrimination is confirmed by the literature reviewed, the interviews, focus group discussion and key informants. Poverty and the difficult living conditions are described in newspaper articles, my observations and community mapping.

Gilgun (2006) argues that there are four cornerstones to qualitative research. The first cornerstone relates to research findings, theory and methodological principles. Theories help the researcher to decide what is important to study, how to interpret findings, and to place the findings within the body of research, and how to replicate these results in other situations. It may help practitioners to become more aware of theories, and give them more confidence that their work has a theoretical underpinning. Gilgun's second cornerstone is the researcher's expertise. This consists not only of academic qualifications, but also first-hand experience,

developed over time. At the beginning of research, the researcher approaches the topic with his/her experience. As the research proceeds, it requires the researcher to focus on the area under study, which inevitably leads to reflection, and incorporation of new bodies of knowledge.

The informants themselves are the third cornerstone. The research becomes valuable when ethical, epistemological (the relationship between the researcher and knowledge) and ontologic (what is the nature of knowledge or reality) requirements are met. Lastly, when a researcher brings practical experience in the area under study, s/he adds more depth to the analysis and discussion. However, one of the criticisms against qualitative research is that it is difficult to prevent or detect researcher-induced bias. In order to reduce bias and confirm the findings, methodological triangulation was used in this study. Data from a variety of sources were analysed to provide convergence of the results (Key, 1997). A second criticism of qualitative research is that, because of its subjectivity, there are difficulties in establishing reliability and validity. The advantages lie in the production of in-depth, comprehensive information, and a fuller description of the context (Key, 1997). Qualitative research also explores power and the relationship between the researcher and participants. Stringent ethical guidelines are necessary because of the potential power imbalance and exploitation of participants.

4.4.2 A Case Study approach

A case study approach was the most suitable for this type of research, because the purpose was to “gather comprehensive, systematic and in-depth information about each case of interest” (Patton, 2002, p.447). Case studies can be used to investigate individuals, groups, institutions or other social units, but the focus of attention is on the individual and not the total population. Cases can also be “critical incidents, stages in the life of a person or program” according to Patton (2002, p.447). This type of research is used in a number of research strategies such as field studies, action research, case application descriptions and ethnography, with a variety of approaches – positivist, interpretivist, deductive, and inductive. Cavaye (1996) lists the characteristics associated with case study approaches. For example, a case study does not explicitly control or manipulate variables. Secondly, it investigates in a natural setting at one of a few sites, and it makes use of qualitative methodology.

Following the aims of qualitative research, a case study endeavours to capture reality by studying the area in a natural context. The variables may be numerous and are not necessarily predetermined.

A case study can be a source of rich, detailed data which provides not only meanings, but reasons for behaviour, thus enabling the researcher to explore further strategies for intervention. By using this method, readers can understand the reality of people in their natural setting which can have more resonance than a numerical analysis. It is possible to establish cause and effect from the context in which events and situations arise (Cohen, Marmion and Morrison, 2000). Case studies endeavour to show what it is like to live and work in a particular situation, acknowledging that humans are dynamic and changing; and they represent a snapshot in time of a particular person. Events and situations are allowed to speak for themselves rather than to be largely interpreted, evaluated or judged by the researcher. Cohen et al. (2000), caution against sensationalizing the case, selective reporting, mere anecdotes, pomposity or blandness.

4.4.3 The research site

4.4.3.1 The Positive Living Program for People Living with HIV/AIDS (PLWHA) now renamed SAHAS

This programme was initiated by the K J Somaiya Medical College and Hospital in Mumbai, India to provide a comprehensive system of care to people living with HIV/AIDS. Up to this time, only government-managed institutions or government-assisted research institutions had comprehensive staff training in the management of HIV/AIDS. In order to implement the training of all medical personnel, and to provide comprehensive care, the KJ Somaiya Trust has worked with the Catholic Relief Services to develop the project. KJ Somaiya Hospital has treated 654 HIV patients since 1999, 437 as inpatients (KJ Somaiya Medical College & Hospital, 2002). Women suffering from HIV deliver babies at this hospital and the Department of Chest Medicine has 40-50 beds filled at any time with patients suffering from tuberculosis (TB) and HIV (Somaiya CRS-HIV Project, 2004). The KJ Somaiya Hospital initiated the project to incorporate strategies to prevent the spread of infection; to cope with the co-existence of other conditions such as tuberculosis with

HIV/AIDS, and to provide comprehensive care and support to both patients and their families who undergo psychological problems such as stress and anxiety.

4.4.3.2 The aims of the Somaiya Integrated Care Program

The Somaiya project has five aims: The first aim is to provide home-based care including medical, nutritional and psychological support to improve the overall health and quality of life of people living with HIV/AIDS, and to provide practical assistance. The second aim relates to the appropriate training of home-care workers. The third aim of SAHAS is to provide a sensitive in-patient service protecting confidentiality, and with a policy of non-segregation of HIV-positive patients. The project also promotes the development of a day-care programme for disadvantaged HIV-positive women with its fourth aim. Lastly, the Somaiya programme aims to develop outreach and awareness programmes, which will help in the prevention of the spread of HIV/AIDS; and also to cope with the difficulties of living with these conditions (Paulose, Langkham and John, 2003; K J Somaiya Medical College & Hospital, 2002).

4.4.3.3 The home-based care program

The program has now been in operation since 2003 and is conducted in the HIV Cell (renamed SAHAS) offices in the medical college and hospital at Sion, Mumbai. 550 people have accessed the programme since then. The staff consists of a Project Director, Project Co-ordinator (Psychologist), Program Assistant, Documentation and Administration (Accountant), two Program Assistants, Outreach workers, and three Community Health Workers. The health workers received initial training. This has been strengthened by exposure visits to organisations such as the Salvation Army's Care and Support Centre for HIV/AIDS, and attendance at conferences such as the International Conference in 2005 on Community Care and Support for Infected Persons (Somaiya Medical Trust, 2004).

Initially, the community health workers were introduced to the community by undertaking surveys. Since then, they have built up rapport with the slum communities of Pratiksha Nagar, Quereshi Nagar and Chunnabhatti (approximately 250,000 population combined), and they visit homes regularly to provide valuable support and information. The psychologist receives referrals from different

departments within the hospital, and provides support, and pre and post-test counselling. She also assesses the client's socio-economic status, and, if needed, recommends the clients for nutritional and medical support (Somaiya Medical Trust, 2004).

Street plays are regularly performed by the students of the Somaiya Nursing School and the community, including children, to provide awareness of HIV/AIDS for a largely illiterate population. The Project has also conducted a poster competition to create awareness of their work in other departments of the Somaiya Hospital. The resulting winner was displayed in the hospital and community. Pamphlets in the languages of the slum communities – i.e. Marathi, Gujarati and Bengali, as well as Hindi, have been distributed in the target communities as well as posters in Hindi and Marathi (Somaiya Medical Trust, 2004).

The Project has initiated self-help groups in the community to set up a savings scheme for health emergencies, and a phone counselling service since 2004. This service has been the catalyst for people to present for voluntary testing. Valuable and extensive networking has taken place with other organizations such as the Lions Clubs, Bharat Petroleum, the Lawyers Collective, AVERT, the Krupa Foundation, as well as local community leaders (Somaiya Medical Trust, 2004). The latest initiative (The Positive Community Polytechnic) started in November, 2005. Its aim is to help infected and affected women become economically self-reliant, and to manage nutritional needs of their families. The course started by training women with tailoring and embroidery with an instructor. It will shortly start training in book binding, envelope making and file making (K J Somaiya Medical Trust's Integrated Community and Home-based Care Program for People Living with HIV/AIDS, 2007).

4.4.4 Collaboration between CIH and Somaiya

The Centre for International Health at Curtin University started collaborating with the KJ Somaiya Trust, in 2004. Since then, the Co-ordinator of the Positive Living Programme has visited Curtin University, and a reciprocal visit was made by my supervisor to the Somaiya Hospital. It has also provided a site for students from

Curtin University to undertake research studies there, for academic visits and the links between the two institutions have been maintained.

4.4.5 The research study

This study was made possible by the above collaboration. The KJ Somaiya Trust agreed to house me in an International Guest House on the nearby College campus, and to provide access to a target group of women who are receiving home-based care through the KJ Somaiya Hospital. A cultural interpreter was recruited, and the Project Coordinator and the Community Health Workers identified HIV-infected and affected women who were willing to be interviewed. Interviews were then arranged and the interpreter, and a community health worker and myself visited the women in their own dwellings. Key informants were also identified and interviewed and a focus group organised. The research was conducted over a ten-week period in Mumbai, India.

The Project team welcomed this study. They supplied accommodation and a cultural interpreter in addition to access to their clients. The researcher spent many hours in the office of the Project team, observing interactions between the Co-ordinator and a steady stream of clients, the office staff and the community health workers, and other health professionals. The small office was used for multiple purposes besides administration. These included interviews, sharing meals and organising staff and distributing food and mats to clients. Most of the interviews took place in the community as I felt the women would be more comfortable. In some cases, the interviewee was in hospital, and so the interview would be carried out in the hospital ward at the bedside.

4.4.6 The participants

There were a number of inclusion criteria. The first was related to nationality. As I had decided to investigate Indian women, all participants were from that country. All participants were either infected by the HIV/AIDS virus or affected by a family member having HIV/AIDS. Another criterion was low socio-economic status. These criteria coincided with the KJ Somaiya SAHAS programme. The exclusion criteria included girls younger than 18 years for ethical reasons, and those women who were too ill to be interviewed.

The target group were beneficiaries of the SAHAS project who had already been selected by the hospital from a population of 32,000 people from the slum areas surrounding the hospital in Mumbai, and the tribal areas at Nareshwadi, in Thane (four hours from Mumbai). A purposive sampling strategy was used because the study required women infected or affected by HIV/AIDS (Patton, 2002). Women aged 18-24 years, 25-45 years and over 45 years were identified. The sample consisted of young adults, adult and older women. The aim, which was achieved, was to interview 45 women across the three age groups. The project team assisted the researcher to identify IWLWHAs from knowledge of their client group.

4.4.7 Recruitment procedures

Participants were selected using snowball, opportunistic and volunteer sampling techniques. My contacts at the research site were developed through Curtin University's collaboration with the KJ Somaiya Hospital. This was vital, from the point of view of difficulty of a foreigner identifying a target group. In addition, I could adhere to ethical guidelines by not making the initial contact. I had previous experience of difficulties in recruiting a target group without an 'insider' in my Masters thesis. Berg and Pearson (2004) also describe difficulties in accessing such a group.

For this study, women aged from 18-24 years made up the 'young adult women' sample. The adult sample was divided so that women aged from 25 to 45 years constituted the 'adult women' sample, and women aged over 45 years made up the 'older adult women' sample.

Women in these age groups were identified in order to represent a wide cohort of participants. Participants were given the opportunity to speak a language of their choice; in most cases this was Marathi (the state language of Maharashtra of which Mumbai is the capital) or Hindi (the national language of India). It was acknowledged that some of the participants were HIV-positive and therefore may be ill or have care giving responsibilities, and therefore caution and sensitivity were used in recruitment. Guidance by the Co-ordinator of the KJ Somaiya SAHAS Project and also the community health workers was crucial in obtaining the necessary rapport and agreement to be interviewed. Assistance and advice was also

sought from the project team with respect to recruitment, interviewing and focus group discussions.

4.5 The research methodology matrix

A matrix of the research methodology is presented below.

Table 1: Proposed objectives and associated methodology summaries

Aims	Methodology	Instrument	Analysis
To investigate and evaluate the stigma and discrimination faced by IWLWAS and examine the perceptions and experiences of IWLWAS in Mumbai	A qualitative approach underpinned by the psychosocial conceptual framework	Interviews with IWLWAS; interviews with key informants; demographics, focus group discussion	Analysis of qualitative data using psychosocial framework and thematic analysis
To identify and explore the Psychosocial needs and the coping of strategies of IWLWAS	The conduction of: in depth interviews, home visits of project participants.	Semi-structured interview schedule open-ended questions, observation perceptive diary, photos, narratives	Analysis of qualitative data using psychosocial framework for emergence of themes
To explore the barriers to accessing health services of IWLWAS	The conduction of interviews with key stakeholders in order to provide understanding of barriers and difficulties Faced by IWLWAS	As above plus FGD	Using psychosocial framework to generate themes and categories
To determine community perceptions as experienced by IWLWAS	Documentary data collection, reports, newspaper clips, NGO publications, and interviews	Documentary data Semi-structured interview schedule	Critical and content Analysis
To document and analyse literature on the individual, societal and cultural situation of IWLWAS	A comprehensive review of the relevant literature relating to stigma and discrimination of IWLWAS	Literature review and documentary data collection	Literature summary /critical content analysis.

The study used a combination of quantitative and qualitative research methods to provide a rich database, and confirmation of the aims of the research. The interview schedule was developed with the underpinning of the conceptual framework of viewing psychosocial well-being within three domains (Figure 1): human capacity (mental health and well being); social ecology (relationships linking individuals within and between communities); and culture and values (the value and meaning given to behaviour and experience). Psychosocial well-being reflects adjustments across the three domains, and at the level of an individual, the impact of being HIV

positive has been mapped, by examining the strengths and threats in each of these domains.

The first aim of the research – the investigation and evaluation of the stigma and discrimination of IWLWHA, their perceptions and experience, was addressed by a mixed quantitative and qualitative approach by the use of demographic data and in-depth interviews.

The second aim of the research was to identify and explore the psychosocial needs of IWLWHA. This was achieved partly by the in-depth interviews described above and the home visits and community mapping undertaken throughout my field research. The interviews were carried out in the participant's home, in order to help with rapport and comfort.

The third aim was to explore the barriers to accessing health services of IWLWHAs. The main source of data in this area came from the interviews with the women, and additional material from the focus group discussion with the nurses, and key informants such as the director of a community-based service, and the community health workers.

The fourth aim of the research was to determine how the community perceived IWLWHA, and how the women internalised those attitudes. This data was collected from government reports, newspaper articles and the interviews, and analysed as described above. The results of that analysis appear in Chapters 8, 9, 10 and 11.

The fifth aim of the research was to document and analyse literature on Indian women. This necessitated reviewing a wide range of material from journals, books, newspapers, films and electronic sources throughout the research period. I have continued to read widely in disciplines such as psychology, nursing and healthcare, AIDS care, home-based programmes, anthropology and development research. This comprehensive and extensive literature informs and underpins the research study. The documentary data collection included relevant conference proceedings, newspaper and other news sources, official reports and communications from key

groups currently or previously involved in researching HIV/AIDS in India, particularly in regard to women.

4.6 The methods of data collection

Methodology consisted of the following methods of collecting data: In-depth interviews, a focus group discussion, home visits, participation and observation, interpreting the interviews, key informants, a reflective journal, and the use of narratives, has been fully detailed and explained in the following sections.

4.6.1 In-depth interviews

In-depth, semi-structured interviews were chosen as a research method, because the interviewing style was informal, and guided by a broad interview schedule. The interview consisted of 50 questions, 15 of which requested demographic information, and this is represented in Chapter 7. The remaining 35 questions were open-ended and explanatory, the focus being on the interviewees' own perceptions, and interpretations. The interview took approximately one hour. In-depth interviews, and a focus group discussion, allowed the researcher to examine and compare responses. In-depth interviewees were identified through the sampling process. Health workers at both the hospital and community health worker (CHW) level were approached for an in-depth interview, as were other key members of the community.

Wherever possible, these interviews were conducted in the person's home environment. This was to help the participants feel comfortable and enabled me to observe at first hand the situational context of living conditions, interactions within the family, and the social milieu. I was very aware that some participants could be unwell, and appropriate care was taken during interviewing so that participants could halt the interview at any time. Participants responded in a language of their choice. All interviews were recorded using both written notes and audio recording, in order to prevent recall bias (Majumdar 2004). All of the respondents agreed to audio-taping. Elaboration of written notes and transcription of the recordings were completed as soon as possible after the interviews. Another person also listened to the original audiotape and checked the translation.

4.6.2 Home visits

Home visits provided the opportunity to observe the minutiae of daily life of a family affected by HIV/AIDS. By observing people in their own setting, valuable information and insights were gained. This is often lost in the formal setting of an office or hospital. Participants are more at ease in their own surroundings, therefore, interviewing at home is likely to gain more information. Home visits were only undertaken if the IWLWHA allowed the visit and was comfortable having the researcher, community health worker and interpreter in her home.

The dwellings were extremely small, by Australian standards. Whole families lived in one room. Disruption to a family through death and illness meant that surviving members of a household, not normally housed together, would be in these dwellings. These windowless dwellings usually had electricity, and therefore electric light, a fan, and a TV. There was access to water for restricted periods very early in the morning when the women had to get up and fill their steel or brass containers for daily use. The surroundings in these communities varied. For example those which were close to the hospital had large mounds of rubbish open to the elements, whereas other communities were in older slums with dank, damp walls and narrow passageways.

4.6.3 Focus group discussions

A focus group discussion (FGD) was used as a research method in this study because it enabled discussions with a relatively small number of people focusing on a specific area of interest. In this case, the FGD enabled the researcher to explore perceptions and experiences of the nurses at the KJ Somaiya Hospital. This provided a rich and detailed set of data about thoughts, feelings and impressions of service providers in their own words. The nurses were able to describe their frustrations in coping with the stigma and discrimination of women. Using the same method of mapping and eliciting themes as the interviews, the data was explored and analysed. Another reason for using a focus group was to validate and confirm the data from the interviews, key informants, and the documentary data collection (triangulation). It also enabled me to increase the sample size efficiently time-wise.

4.6.4 Participant observation

This involved being part of the interview in the sense that I was physically present, and observing the conditions and keeping detailed records of what occurred. However, I was also aware that I remained, to some extent, an outsider in the process - an observer, rather than in the more familiar role of counselling psychologist (Key, 1997). There was a feeling of relinquishing my usual role, in order for the interpreter and community health worker to establish rapport with the interviewee because of the language and cultural differences. Key (1997) identifies this type of participant observation as *passive participation*.

4.6.5 Working with cultural interpreters

An interpreter/translator was vital in order to elicit responses, and provide a culturally sensitive approach to the research process (Pryor and Reeder, 1993). I was totally dependent on the interpreter to build rapport, conduct the interviews, and allay any fears of the participants. An interpreter/translator was assigned to the researcher for the period of data collection. She was a young woman who was skilled in several languages, studying psychology and had experience in data collection.

I had several meetings and discussions before the research study started, in order to ensure that she understood the concepts and aims of the study, and the need for accuracy. The journeys to and from the hospital provided opportunities for us to discuss any issues, difficulties or problems encountered. The Co-ordinator of the SAHAS programme provided added guidance at the beginning of the study and the translation. The back translations of the third person, namely the Co-ordinator, provided a discussion point, whereby the interpreter was guided and trained in the art of translation. Werner and Campbell, (cited in Edwards, 1998, p.101) regard 'back translation' as "the most powerful assessment and checking device available".

Several researchers have outlined the challenges of working in a cross-cultural environment and the care required to maintain cultural integrity (Grbich, 1999; Birbili, 2000). There are acknowledged difficulties in obtaining the desired meaning from one language to another, not only in the translated word, but also in cultural meaning and contexts. Birbili (2000) argues that both the researcher and the participant may not share the same worldview, but may understand each other

through dialogue. When we try to understand a culture we are essentially dealing with interpretations and interpretations of interpretations (Taylor, 1987). All interviews were translated by the same interpreter (Kapborg and Bertero, 2002). The translated interviews were back-translated by the Co-ordinator of the SAHAS programme as a check for meaning and understanding and congruency (Birbili, 2000; Kapborg and Bertero, 2002). The translator/interpreter has a pivotal role which cannot be ignored (Edwards, 1998).

In this study, I had to trust that the interpreter acted with the best intentions and commitment to translate the meaning intended as nearly as possible, given time and opportunity constraints. Just as the researcher cannot act without bias, the situation is the same for the translator. Both work in the area for a short time, and then resume their own journeys. In this case, the fact that the interpreter spoke other languages than that of the researcher adds another layer of interpretation (Temple, 1997). There is no one truth or meaning, according to Denzin and Lincoln (2000). I endeavoured to capture the women's narratives as faithfully as possible, in all their voices, realizing that they were not a homogenous group.

4.6.6 Key informants

Key informants were selected on the basis of their expert knowledge. Johnson (cited in Lewis-Beck, Bryman and Liao, 2004, p.537) considers this form of data as "an essential component of any ethnographic enterprise". Their opinions were used to support the data gained from interviews with the participants. I interviewed the team at SAHAS, the Honorary Secretary General of the AIDS Prevention and Research Organisation, and Reader at the Tata Institute of Social Sciences, the Director of Nirmela Niketan, and a social worker from the Ra Foundation. In Perth, I sought discussion of the socio-cultural context of Indian women with my supervisor, and also a sociologist with wide experience of India.

4.6.7 Maintaining a reflective journal

A reflective diary gives a voice to the researcher to record observations with sensitivity (Warren, 1996); and the diary can be an integrated part of the research process. In addition, credibility and trustworthiness are added when the researcher's thoughts and decisions are recorded (Koch and Harrington, 1998). A reflective

journal brings together the professional and personal elements (Darell, 2003); and reflection is a way of opening up feelings of vulnerability and a form of coping in isolation.

During data collection, I wrote three separate journals. The first was a daily log of events, with details of home visits, and interviews. The second journal was in the form of emails in which I wrote my reflections and observations. The third journal was a summary of those reflections and impressions. Note-taking of incidences, situations and the research process was carried out constantly, and in extensive detail during the period of data collection. Chapter 13 and 14 are summaries of those journals. These reflections were discussed with the interpreter and the SAHAS team to identify key issues that arose during visits, interviews, and discussions. The diary could also be seen as a “confessional tale” described by Emihovich (1995, p.41), outlining the pitfalls and difficulties encountered in field research. Emihovich draws on the work of Bateson (cited in Emihovich, 1995, p.45) who says that:

“Change can happen if we keep recirculating the visions. If we collaborate in the work of making real to ourselves the innerness of others’ lives and find ways to restore passion and genuine commitment, the texts we create today will become the blueprints for tomorrow, guiding us to the most critical narrative of all – becoming human.”

4.6.8 Use of narratives

Narrative researchers describe the lives of the participants, collecting and telling their stories according to Clandinin and Connelly (1994). They describe the essentials of such work as temporality, scene, plot, multiple researcher “Is” and character which combined make up the experiential quality of narrative. In Chapter 14, I have used narratives to illustrate more clearly the social conditions of the women I interviewed. Four of those narratives have been constructed by using data collected from the interviews, whereas the last two are composed from my observations of daily life in the slum communities.

4.6.9 Observations of conditions and home visits

These observations were recorded daily, on my return home, and later summarised. My perceptions, experiences and observations then were condensed into an

interpretive commentary of the research process and reactions to the conditions. This record of a field researcher maps the daily frustrations and difficulties of working in another country.

4.6.10 Use of photos

Although photographs have not been used extensively in research because of our trust in the written word, they can offset the limitations of language in cross-cultural research, and play an important part in reflexivity, according to Nichols, Tippins, Bilbao, Barcenal, Castellano and Morano (2001). They can also be a trigger to memories (Clandinin and Connelly, 1994). Whilst engaging in the research, I endeavoured to find multiple modes of describing and setting the scene. In addition to writing and recording, I photographed the conditions in the slums. With regard to the participants, however, I felt a constraint in the ethical dilemma of voyeurism, which resulted in my not photographing the most dismal slums and the inhabitants. I felt that these people deserved privacy and respect. Some of the photos taken by me have been included with commentaries in the Appendices

4.7 Data analysis

4.7.1 Use of the Framework Analysis to analyse in-depth interviews

Analysis occurred throughout the data collection phase to enable early information gathered to inform later parts of the research; and to allow for questions and coding to be refined, and new avenues of inquiry to develop (Pope, Ziebland and Mays, 2000; Thomas, 2003). Data analysis was guided by the Framework Approach to Data Analysis (Pope et al., 1999; Lacey and Luff, 2001). For the interviews, thematic analysis and the psychosocial framework were utilised.

The IWLWAs participated in thematic interviews relating to their experience of being HIV positive, or affected by HIV/AIDS, and the impact on their lives. This formed the very core of the study. I decided that because of the wealth of information from the interviews, that every woman's voice should be heard. The issues emerging from thematic analysis for each of the three groups of women were examined for similarities and differences. Themes distilled from interviews and focus group discussions explored the social, cultural and human contexts of the lives of

IWLWHAs. Additionally, the sense of discrimination, security and community cohesion experienced as the women adjusted to being HIV positive was evaluated. Changing social identities resulted from their illness and these linked to perceptions and anxieties about their future; and the mediating influence of the community were also highlighted. Interviews were carried out by the interpreter with a community health worker and myself being present. They were audio-taped, and translated into English by the interpreter. Then the translated interviews were examined by the Coordinator of the SAHAS Program for accuracy and then given to me. I decided to analyse the entire interview for every participant. I assigned a pseudonym to each interviewee, and ensured that every interview had a date and number.

The in-depth interviews were then analysed in stages, which involved familiarisation, identification of a thematic framework, indexing, charting, mapping and indexation. Firstly, I familiarised myself by immersing myself in the raw data, in order to list key ideas and recurrent themes. The second stage involved the identification of a thematic framework - identifying the key issues, concepts and themes by which the data could be examined and referenced. A framework grid was developed with the psychosocial domains on the vertical axis, and the data sources on the horizontal axis, and content analysis of generated themes was conducted.

The third stage was indexing - applying the thematic framework or index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index. In the fourth stage, I rearranged the data according to the appropriate part of the thematic framework to which they relate and forming charts. The charts contain distilled summaries of views and experiences. In the fifth stage I used mapping and interpretation by using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings. There was an interweaving of data collection and analysis from the beginning. For example the FGD with nurses was developed from the interviews with the participants.

4.7.2 Use of Frame Analysis to analyse newspaper articles

The documentary data collection was also analysed in stages. The first stage involved summarising the articles collected from newspapers. The next stage

involved the examination of these articles so that themes could emerge, and could be subjected to frame analysis. Themes such as the living conditions in Mumbai, the status of women in India, the presence of stigma and discrimination for women, information regarding HIV/AIDS were thus examined. Their meaning, and the way that the themes were portrayed by the media, were analysed. Although some attempts were made to inform the public of HIV/AIDS, taboos on discussion of sexual matters prevented a comprehensive approach. The availability of information via the news media for the women in this study was negligible given their low level of literacy.

In addition to the interviews, I sought confirmation of the data by interviewing 11 key informants and conducting a focus group discussion with the nurses at the KJ Somaiya Hospital. The semi-structured schedules for these interviews was developed as a result of preliminary interviews with IWLWHAs, and emerging themes which I developed as I reflected on the research process. These interviews and the FGD were analysed for their main themes. The interpreter and one CHW and myself would visit various slum communities according to the interviews which could be fitted into the participants' day. This enabled me to observe the poor conditions of not only homes, but also the pollution, surrounding squalor, and potential for disease.

4.8 Ethical considerations

The case study was granted ethical approval by Curtin University's Ethics Committee, as part of the candidacy process for the Centre for International Health.

My dictum in my professional practice as a psychologist is to: "Do No Harm". I am aware of the potential to invade personal space, to persuade people to participate, and to otherwise use position to undermine people's power. I consciously abide by principles imposed by my profession (i.e. Psychology and Counselling), in order to minimise power imbalances. England (1994) argues that although it is not possible to remove power imbalance, it is important to take responsibility and to use research for the best purpose. At times, it seemed that the power lay with the interviewee, in that she could refuse to be interviewed or not appear; however there may also have been pressures, unseen and unheard by me as a researcher, as they were all beneficiaries of

the K J Somaiya services. I arranged to interview the women in their own dwellings so that power would be more equal between us as Horton (2007) suggests.

In this study, it was imperative that IWLWHAs were protected and respected. It was acknowledged that all of the participants were vulnerable because they were stigmatised or feared discrimination and were affected by HIV/AIDS. Caution and sensitivity were necessary in recruitment, and in the interviewing process. I was guided by the SAHAS team as to the suitability of the interviewees from the point of view of their current health condition.

I agree with Hutchison, Wilson and Wilson (1994), that women who cannot bear to talk about certain topics will not do so; and I trusted the women to react if they were uncomfortable. One woman refused to talk about a certain topic. In general, the participants appeared eager to talk, and to have a cathartic response regarding their experiences, and to appreciate the opportunity to share their feelings (Smith, 1999). There was little discernible hesitation in the answers or the length of the replies. The data is testimony to the ability of the interpreter and the CHWs to help the participants feel comfortable and open in their replies.

I deliberated on the problem of my identifiable presence in the community which may have alerted others to the HIV status of the participant. It was agreed that I would be introduced to the community as a researcher. If the team considered that women were at the slightest risk of being identified through my presence, the interview was not conducted. For that reason, several interviews were carried out at the KJ Somaiya Hospital. My presence in the wards would have been very visible, and for that reason, the interviews were carried out by the social worker and the interpreter. This was late in the interviewing process when the interpreter had gained experience.

Another dilemma came in the pleas for help from three interviewees. In these cases, because of the delays in receiving the transcripts, I was unaware for some time about these pleas. My initial emotional response was to ask myself how I could help. I thought about confidentiality, and discussion would breach my agreement; however, on the other hand, sometimes these concepts are not used in the client's best

interests. I concluded that because there was a community health worker from the SAHAS Project present, that the interviewee's plight would be relayed to the Co-ordinator and they would respond more appropriately than myself. This weighed on me, and the only conclusion of 'help' I could give was to ensure that those women's narratives were reported as honestly as possible. Berg and Pearson (2004) describe a similar plight during their research.

I was also concerned about the research from a feminist perspective, and how it fitted into Haraway's criteria for accountability, namely that the researcher should not continue the stigmatisation of women as "powerless and unequal" (Haraway, cited in Bhavnani, 1993, p.91). In reality, this was not such a problem, as the women interviewed showed pride, resilience and adjustment to their problems. Another difficulty I grappled with was my distance from the interviewee. My everyday practice as a psychologist demands a closeness and rapport. In this situation, I understood that my position was that of a researcher maintaining a neutral stance. In the first interview, I noticed that the interpreter was talking to the interviewee after the interview had been terminated. When I asked the reason, the interpreter answered that she was giving the woman advice as to how to cope better. We discussed this and I emphasized that our role was one of research, and not counselling, however tempting that appeared to both of us. These difficulties have been noted by other researchers (Denzin and Lincoln 2000). It was impossible not to respond emotionally to the women, but at the same time, it was important to respond at a level beyond feelings, and to maintain neutrality.

The second question is about delineating the micro-politics of the research relationship which I have endeavoured to do by pointing out the realities of power difference. Haraway's third question relates to difference (Haraway, cited in Bhavnani, 1993, p.91). It is important to honestly disclose all opinions from the respondents, whatever the researcher's interpretation. This is one of the reasons I have included all the interviews. There was a dilemma about a question in the interview relating to knowledge of transmission of HIV/AIDS. The Co-ordinator said it was too sensitive an issue to enquire about. I weighed up the loss of important information against her knowledge of the participants and respect for cultural values, and decided to omit the question (Marshall and Marshall, 2003). However, as is

shown in the interviews, some women commented spontaneously on this topic. In order to protect participants' rights, the following areas were considered:

Informed consent: I approached this area with some trepidation. Although the objectives of the research were clear both verbally and in writing I was aware that this is a Western concept. I had learned that signing documents in India may have a different meaning to ours (Riessman, 2005), and that the participants may not clearly understand the principles. I could only follow the ethical guidelines which meant that because some interviewees were illiterate, the translator read an information sheet. Potential language misunderstandings were met by having a competent translator present during all interviews. Written permission was obtained on a consent form in the participant's own language. Some participants could not write their names, and were identified by a thumbprint. The participants were informed of all data collection devices and activities. The participants' rights, interests and wishes were considered first when choices were made regarding reporting of the data. Permission was sought to access records of diagnosis, and date of inclusion in the program. All records were then de-identified and a code assigned to the participants. The records have been further de-identified with a pseudonym, so that the participants could follow the record of their interview if they so wished.

Confidentiality and anonymity: All participants were reminded that neither participation nor refusal would have any beneficial or negative effects on their receipt of health care. They were also informed about what would happen to the data. Coded data was used to protect confidentiality. No remuneration was offered for participation. The participants in this study were vulnerable and in dependent relationships, due to the nature of their illness so every attempt was made to ensure confidentiality. The project involved no invasive techniques, deception or use of hazardous techniques or material. No minors were used as participants in this study. Privacy was another concept that is different in India where crowded living makes confidentiality less likely. Riessman experienced the same when working in Kerala (Riessman, 2005). I have assigned a pseudonym to every participant rather than a number. The participants therefore can trace every opinion with the assigned name.

The right to withdraw: This issue was emphasised. Interviews were to be discontinued, and continued at a later stage if a participant felt ill. Participants had the right to withdraw at any point without coercion or pressure, and their information destroyed forthwith.

Privacy and data storage: I keep all field notes, interviews and other information in a locked cupboard with myself having the only access. Computer data is protected by a password. Data collected will be held safely and only myself and my supervisor at the Centre for International Health will have access to the data.

4.9 Rigour in the study

Credibility, transferability, dependability and confirmability are the criteria used to demonstrate the trustworthiness of qualitative research, according to Krefting (1991). These criteria have been met using the strategies of Devers (1999), Krefting (1991). Credibility is the first criteria to be met, and includes establishing the authority of the researcher by prolonged and varied field experience, time sampling, reflexivity and triangulation. Koch and Harrington (1998) argue for an expanded conceptualising of rigour to include incorporating the social self of the researcher into the project. I have a varied background across the disciplines of psychology, sociology, anthropology and nursing in Australia, England and South Africa. I had some field experience during my Psychology degree, and my Masters thesis was a study of Eurasian women who had migrated from Singapore to Perth. My studies and research have been completed over a considerable number of years; and I have been required to absorb new areas of knowledge necessary to the study (Gilgun, 2006). It is acknowledged that my situation and background influenced the interpretation of the interviews; but also contributed to the understanding of complex issues in a different cultural context (Koch and Harrington, 1998). The second criterion of time sampling means that an adequate time is spent on field research which was fulfilled.

Trustworthiness of the data includes the third criterion of reflexivity. This was met by a process of everyday reflections described above. These observations and reflections were vital in the research process and resulted in a perceptive diary and narratives. Methodological triangulation is the use of different methods to

substantiate and reproduce findings to gain validity and robustness (Burns, 2000; Farmer et al., 2006). Additionally, triangulation was also met by data from different sources such as the interviews, FGD, documentary data collection and key informants. Member checking is another strategy to ensure trustworthiness. This has been addressed by asking Indian women to comment on my observations. Patton (2002) recommends both openness and integrity in the conduct of the fieldwork and in the reporting of the results. This study has endeavoured to present the data in such a way that others reading the results can understand and draw their own interpretations (Patton, 2002).

The search of literature to establish the history and background of the study was not only necessary for the researcher to fulfil the criterion of referential adequacy. It was also necessary for me to understand the cultural underpinnings of the women's emotional reactions and behaviour, as described in Koch and Harrington (1998). The constructions which inform our research are important as the starting point (Lincoln and Guba (1986, p.76) suggest the

“use of data, a range of literature, a positioning of this literature, positioning of the researcher, moral socio-political contexts, self critique and self appraisal as well as auditing”.

Transferability is the second strategy to establish trustworthiness of the data, according to Krefling (1991). In this study, the criterion of a nominated sample was met by using the consumers of the SAHAS program as a target group. The sample's inclusion and exclusion criteria have been discussed above. The sample's characteristics have been compared to demographic data obtained by health and government reports and other studies in the field. The discipline and rigor of qualitative analysis depends upon presenting solid descriptive data, which are often called “thick” descriptions first described by Ryle, (cited in Ponterotto, 2008, p.539). The study has described concepts such as living conditions, emotional reactions, evidence of stigma and discrimination, in rich and comprehensive detail.

Dependability is the third strategy to establish trustworthiness. An audit trail consisting of a daily log and perceptive diary, full audio recordings, transcriptions and coding procedures provide sufficient data to leave a complete and transparent record of the study process. This also provides transparency of the process from data collection to findings (Krueger and Casey, 2000; Thomas, 2000), and adequate information to provide replication (Miles and Huberman, 1994; Stajduhar and Davies, 1998); dependability and accuracy (Hall and Stevens cited in Koch and Harrington (1998, p.887). The research methods have been described in as much detail as possible. Stepwise replication has been addressed by the daily journal and detailed description. Triangulation has been addressed above. Through consultation with peers and presentations at colloquiums and conferences, the criterion of peer examination has been fulfilled. Code-recode procedures have been described and utilised in this study. Confirmability is the fourth criterion that Krefting (1991) uses to establish trustworthiness. The three criteria of confirmability through audit, triangulation and reflexivity have already been discussed above.

In order to guarantee construct validity, this study used multiple sources of evidence and key informants who have reviewed draft reports at regular intervals (Ritchie, 2000). Content validity was sought by sampling times, events, persons and settings as widely as possible. Reliability and accuracy of data were ensured by conducting the interviewing in the presence of a community health worker and interpreter, who discussed transcripts with the researcher to determine understanding, and reduce bias. It is acknowledged I brought my own biases as a person outside the culture, as a person of my age, background and education from a very different country. However, it is also impossible to be neutral, and one can provide a level of objectivity to examine a culture from a different viewpoint, as long as there is support from other viewpoints. I have endeavoured to be faithful to my original concept, and to be as honest as possible in the telling of the story, and taking into consideration events as they actually happened (Hatch and Wisniewski, 1995); through representation of every participant's narrative (Fleming, Gaidys and Robb, 2003). Through providing clarity on the distinct cultural context and participant base, issues of transferability, according to Graneheim and Lundman (2004), were answered.

4.10 Summary of chapter

A detailed description has been given of the research design and intention. The theoretical underpinnings and rationale of the process of the study have been discussed and a full account of the actual processes used in the study provides an audit trail.

CHAPTER 5

CONTEXTUALISING INDIAN WOMEN

“A woman’s biology is not in itself destiny.” (Sen and Ostlin, 2007, p.2).

5.0 Introduction to the chapter

This chapter examines the history, and socio-cultural dimensions, relevant to women in the Indian context. I felt it was necessary to contextualise Indian women before commencing the analysis, so that I could begin to understand their cultural identity. By setting the background of history and culture, the behaviour and attitudes of Indian women became more real to me as an outsider. The other imperative comes from the previous chapter, where it is evident that, in order to bring about change, peoples’ motives and underlying beliefs have to be considered. There was great difficulty in condensing such a rich, diverse and long history into one chapter, particularly as women have been neglected in history throughout the world. The following discussion may therefore lack depth, but it is an attempt to place Indian women in some perspective in thousands of years of Indian culture, and social mores. It was difficult to place some events because of conflicting accounts, and the fluidity of Indian history. As Kapur, an Indian film director, remarked recently in a newspaper article:

The writing of the chronology of history is less important to us (Indians) than the meanings and the myths and morality of history.” (Naglazas, 2007, p.8).

The following exploration has helped me to understand the source of beliefs and attitudes towards Indian women. I have focused on the religion and history, by which most of the women in this study would be influenced; however it must be remembered that India is a multi-cultural, multi-religious country. Different

religions have co-existed in India for a very long time - presently Jews, Parsees, Muslims, Jains, Christians and Buddhists (Sen, 2006). India has 28 states, and 7 union territories (India, 2008), 14 official languages, and 30 recognised political parties. There are 22 official “scheduled” languages although over 428 are listed (Languages of India, 2008).

5.1 History of women in India

5.1.1 Her story

In this section, I have endeavoured to provide a brief synopsis of Indian history as it relates to women. There is a disparity between the quote below, and the reality of Indian women’s status and identity.

“In the beginning, according to Indian mythology was Shakti, and Shakti, which means energy, has in Sanskrit, a feminine gender. The cosmos was her creation, her child....and what could be nobler than to see the Creator as a Mother? It is the mother, not the father, who comes to mind first whenever the word ‘creation’ is mentioned. Woman’s eternal energy, her natural ability to give and feed lift to add cell to cell, make Man look relatively unimportant to the scheme of things. One can be sure of one’s mother, if not of one’s father; and if this is true on earth, it may also be true of the cosmos...” (Shridharani, cited in Lannoy (1971, p.37)

5.1.2 Vedic period

In the Vedic period (3000 BC) men and women were equal partners, and women enjoyed complete freedom (Lannoy, 1971; Paranjape, 2003). Women had a role in religious ceremonies, and even participated in some of the Vedas (discussions of wisdom), which took roughly a thousand years to compose, and were not written down until much later. Gargi was a woman philosopher, who disputed with some of her male peers very capably in this era (Holroyde, 2006). Prayers blessed men and women equally, and were very beautiful. Daughters were desired, and welcomed. Men and women were free to choose their marriage partners. There were no *satis* (widow sacrifice) and widows could, and did, remarry (Das, 1994). In fact, when a man died, the widow lay on the funeral pyre until a male relative coaxed her from it, and welcomed her back into the home in a new role (Paranjape, 2003). The male was

still in power in the public domain, and women were excluded from politics (Jha and Pujari, 1996); but women ruled in the family domain. The role of motherhood was, and still is, most important. Women were able to move freely, and they had a position of dignity and respect in society (Jha and Pujari, 1996).

5.1.3 Jainism and Buddhism

The Vedic Age ended about 2000 BC (Rajaram, 1995). The Brahmins, (who were the priestly ruling class), realized that women posed a great threat to their power, and systematically set about taking away their cultural and religious rights (Das, 1994). Rituals are defined as the knowledge, which delineates a special group in society. In this case, it was the priestly class, who held the information to which women were excluded, and therefore discriminated against (Seshan, 2003). Sixth century Brahmins rigidly prohibited women from remarrying after the death of their husbands (Jha and Pujari, 1996).

5.1.4 Maurya period

Smitha (2006) has written the following account of Chandragupta, who was the emperor of the first great empire in India, after Alexander the Great had died. The Seleucus, who had been vanquished by Alexander, sent an ambassador Megasthenes to the court to report on the society there. Megasthenes wrote that some upper-class women received an education, and some were accomplished in the arts. He added that, usually, Brahmins did not wish to educate their wives, as they believed that knowledge and learning were not for females. Chandragupta, the emperor, surrounded himself with courtesans and dancing girls. As the role of courtesans increased, the position of women generally deteriorated. It was as early as this, (i.e. 320 BC to 120 AD), that females could be married as young as eight years of age, so that there was a better guarantee that the woman would be a virgin at marriage.

There followed a period of Buddhism under Bindusara, and his son Asoka. This was a period of peace, economic prosperity, coexistence and tolerance for other religions such as the Hindus and Jains. Then followed the great invasions of India from Greece and Scythia, in central Asia and Indo-European speaking tribes, the Kushans. However, these invasions did not reach southern India, which was ruled by the

Dravidians. In 1192, the Muslims defeated the Hindus under Prithvi Raj, and Buddhism as an organised religious force disappeared (Smitha, 2006).

5.1.4 Manusmriti

The uncertainties of this time of invasion may have inspired the new book of laws called the *Manusmriti* or *Law Code of Manu*, which combined Hinduism with sacred law. Manu lived around 1500 BC, and was described in the Vedas as the world's first king, the father of the human race, and the one who had received the god Brahma's plans. He was the first to describe the universe, and the first to sacrifice to the gods. The law code described the creation of the universe, the commandments of Brahma concerning ritual, custom and caste (Smitha, 2006). Unfortunately, for Indian women, this damaged their cultural, social and political rights, for many centuries to come. The Law Code of Manu is worth noting, as it forms the basis for Hindu religion, and cultural mores even today.

Firstly, Manu decreed that women were forbidden to act as priestesses or worshippers. The only way a woman could reach a deity was through her husband (her guru and her god). Indeed, she could only get to heaven through her husband. Although women had created some of the Vedas, they were now forbidden to study them, and any religious texts (Belsare, 2003; Nabar, 1995). Women were not allowed to act for their own pleasure; and were expected to be dependent on their nearest male relative or the king. They were to be guarded, and protected day and night. To some degree, this mirrors the way women were seen in the early Christian church as temptresses and harbingers of evil (Holroyde, 2006). A woman was to be under her father's control in childhood, her husband's once married, and her son's when widowed - in fact a "non-role" according to Nabar (1995, p.66).

5.1.6 Manu's marriage laws

Marriage laws were made different for men and women. Men could marry only those of equal rank, but could take a second wife, of lower caste. However, women must get permission from their father or brother to marry; and women's consent was considered unnecessary. It was made legal for a 30 year old male to marry a 12 year old girl, or a 24 year old male to marry an 8 year old girl; however, consummation of the union would not take place until menstruation. In the meantime, the bride would

live with her own family (Holroyde, 2006). In dissolving a marriage, a man could leave his wife for trifling reasons, but a woman could never escape the marital arrangement.

The laws of Manu laid down that a widow could never remarry, because of the disapproval of society, and also because she would never reach heaven. She was not allowed to even pronounce the name of another man, and had to renounce sex, and live on fruits, roots and flowers. Husbands were permitted to beat wives with a cord or bamboo cane (the size was unspecified). A woman was not permitted to eat with her husband – only afterwards, and she was informed that she was unclean at the time of childbirth and her touch at that time polluting. It was even prescribed that a man must not marry a “tawny” (dark) girl (Das, 1994, p. 61).

When a woman married, she was to “remain cheerful, clever in the management of her household affairs, careful in using utensils, economical in spending, and do nothing independent of male authority” (Smitha, 2006, p.1). Manusmriti (the Law code of Manu) enshrined the idea of a woman’s total devotion to her husband, and that if she transgressed; she would become the object of social ridicule. Her only way to gain honour was by strict observance of these laws. The grand epic, *Mahabharata*, which still wields such influence on Indian culture, has a strong, warrior male emphasis (Holroyde, 2006).

5.1.7 The concept of karma

In addition to Manusmriti, Das (1994) asserts that the doctrine of *karma* is the most important factor in determining women’s position in society. This concept became a dogma of Hindu belief, and proclaimed that the law of cause and effect was immutable, absolute, and universal. A person therefore cannot escape from the consequences of his/her actions. Furthermore, this accumulated balance of virtue or sin, is carried forward to the next life, by reincarnation. Religious sanction made it easy to blame women for not only their personal failings, but also the “very evils which resulted from forcing women into unnatural surroundings” (Das, 1994, p.55). This had a positive aspect in that there was a high moral or ethical impetus towards doing the right thing. The negative aspect is that all blame comes from a past life and is therefore irrefutable. Women could be blamed for things beyond their control,

and men could point to religious authority to support this idea. These laws took a long time to permeate, but remained for a long time. The Kshatriya (warrior) caste held out for a long time against the Brahmins. Revolts resulted in certain breakaway groups like the Sikhs and the Jains. At the same time, Buddhism provided a means of escape for women, especially for widows and wives without children. They turned into Buddhist nuns, and retreated into monasteries (Das, 1994).

5.1.8 The arrival in India of Muslim women and purdah

In the 11th century, India was invaded by wave after wave of Muslims, who were culturally different people. Belsare (2003); Kulkarni (2003) and Das (1994) all agree that the Muslim invasion intensified already existing Hindu restrictions on women, and the relatively privileged position of women in Muslim society of the invaders was ignored. Lannoy (1971) and Sahai (2008) claim that Hindus were already moving towards *purdah* before the arrival of Muslims, in the late part of the 10th century. *Purdah* (literally a curtain) meant that women were kept in seclusion and heavily guarded, and this led to unhealthy and crowded living conditions for women and children. Some never saw the light of day, leading to illness and early death (Lannoy, 1971). The seclusion applied primarily to higher caste women (Das, 1994). Lannoy (1971) estimates the number of women to be 15% at the most in *zenanas* (women's living quarters) and harems.

Lower-caste women were not as tied to these practices, only because they were needed to carry out back-breaking work in both rural and urban India. Even within the *zenana*, conditions for women could be different, depending on their relationship to the ruler, forming class stratification, even within this enclosed world (Dalrymple, 2006). Maheswari (1995) notes women rulers in the Amgiya family of the Marathis. One such ruler, Naganika, performed many religious sacrifices and after her husband died, she assumed regency and administered efficiently and with religious tolerance. There was a great queen, Silamahadevi, in 786 AD, and in the time of the Kakatiyas, women played influential and powerful roles in shaping the destiny of their dynasty. Around 1219 AD, Ganapamba assumed power after her husband's death. She had been well trained in riding horses and elephants, chariots, welding weapons, and she was proficient in theology, poetry and epic lore. There were other female leaders such as Rudramadevi who ruled benevolently, and women like Meera, who lived

from 1498-1546, and stood up to the Hindu priestly class (Nabar, 1995). The following four women were queens turned warriors by widowhood – Durgawati, in 16th century central India, and Ahilyabhai of Indore, in the 18th century, Channamma, in Kartanaka, in the 18th-19th century. Rashoman lived in the 18th-19th century in Bengal. Lakshmibai stood up to the British during the 1850's (Holroyde, 2006).

5.1.9 History of women in Maharashtra

It is difficult to make sweeping statements about all of India at any one time. Because the study took place in Maharashtra, I wanted to know if the history of women, in this state, was any different. The history of Maharashtra appears comparable to that above. In the 11th century, there was concern about the social injustice done to “*untouchables*” but nothing was done (Deshmukh, 1993). Women were not confined to harems. After the Muslim invasion, there were women rulers and higher caste women had some access to education. For example, in the 15th century, there were female Muslim leaders. There was a period of Muslim expansion, and a backlash against the Brahmins in the form of the Bhakti movement which sought to fight the evils of casteism.

In Maharashtra, the Marathas rose up under Shivaji and took control, and the Hindu religion flourished. In the Maratha period from the 1600s, females and their education were completely neglected (Deshmukh, 1993). The uprising had the effect of uniting the Marathas into a nation, and was a sense of pride for males. Bahuguna (2004) asserts that the Marathi tradition assured women the right to lead a life of their own. The Maharabhava sect further protested about the rights of women. However, today, that sect has not ensured a prominent place for women. Nevertheless, women are very prominent in this region in creating reforming bodies, community work and *panchayats* (community councils of five people) according to (Holroyde, 2006).

5.1.10 The British colonial period

At the time of the British occupation, there were a few exceptions to the lower status of women. For example, the Nair women of Malabar had fewer restrictions, because the Moghuls did not reach southern India, which was ruled by Dravidians. The Hindu goal of life is spiritual perfection, and not material possession. Das (1994)

asserts that this explains why Buddhism has always had a special place in India, whereas the British philosophy has not gripped the nation. England, as a government, has done more harm than good to Indian women. English rule did shake India out of its somnolence, and influence Hindu reformers. Christian religion and the ideals of the French Revolution did have some effect (Holroyde, 2006). The British were there primarily as colonialists, and as such, they were not very interested in advancing the cause of women. There was always the difficulty of translating laws into practice. They did ban *sati* (widows throwing themselves onto funeral pyres), but this did not prevent widows' lives turned into endless deprivation. In 1855 Vidyasagara spoke of widows remarrying, and so did Raja Ram Mohan Roy (Jha and Pujari, 1996).

Raja Ram Mohan Roy was a great Bengali who influenced the British Viceroy Government which was then based in Calcutta. Liberal views from Europe seemed to influence Bengali Brahmins in particular. In 1856, the Widows Remarriage Act was compromised by the fact that widows lost property rights on remarriage (Jha and Pujari, 1996). In the early 19th century, reform was primarily concerned with issues of the upper class – the age of marriage, life of widows, their right to remarry, and education (Jha and Pujari, 1996). There is still an anomaly in Indian law which bans polygamy amongst Hindus, but permits it in Muslims (Patel, 2007). By the end of the 19th century, elite Hindus had recognised the need to modify traditional views on women, and reform societies were set up and Raja Ram Mohan Roy campaigned on behalf of women.

British women kept themselves apart from Indian women, and were caught in their own class structures. Indeed, Kingsley Martin in the early 60s, writing in the *New Statesman* (cited in Holroyde, 2006) went so far as to say that the influence of the memsahib lost the British their empire. It was, in fact, Indian men educated in the British system, however, who did develop awareness about women's rights and helped to form the legislation required (Jha and Pujari, 1996). For example, the 1976 Marriage Act permitted divorce, the 1961 Dowry Prohibition Act was supposed to put an end to those crimes. In 1956, the Hindu Adoption and Maintenance Act permitted adoption of male and female children, and accepted a mother's consent was necessary for adoption. The Hindu Succession Act protected women's rights to

property, and the Maternity Benefit Act in 1961 legalised equal pay for equal work (Jha and Pujari, 1996). Westernisation influenced women to move from the private sphere, into the public domain. There was a push and pull effect of revivalism versus Westernism (Belsare, 2003), as India struggled to assert her own identity.

5.1.11 Women's role in India's Independence

In spite of these challenges, Indian women organised themselves into revolutionary groups to further the push towards the independence of their nation. They boycotted liquor shops (Mishra, 1999), went to prison, broke the Salt Law, and entered into the political arena (Jha and Pujari, 1996). Women politicians made it acceptable for women to work outside the home. After India's Independence, women were pushed back into the domestic sphere, and after playing a vocal and visible part in the struggle for Independence, they became marginalised, once more (Mishra, 1999). Moreover, Mishra (1999) points out that, to some degree, Indian women's rights stalled at this point.

5.1.12 Women's progress in India

Two areas which promised progress for Indian women based on other countries' history were education and nursing. In 1896, Maharishi Karve set up institutions for the education of widows. The Brahmo Samaj discarded caste, *purdah*, child marriage, and the restrictions on widows. They also set up schools for girls, and worked towards the empowerment of women (Nussbaum, 2007). Originally, girls' schools had been initiated by missionaries in India, i.e. the first girls' school in Bombay, (now called Mumbai), but people were suspicious of the missionaries' motives as colonialists, and Christians (Jha and Pujari, 1996). In the north, Swami D Lapanand founded the Arya Samaj Society which supported women's education, and which still has adherents today (Jha and Pujari, 1996).

Some barriers to the advancement for women appear in the history of education for girls in modern India (Jha and Pujari, 1996). When the British came, the old system became completely disorganised and disappeared. There was no funding for girls' education, and Macaulay's decree, in 1834, that all education should be in English had the effect of separating women in higher castes from lower. By 1881, more Indian women studied English than their own native language. The administration

needed English-speaking clerks and civil servants, and the emphasis on English led to a top-heavy system which exists today. Girls could go to boys' schools, but this ran counter to cultural ideas of separation of the sexes (Jha and Pujari, 1996). Das (1994) feels it would have been better to modify the Brahminical system than to lose all the traditional system of learning.

Education is undoubtedly a strong factor in advancing the status of women, and most authors subscribe to it, however, it is pointed out that the education system has failed to achieve women's equality; and that cultural information was being taught, but not traditional culture. In any case, India is caught between Westernisation and clinging to traditional values, as globalisation threatens the fabric of society (Lannoy, 1971). Women are expected to use Western modernity, and ancient Indian values, at the same time (Jha and Pujari, 1996).

Another way for women to possibly advance was through nursing training, which started in colonial days, when hundreds of Western women began medical work in India between 1871 and 1900, with strong religious zeal (Singh, 2005). Nursing was associated with lower social status with hands-on care across castes, and was not considered suitable for higher castes. Early medical schools grew out of women's hospitals and nursing. Some of the early matrons were highly respected, and regarded almost as cult figures. This did not apply to the nurses, and Sehrawat (2005) notes that the possibility of greater intellectual possibilities was tempered by strict supervision. The Association of Medical Women in India (AMWI) accepted the prevailing patriarchal norms, so that women were not free to make sexual choices, and were supervised, and limited in their way of life.

5.1.14 The rise and fall of feminism

Nabar (1995) says that there has been no organized radical revolt against gender discrimination. At times there has even been backlash against any moves towards women's liberation, as seen in the Bharatiya Janata Party's women's wing, in Pune, demonstrating against such groups, in 1985. Factors such as caste, class, economic deprivation, sectarian fragmentedness, size and numbers, overpopulation, the rise of fundamentalism, superstition, female foeticide and Hinduism all prevent an easy solution (Nabar, 1995).

It is also true that the way feminism has been portrayed in India has not been helpful, nor was the period in the sixties when parts of India became havens for hippies. The observed behaviour of Western women in public did not endear them to Indians, nor did the stridency and alien language of some American women's liberationists (Holroyde, 2007). As an English woman, she lived in India and observed: "My liberated Indian women friends in high professional jobs and influence, were shocked by Western women's nudity, free love and promiscuous ways just as our parental generation were" (Holroyde, personal communication, 2005). The old debate of individualism versus communal rights is very relevant. Nabar (1995) acknowledges that a good hard look at the obvious discrepancies is very necessary, but how to alter things remains somewhat of a mystery.

Feminism as a movement created awareness in gender inequities in Western societies. Has it been successful in India? Nabar (1995) suggests that feminism has not moved women's position at all; partly because of ignorance of its aims, and misapprehensions about it. Western feminism cannot be arbitrarily imposed onto Indian society. Issues such as equal pay, discrimination laws, help for parents in the form of childcare, and prevention of violence against women, seem universal aims, but the religion and ideologies of a culture have to be acknowledged. Nabar (1995) asserts that most Indian women relate to the traditions of Hinduism, and that it can be said that religion plays a greater part in the life of Indian women. Sen (2006) points out that what is lacking is agency freedom – the freedom to think freely without being constrained by the culture and being ignorant of what is possible (i.e. in other countries). A Muslim woman says: "What is needed is the willingness, ability and courage to reassess critically the dominance of received and entrenched messages" (Sen, 2006, p. 12).

5.1.15 The rise of the middle class

It is important to note the rise of the middle class in India, estimated at 400 million, or one third of the population, which showed rapid changes in the status of women and also regional differences in attitudes towards women and education (Holroyde, 2006). Belonging to a privileged class will help women to overcome some of the barriers, whereas even affirmative action has not been able to break down the

obstacles sufficiently enough for women in lower socio-economic groups to achieve their potential. More and more, India is moving towards a society of 'haves and have-nots' (Sen, 2006).

Nabar (1995) places her hope in middle-class women, and there is no doubt there have been strong women who are from the middle to upper classes, such as the lawyers, particularly in Mumbai and Chennai fighting for women's rights. Women have achieved in all sections of Indian society. For example, Dhondo Keshav Karve founded Shreemati Nathibai Damodar Thackersey (SNDT), the first women's university in India in 1916. Kalpana Joshi was a heroine of the armed resistance against the British. She worked as a guerilla, and carried bombs and arms until her arrest in 1933. Vina Mazumdar is a pioneer of India's women's movement and a reformer in education, and campaigner for gender justice. In 1966 Indira Gandhi became the first female Prime Minister of India. The Panchayat Raj institutions have enabled over a million women to enter politics (Holroyde, 2007), however Mishra (1999) feels these institutions could have achieved even more. Laxmibhai, the Rani of Jhansi made a stand against the British in the 1850s (Holroyde, 2007) and Sarojini Naidu was the first Indian woman to make politics her full time occupation, becoming President of the Congress in 1925 (Jha and Pujari, 1996). Pratibha Patil has just been elected the first woman President of India (Roche, 2007). The presidency in India does not have great power, but the position does have a symbolic value for women. Women became social leaders showing strength in early environmental protests like Chipco in the Himalayas in the 1970s (Marshall, 2004).

5.2 Barriers to women's progress

In addition to the history of Indian women, there are significant barriers in the interlocking domains of social ecology and culture. From her earliest experiences in the family, the girl child learns her subservient place. In the wider community, the situation is similar, and the law and politics echo these rules. Chhatre (2003) speaks from a Buddhist perspective, and suggests that there are three reasons why women have not made headway in India: firstly, woman's attitude towards herself, secondly woman's attitude towards society and thirdly, society's attitude towards women. I

would add two other major dimensions; namely men's attitude towards women and the possible negative effect of women on women.

5.2.1 Woman's attitude towards herself and society

From a historical perspective, it is obvious that when the Brahmins became powerful, women were relegated to an inferior status. This affected a woman's perception of herself, and she became afraid to violate the laws, and, therefore, reap social ridicule. In any case, she had to work hard to redeem herself by adhering to the laws, as this was the only way to achieve any status (Chhatre, 2003). Chhatre (2003) believes that women have forgotten that the religious rules are man-made laws, and that women are not inherently evil, and until women can break the traditional framework, they cannot accept the opportunities which society may offer. It is therefore up to women to change their mindset, and the negative self-perception of women will only be removed, when she realizes that she has to draw a line between her own qualities, and that society imposes on her. This point of view does not acknowledge the power of male domination, and how it saps women of even the ability to make decisions, which is evident in my interviews. Jha and Pujari (1996) assert that new laws fail to propel women forward, because women remain unconvinced of the propriety of doing so.

5.2.3 Society's attitude towards women

India is a strongly patriarchal society which often leads to the double standards regarding sexuality and sexual expression. The situation is changing, and the prevalence of premarital sex may be underreported, as well as the numbers of both unmarried and married women seeking sexual pleasure (Savara and Sridhar, cited in Bharat and Aggleton, 1999, p. 32). Holroyde reports a survey in *India Today*, carried out in Bengal, Tamil Nadu, Delhi and Mumbai, found that 30% girls had experienced premarital sex (Holroyde, 2006). Sharma (2001) found in a study of Indian young people, that 25-33% admitted to premarital sex. However, this study was carried out in Delhi and Lucknow slum communities, and may not be representative of rural areas.

Job respectability is a factor – women may not be able to work in certain areas and still be respected in their communities. Lack of labour-saving devices keeps women chained to domestic chores without time to work outside the home, and lack of

education has meant that women have not been trained in politics. Indian men have not actually opposed women's progress. Given the unfair status of women, men do not have to oppose, just maintain, the status quo. This approach does not address the power of domination. Women may internalise, and believe in, the norms of society, even enforcing them, if those norms hold out the promise of improvement of their status with age (Sen and Ostlin, 2007). Women will even advocate the dominant cultural mores when they are socially conditioned to do so (Jha and Pujari, 1996).

5.2.4 Women's and men's attitude to women

Nabar (1995) proposes that female bonding, which has been emphasized in western discourse, may actually be the cause of women's oppression in India. Young women are taught by other women that they have no choices, although this situation is rapidly changing, due to the influence of TV and other media (Holroyde, 2006). Another reason may be that the mother, confined to the home, ends up surrendering to the tradition of glorifying the status of wife and mother. Because of the unequal power relations, this may be the only way that she is able to attain some status (Nabar, 1995). Women may also be honored if they give birth to sons, hence the title of the book: "*May you be the mother of a hundred sons*" (Bumiller, 1990).

As India has strong patriarchal attitudes towards women, this obviously affects the way in which women perceive themselves. It is easier to stay within the confines of an unequal system than risk societal opprobrium and disgrace. If one has been told that the only way to reach heaven is by obeying the rules, it must be very difficult to make any headway. Das (1994) asserts that the denigration of women arises from the Hindu male's adoration of his mother, and denigration of his wife, and this leads to the search for a mother in the wife instead of a partner.

5.3 Culture and values

Culture is a term with many meanings. It generally refers to characteristics such as non-physical traits such as values, beliefs, attitudes and customs that are shared by a group of people, and passed from one generation to another (Spector, cited in Im et al., 2004, p.892). It results from learning as a child, and keeps changing

dynamically. This is evident in India, where succeeding invasions have brought changes to the original population.

5.3.1 The caste system

The caste system is a complicated and difficult system for a person outside the Indian culture to understand. I learned that caste could be ascertained by occupation, name, appearance, dress, and to some extent, living conditions. I cannot hope to cover fully the intricacies of such a system; and will focus on the lower end of the socio-economic scale and women. The word caste comes from the Portuguese word used in India in the 16th century – “castas” which in turn is derived from the Latin word “castus” meaning “pure” (Holroyde, 2007, p. 76). It is a system of stratifying society and separating people into groups with strict divisions (Holroyde, 2007). With modernisation of transportation and communication, the caste system is altering. Mandelbaum (1957) notes, however, that new development programmes do not necessarily help the lower castes particularly in rural areas. These groups are landless, and gain nothing from new irrigation projects and the redistribution of land, as they had nothing to begin with, and therefore nothing that can be improved, and so the gap may actually widen between them and other villagers. The rights and obligations which may have existed before have weakened.

Caste plays a crucial role in the socio-economic life of the community where the lower castes are often the most deprived in terms of quality of life, including health, education, employment, income, and limited access to power structure. Historically, the upper castes dominated the social and political power structure, treating other lower caste people like slaves, without human rights and scheduled castes bear the brunt of it. Though the degree and intensity of discrimination has decreased over time, often the low caste status results in major impediments to the scheduled caste’s vertical mobility in social life (Thresia, 2007). Nabar (1995) sees discrimination against women as three-layered. Firstly, there is sex-based (stri-jati), secondly caste-based (jati), and thirdly, class-based. Caste has an effect on health. Membership of scheduled or backward castes impinges negatively on health (Bajpai and Goyal, 2004).

5.3.2 Religion

The World Health Organisation carried out a study in eighteen countries, and found that the domains of spirituality, religion and personal beliefs add to quality of life, particularly in people with poor health. Religions are a major force in many communities. They can use concepts such as sin, guilt, evil and damnation to promote acceptance of certain moral positions. Most Indian women identify strongly with Hindu traditions according to Nabar (1995). The Jain religion, in particular, views women as inferior and therefore undeserving of spiritual freedom. In the old texts of the Jains, women are described as “bearers of the seed” with no independent role in creation (Kulkarni, 2003, p.15). A recent statement of the Indian Catholic Church was seen as significant for its more tolerant stance on homosexuality (Krishner, 2005). Dilemmas arise from compassion on the one hand, and judgement and divine punishment for transgressing laws, on the other (Gilmore and Somerville, 1994). For them, the level of independence, environment, spirituality, religion and personal beliefs play an important part. Women reported greater feelings of spiritual connectedness and faith than men. Those with less education had greater faith but were less hopeful (UNAIDS/WHO, 2006).

5.4 Social factors

5.4.1 Family

India is notable for its strong family associations and ties, which endure despite globalisation, urbanisation and modernisation. Krishna et al. (2005); and Sharma (2005) regard the family as a potentially significant source of strength and support. Globalisation has affected women and their employment. Although women see their primary role within the family, they may be driven beyond those boundaries to seek work in unprotected jobs. Men have priority in careers, so women face unequal access (Sharma, 2005). And globalisation merely continues the patterns of exploiting women’s time, work and sexuality.

Lannoy (1971) writing 30 years ago, describes the emotional control that is necessary to develop under such crowded conditions of everyday life. The size of Indian dwellings for the poor has not changed in thousands of years. (I remember the model in the Prince of Wales Museum in Mumbai of the ancient city of Mohenjo-daro, where the dwellings were just the same as the ones I saw in the slums of Mumbai).

Lannoy (1971) says that there are constant feuds amongst women who live closely but are not related. Children soon learn that women are subservient to the needs of men. Although the Hindu ideal is to indulge children, this may be a luxury only in more affluent homes. Because of the onerous workload of mothers, a number of babies under one roof, and the frustrations of joint family living, children may receive only limited attention. Urbanisation has broken down traditions of family life (Jha and Pujari, 1996), with nuclear families living far from their original villages. At the same time, women have always migrated from their family of origin to their in-laws (Sen, 2005).

5.4.2 Community

It is essential to understand that if stigma is community-driven, that interventions involve community in their design and implementation (Hadjipateras, 2004). Issues of power have to be addressed on several levels – the macro-social level (health agencies, multinational drug firms, and agribusiness), intermediate level (health administration), the micro social level (doctor/patient), and the individual level (Baer, Singer and Johnsen, cited in Abrums, 2000, p.91). Social and cultural taboos make it difficult to discuss areas such as HIV/AIDS, but also to confront issues such as prostitution, where women may be too fearful to negotiate safe sex. Similarly, homosexuality which is illegal and hidden in India, is an important mode of transmission. This makes it difficult to address practices such as boys experimenting with sex with other boys before marriage, and the relationship between truckers and their young male assistants (Schaffer and Mitra, 2004).

5.4.3 Structural considerations

The census of 1921 reported that in every thousand Hindu women, 14 had been married under the age of 5 years, 111 under 10 years, and 437 under 15 years. This had persisted because of the Shastric injunction that a girl should have intercourse at the first signs of puberty, and therefore be married earlier. Gandhi himself was betrothed aged 7 years and married at 13 years (Jha and Pujari, 1996). In 1929, Hari Bilas Sarada introduced a Bill to raise the minimum age to 14 years because of the physical and psychological damage to young girls, and the lack of education possibilities through early marriage (Jha and Pujari, 1996). However the law has been constantly flouted since.

Mishra (1999) says that governments knew as far back as 1939 that structural considerations were blocking women's progress. The constitution which had assured women of political rights was never backed up. Jha and Pujari (1996) claim that the state has shown a complete apathy towards the education of women, especially rural women. The 1975 International Women's Year brought on a flurry of activities to raise awareness. However, some facts and figures show that, despite the earlier promise of social struggles and reform, these may have been overwhelmed by globalisation and capitalism, so that any gains that have been made are not working for people in the lower socio-economic groups and particularly women (Mishra, 1999; Mohanty, 2004). In fact Mohanty (2004, p.399) says that the responses of the Indian state to such struggles have been "increasingly repressive and violent" because the state does not recognise the formation of a "creative society." It is interesting to compare statistics related to social problems from 30 years ago. For example, estimates of poverty have halved from rural poverty of 261 million, or 56.4% in 1973-74, to 193 million (27.1%), in 2000. Urban poverty of 60 million (49%), fell to 23.6%, although numbers increased to 67 million (Mohanty, 2004).

Literacy rates of the male total population rose from 34.44% in 1961, to 64.13% in 1991. Female literacy rates climbed from 12.95% in the same time period to 39.29%. This figure alters in different states. For example, in Kerala, the female literacy rose to 85%, where there is a long tradition of women's education firstly in upper classes, but now across the whole population (Holroyde, 2006). The actual growth of employment in the urban sector declined from 3.2% in 1983, to 1.5% in 2000. Although the number of Cabinet and state Ministers increased for men from 40 (1985), to 74 in 2000, the number of female Ministers made a miniscule improvement from 4 to 8 (Mohanty, 2004).

5.5 International and national law

India is signatory to the following international agreements, conventions and laws which have implications for women: *The 1979 Convention of All Forms of Discrimination Against Women (CEDAW)* in which Article 10 provides that the State must ensure that women have equal rights with men to education. Article 12

provides that the State must take all necessary steps to ensure that women have equal rights to health care. Article 15 provides that the State must eliminate discrimination against women in marriage and family relationships.

The 1993 World Conference on Human Rights, Declaration and Programme of Action (Vienna Declaration) included Article 41 which recognizes the importance of women's right to have the highest standard of physical and mental health, and makes statements on human rights and violence against women. In the same year there was a *Declaration on the Elimination of Violence against Women*. Article 4 calls on governments to condemn violence against women. It also asks that custom, religious practice or religion not be used to promote violence towards women.

The 1994 International Conference on Population and Development (ICPD) Programme of Action addresses sexually transmitted diseases and the ensuing vulnerability to HIV/AIDS and provides recommendations in Article C for reproductive services. The *1995 Fourth World Conference on Women (Beijing) Declaration and Platform for Action*. Strategic Objective C3 undertakes to provide gender-sensitive initiatives to address STDs, HIV/AIDS and sexual and reproductive health issues.

2000 Millenium Declaration and Development Goals. Goal 3 asks governments to promote gender equality and empower women; and the 2001 UN General Assembly Special Session (INGASS) on HIV/AIDS, Declaration of Commitment Article 14 declares that gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS (UNAIDS/UNFPA/UNIFEM, 2004).

The failure of such agreements to protect and empower women prompted Stephen Lewis, Canadian envoy to the United Nations, to make an impassioned plea for women. He said that "the greatest single international failure in the response to HIV/AIDS is the failure to intervene, dramatically on behalf of women" (Lewis, 2005, p.3). These accords are important in setting policy and providing a framework, but without the political will to ensure that these principles are implemented, they do not alter the status of women. India's constitution prohibits discrimination on the

basis of gender, but it has failed to protect the rights of women, especially sex workers.

High levels of violence in the sex trade, child sex workers, and lack of access to health care and high levels of HIV infection still exist (Mawar et al., 2005). Schaffer and Mitra (2004) argue that what is needed is a social reform movement which would deal in fundamental ways with the social attitudes which have fuelled the growth of the epidemic. The critical dimension here is the status of women, which affects the epidemic at every stage, starting with the vulnerability of women to initial infection, and continues through treatment where women are in danger of having their drugs pre-empted by their partners, even when the women are the intended recipients (Schaffer and Mitra, 2004).

5.6 Summary of the chapter

In summary, in the Indian lower classes, education has not reached the level it promised for women; laws are difficult to enforce, suffrage has not been sufficient, and women's status has not improved sufficiently. Some authors say that the answer lies with women themselves. History shows that it was sometimes the British and sometimes male leaders like Gandhi and Raja Ram Mohan Roy who advanced the cause of women. Men educated in the British system provided sympathy for women's rights (Jha and Pujari, 1996). It is still a fact that women in lower castes are unable to advance unless they have more education, self-esteem and confidence.

CHAPTER 6

THE EFFECT OF STIGMA AND DISCRIMINATION PRECEEDING AND FOLLOWING HIV/AIDS FOR INDIAN WOMEN

“At every stage of childhood, through all the initial years of development, a person either learns or grows to be an actor or an adjunct. If the needed foundation investments are made, the girl child prospers as a person.” (Razia Ismail Abbasi, International Convenor of Women’s Coalition for Peace and Development with Dignity, 2006, p.7).

6.0 Introduction to the chapter

Chapter 5 noted the effect of history and socio-cultural dimensions on Indian women. In this chapter, stigma and discrimination emanating from those areas, is summarised to highlight the effect on Indian women’s vulnerability to HIV/AIDS. The acquisition of this debilitating condition, in turn, adds another layer of stigma and discrimination onto Indian women, forming an inescapable cycle.



Figure 5: The process of HIV/AIDS, Stigma and Discrimination for IWLWHA

I have created this figure to demonstrate how Indian women with lower socio-economic status become vulnerable to HIV/AIDS because of stigma and discrimination. When they are exposed to HIV, the ostracism and labelling become even more pronounced.

6.1 Vulnerability issues

The psychosocial framework used in this study considers how the three major domains of human capacity, social ecology and culture/values are affected by events, either conflict situations or natural disasters. These events can be catastrophic or cumulative, and are said to challenge the individual and community (Strang and Ager, 2007). Chambers (cited in Yamin, Rahman and Huq, 2005, p.4) defines vulnerability as “defencelessness, insecurity and exposure to risk, shocks and stress”. I consider that the interface between events and the effects can be conceptualised as vulnerability. There are dimensions which are known to affect all women’s vulnerability to HIV/AIDS, such as biology and general nutrition. Indian women in lower socio-economic situations are even more vulnerable because of socio-cultural factors such as poverty, gender inequality, knowledge and awareness of HIV/AIDS, and their beliefs regarding general and sexual health. Violence further diminishes Indian women’s capacity to prevent them from contracting the disease. Stigma and discrimination prevent them from accessing testing and services.

6.1.1 Biology of women

Women are known to be at greater risk of contracting AIDS for the following biological reasons: There is a greater exposed surface in the female genital tract, and the HIV virus accumulates in higher concentrations in semen than vaginal fluids (UNAIDS/UNFPA/UNIFEM 2004). During unprotected vaginal intercourse, an HIV-positive male is at least twice as likely to transmit the virus to an uninfected female as an HIV-positive woman to infect a male (UNIFEM, 2007). Coercive, or forced sex, and female genital mutilation, may lead to injuries to the genital tract which make it easier for HIV to enter (UNAIDS/UNFPA/UNIFEM, 2004).

Women are more likely to be infected with a sexually transmitted infection (STI) from a single sexual act (Baden and Wach, 2006). In addition, researchers note that STIs, if untreated, increase vulnerability to HIV/AIDS (Engender Health, 2006; Weiss and Ramakrishna, 2001; Aggleton, Wood and Malcolm, 2005). Various independent studies show that the rate of STIs in India is very high. In a study in Pune, 25% of women (n=400) had STIs, and 93% were married (UNAIDS/UNFPA/UNIFEM, 2004). Yasodhara, Raghunath, Sreeramulu, Venu,

Hemalatha and Krishna (2003) conducted a study in Hyderabad, and found 57% women had STIs, which was highly correlated with severe under-nutrition.

6.1.2 Nutrition

Good nutrition is difficult to achieve for many Indian women because of poverty, undernourishment, neglect and discriminatory practices in food allocation from birth. This results in foetal growth retardation, underweight babies and children, and finally possibly heart problems (Sen, 2006). India has the largest number of malnourished children in the world – about 50% of children under four years of age are undernourished, 30% of newborn children are significantly underweight (Ekstrand et al., 2003). Poor nutrition leads to lowered immunity (through lack of Vitamin A), and anaemia (Baden and Wach, 2006). It has been estimated that 60% of the women in India suffer from anaemia. Women with anaemia are more likely to require blood transfusions, especially after delivery. This increases the possibility of infection by HIV/AIDS through transfusion, particularly in India, where a safe blood supply cannot always be guaranteed (Baden and Wach, 2006). The poor are particularly at risk. Figures show that the poorest 20% of Indians have double the mortality, and malnutrition, compared to the richest groups (Ekstrand et al., 2003). In rural areas, the increasing degradation of the environment means unsafe water and poor sanitation, leading to disease. The national average daily per-capita consumption is 2,400 kcal. In rural areas, the average daily per capita consumption is only 2,150 kcal (Ekstrand et al., 2003). Recently, it was reported in *The West Australian* (8 June 2007, p.37) that 700 tea workers had died from diseases linked with malnutrition, following the forced closure of tea estates in West Bengal. Sixteen tea estates had closed down because of low yields and poor production, leading to loss of income for workers (Dandona, 2004).

6.1.3 Poverty

Poverty is said to have reduced in India, according to official estimates, however the rate of reduction is disputed. There is also disparity between the states, as the richer states have been more successful at reducing poverty, whereas poorer states such as Bihar, Uttar Pradesh, Orissa and Madhya Pradesh have increasing poverty levels (Ekstrand et al., 2003). Differences exist between urban and rural poverty and the lower castes (i.e. scheduled castes and scheduled tribes) are particularly

disadvantaged (Ekstrand et al., 2003). Poverty is a risk factor in itself, and it also accentuates all the other dimensions, increasing vulnerability. If women cannot afford proper nutrition and health care, are not sent to school, or are abandoned, then they are even more disadvantaged.

Women may be lured into prostitution because of poverty (YOUANDAIDS, 2005); and for many women in the city slums, it is the only means of survival (D'Cruz, 2004). The highest rates of female commercial sex workers in 13 districts of Andhra Pradesh were found to be women from scheduled castes and tribes, illiterate, and separated/divorced women (Dandona, 2004). In Maharashtra, 83% of female commercial sex workers were found to be illiterate. Mumbai has the country's largest brothel-based sex industry with over 15,000 sex workers, of whom 70% are surmised to be HIV positive (YOUANDAIDS, 2005). Deviance from the social norms such as the practice of commercial sex and homosexuality, are treated as criminal offences, and attract their own stigma, as in western societies (Solomon et al., 2004; Worth, 1990). However, in India, HIV-positive female sex workers face greater discrimination, even to the point of a government proposal to brand them on the thigh (Jayaraman, 1998). This plan resulted from the belief that the commercial sex workers were responsible for the spread of infection.

6.2 A lifetime of stigma and discrimination

Stigma and discrimination occur very early for Indian women. Gender bias begins for Indian females even before they are born. Bumiller (1990) argues that upper-class women will use prenatal tests to determine the sex of a child, and may resort to sex-selective abortion. Poorer women may resort to female infanticide. From birth, women have a lower status than men (Bharat and Aggleton, 1999; Solomon et al., 2004). This is accentuated by caste, socio-economic status, poverty and membership of a marginal group (Bhattacharya 2004a; Thomas and Bandyopadhyay, 1999; YOUANDAIDS, 2005).

6.2.1 Girl's childhood

From birth onwards, a girl may be regarded as being of lesser value, and an economic burden. In Goa, even the sweets selected to mark the child's birth are

different - *jellabis* for a girl and more expensive sweets - *pedhas* to celebrate a boy's birth (Embassy of India, 2007; Rodrigues, Patel, Jaswal and de Souza, 2003). A girl in India has first to survive sex preference before birth. Families still prefer to have boys, and may engage in sex-selection or foeticide in order to ensure a male child. This is the extreme form of discrimination. A girl child comes last with everything, including food, leading to malnutrition and anaemia, as discussed above (Sen, 2001). There is disparity between the official government policies regarding girl children in India, and the cultural practices and existing discrimination towards females (Abbasi, 2006).

For example, the Indian Constitution, the National Policy for Children, and other policies and legislation prioritise children's needs. Sustained educational campaigns have attempted to reduce discrimination. Education for all children has started, and there is a National Plan of Action for the Girl Child 1991-2000 aimed at preventing female foeticide and infanticide, eliminating gender discrimination, providing safe drinking water and food, and protecting girls from exploitation, assault and abuse (Embassy of India, 2007). Other programmes have targeted the 314,700 street children in Bombay, Calcutta, Madras, Kanpur, Bangalore and Hyderabad (Embassy of India, 2007). These children are particularly vulnerable. There are disparities between rural and urban situations and variances from state to state (YOUANDAIDS, 2005).

The figures of the 2001 National Census show a continuing decline in the sex ratio in urban areas, particularly in the 0-6 years, 927 females (F) to 1000 males (M), compared to 1991 figures of 945 (F) to 1000 (M), (WHO & Regional Office for South East Asia, 2004), and were not cited in the Government of India report, according to Abbasi (2006). The figures differ from state to state. The most severe situations exist in Punjab, with a ratio of 793 (F), Haryana 820 (F), Chandigarh 845 (F) and Delhi 865 (F); and the statistics also show that the disparity between the male population (531,277,078) and female population (495,738,169) is 35 million fewer women (Acharyra, 2004). The most recent UN review of India's implementation of the Convention on the Rights of the Child, in January 2004, noted that discrimination against girl children has not reduced (Abbasi, 2006).

Indian girls are trained to be ‘good’ women with virtues of submission and docility, skill and grace in household duties. A ‘good’ woman is a good wife and must regard her husband as godlike. It is only through performance of her duties properly, that a woman has any identity, or status, in this world, and heaven, in the next (D’Cruz, 2003). There is little difference between the statement from an Indian researcher, above, to the Princess of Jaipur’s reminiscences, from 65 years ago: “The ideal wife...is pure, she is modest, she is self-effacing, and she literally worships her husband.” (Dwivedi and Holkar, 2005, p.14).

In their old age, poor parents do not want another adult mouth to feed, nor do any parents want the shame of a spinster daughter, for it means they have failed in their duties towards her. Sons on the other hand are very useful. They earn, they support their parents even from afar. Non-resident Indians send money to support families at home. When the time comes, Hindu males perform their parents’ death rites. If this does not happen, people believe they will be ‘hungry ghosts’ in the afterlife (Holroyde, personal communication, June 17, 2006). These are cultural mores which have no specific justification, as females could perform these rites (YOUANDAIDS, 2005). In the case of one respondent in my interviews, she had to carry out the death rites, because all the male members of her family had died from HIV/AIDS (Interview 1, Kamla).

6.2.2 Child marriage

The legal age of marriage, in India, is now 18 years. Very early marriage (i.e. before the age of 13 years), has almost disappeared in urban areas, and is rare in rural areas (YOUANDAIDS, 2005). Marrying at an early age means husbands may be older, sexually experienced men, who are already infected with HIV/AIDS. At such a young age, girls lack power in the relationship to negotiate safe sex, and may drop out of school, thus limiting their education and awareness (Disabled women’s network Ontario, 2007).

6.2.3 Gender differences in stigma and discrimination

The following table summarises and highlights differences in stigma and discrimination of Indian men and women in various areas. The table has been developed by the researcher and draws on the literature and the following authors:

(Bharat and Aggleton, 1999; Bhattacharya, 2004b; Ratnathicam, 2001; Jayaraman, 1998; Solomon et al., 2004, Sridhar, 2002; Ashraf and Godwin, 1998; Thomas and Bandyopadhyay, 1999; UNAIDS, 2004a; UNAIDS, 2004b; Ekstrand et al., 2003; Gupta, 2002; Nabar, 1995; Pradhan and Sundar, 2006; and Warren, 1996, 1997).

Table 2: Differences in Stigma and Discrimination of Men and Women in India

AREA OF STIGMA/DISCRIMINATION	<i>MEN</i>	<i>WOMEN</i>
Gender before and at birth		✓
Caste/class	✓	✓
Ethnic minority	✓	✓
Literacy		✓
Wages		✓
Poverty	✓	✓
Social expectations (virgin at marriage)		✓
Lack of power in sexual relationships		✓
Low risk sexual behaviour		✓
Marriage		✓
Divorce and widowhood		✓
Domestic violence		✓
Dowry disputes		✓
HIV/AIDS	✓	✓
Vulnerability to HIV/AIDS		✓
Knowledge of HIV/AIDS		✓
Decision making		✓
Environmental degradation		✓

6.3 Gender inequality and HIV/AIDS

Women are more vulnerable to acquiring HIV/AIDS through lack of options, choices, rights, and information. Cultural taboos on knowledge and discussion of sex apply even more to women. However, the assumption that men are more experienced and knowledgeable about sex may prevent them from accessing knowledge, and in turn, this affects women (Altman, 1999). Men are encouraged to show sexual prowess by having multiple partners, or consuming alcohol. Communities may deny the existence of men having sex with men, which results in lack of prevention and care for women (Engenderhealth, 2006). In addition, homosexual males may stay in a marriage to protect them from stigma. Women may believe that marriage itself prevents HIV/AIDS (Bhattacharya, 2004a).

Double moral standards mean that, whilst sex outside marriage is common for men, it is uncommon to find women acting on sexual desires outside marriage. Women are encouraged to abstain from sex until marriage (Bharat and Aggleton, 1999). After marriage, there is pressure to produce an heir, preferably male (Bumiller, 1990). The Indian National Family Health Survey (1998-9) found that one third of participants wanted sons, and a negligible number wanted daughters. Sen (2001) estimates there are 36 million missing women as a result of sex-selection practices from 1961-2001. There is a lack of power to demand safe sex (Bharat and Aggleton, 1999; Bhattacharya, 2004b). Although both men and women suffer stigma and discrimination, the impact on women is much greater, and across more areas of their lives.

6.3.1 Lack of decision-making and power

Decision-making is another area where Indian women find themselves at a disadvantage. This is related not only to the economic decisions which preclude them, or put them at the lowest end of receiving medical treatment, but also decisions about leaving the marriage. In a study of low-income women in Mumbai, Gupta (2002) found that the economic consequences of leaving a relationship were far worse than the health risks of staying in the relationship. Men make decisions about how and when to have sex (Chatterjee, 2002; Weiss and Ramakrishna, 2001), whilst women lack the social power to reduce risk of infection. Women lack knowledge

about safe sex, and have little control over their bodies (Pradhan and Sundar, 2006; UNAIDS, UNFPA and UNIFEM, 2004). George and Jaswal (1997) assert that women need mobility, information and skills, money and social support, in order to have power over their lives; and that having access to money enables women to make significant life choice, such as careers, and to end abusive, or unfulfilling marriages.

In many cases, Indian women are dependent on their husbands - socially, financially and for health decisions. Paxton (2004) found that Indian women were twice as likely to lose financial support through AIDS (11% versus 5% males), and twice as likely to be deserted (13%, versus 6% for males). When IWLWHA lose their partners through illness or death, they may be forced into sex work, or bartering sex for survival. Their position is further weakened by discriminatory inheritance, property and possession rights (Pradhan and Sundar, 2006).

6.3.2 Lack of education and awareness

Awareness and knowledge of the disease of HIV/AIDS varies from state to state, rural to urban, and from gender to gender, and this affects the ability to take steps to prevent infection. Pallikadavath et al.'s (2006) study found that 29.7% rural married women, and 70.3% urban married women, were aware of HIV/AIDS. Women are compromised by more lack of knowledge than men. For example, Abdul, Yarnal and Loni (2003) found that only 40% women had heard about AIDS from the mass media in their study. Only a small number (6.5%) of married women are said to be aware (Population Foundation of India, 2007). This may be attributed to taboos on sexual discussion, as well as general education, and incomplete knowledge from sources such as TV, family and friends. However, Pallikadavath et al. (2005) found, in their study of women in northern India, that if women were not exposed to television, they were less likely to have awareness of HIV. Khaparde (2006) carried out a survey of 1546 adolescent boys and girls in Mumbai slums, and found that, despite exposure to mass media, boys had low-level knowledge of HIV/AIDS, and girls even lower.

6.3.3 Husbands

When HIV/AIDS reached India and increased, concern focused on groups with high-risk behaviour such as female sex workers, injecting drug users, and men who have sex with men. With alarming figures such as 60% of CSW in Mumbai being HIV positive, there is certainly room for concern (Khanna and Dhar, 2004). The figures for incidence in women were based on hospital records, and antenatal clinics. It is now accepted that there has been severe under-reporting of women who are not sex workers, but married women in heterosexual relationships (Bharat and Aggleton, 1999; YOUANDAIDS, 2005).

In addition, it has been said that the main risk factor for married women in India is their husbands (Gaitonde, 2006). Sakthi (2006) also claims that the gender issue is the primary factor for rapid spread of HIV infection in India. In Hyderabad, Schaffer and Mitra found that 77% of the pregnant HIV-positive women had HIV-positive husbands. In Pune, in a study of 400 women, 91% had had only one partner – their husbands (UNAIDS, UNFPA and UNIFEM, 2004). The majority of Indian women who contract HIV/AIDS have not engaged in high-risk behaviour, reflected in the figures of 85.7% (NACO, 2002-2004). In fact, an Indian woman who is following the strict prescripts of a male-dominated society in marrying exactly how her family has dictated; and engaging only in heterosexual sex with her husband, is very vulnerable (Bharat and Aggleton, 1999). Furthermore, being the innocent recipient of HIV/AIDS does not protect women from stigma and discrimination (Mawar et al., 2005).

6.3.4 Highly mobile populations

India's population is highly mobile, for the following reasons: Seasonal workers move when there is no work available in rural areas; numbers of migrants enter India for work, whilst others leave to seek work, i.e. in the Gulf states; and people are dislocated through natural disasters such as floods, and conflict. Refugees seek asylum, and there is the army of truck drivers who transport goods across the sub-continent. Hotel and tourism workers, commercial sex workers, trafficked persons and the military are all highly mobile groups of people. Women may be forced to migrate because they are perceived to be a burden on their families, or to escape domestic violence (Ekstrand et al., 2003).

These migrant groups contribute to the vulnerability of women. When husbands are away for long periods of time, women may resort to commercial sex work, or may be infected by their husbands on their return (Ekstrand, Garbus and Marseille, 2003). In Hyderabad, HIV-positive men were not just confined to truckers and drivers, but were agricultural labourers, businessmen, skilled and unskilled labourers. Therefore, it is not only the high-risk group of highly mobile men who infect their wives. Mumbai has a huge migrant population, and the International Institute for Population Sciences found that far fewer migrants had knowledge of STIs, and the prevalence of risk taking behaviour (i.e. alcohol consumption, visits to CSWs and extramarital relationships), was much higher amongst migrants living alone. The People's Health organization found 29% of the men living in Mumbai are single. Whether they are married and away from their families, or unmarried is not stated (Ekstrand et al., 2003).

6.3.5 Violence towards women – sexual and physical

Sexual violence is acknowledged to be a major contributing factor for HIV infection (Duvvury, Prasad, Kishore, Agarwal and Dharmaraj, 2006). This arises from the lack of protection of family life, lack of sustainable income for the women, and shelter. As women have no negotiating power regarding their sexual lives, they can be abused physically, or emotionally, if they refuse (Sharma, 2005; Sharma, Sujay and Sharma, 1998). Many older women commit suicide as a result of abuse (D'sa, 2005). Physical violence, or fear of same, can be a significant deterrent to negotiating safe sex (Centre for Advocacy and Research, New Delhi and Positive Women's Networks, Chennai, 2007). In my study, the SAHAS community workers and one of the community leaders commented on a group of women, which was formed to cope with the effects of domestic violence and alcohol.

Parkar, Fernandes and Weiss (2003) conducted a study in Malavani, a Mumbai slum, and found violence in many forms. There was fighting between individuals, different gangs, and different ethnic and religious groups. The causes of fighting were often over the sparse services, such as where to leave water, or use toilets. Domestic violence was a daily occurrence, as men beat their wives, and the women beat the children: 60-70% women reported routine beatings. Because of male

unemployment, women were forced to work, but did not receive commendation, only frustration from the men who had resorted to alcohol.

The pressures exerted on women to produce a child force them, either knowingly, or unknowingly, to have sex with infected partners (UNDP/UNFA/WHO/World Bank, 2003). Men do not usually disclose their positive status to their wives (Pradhan and Sundar, 2006). An estimated 20% of women experience domestic violence, which gives men the opportunity to demand sex and to seek multiple partners (Ekstrand et al., 2003). Indian women report fear of bringing up condom use can result in violence (Gupta, 2002).

6.3.6 Healthcare discrimination

In addition to the discriminatory practices which have been noted for all PLWHAs, the position for women is even worse and reflects other socio-cultural dimensions. Women in India are expected to tolerate more suffering and pain. They tend to put the other members of the family, particularly their husbands, before themselves. In poverty-stricken households, financial resources may only stretch to one person being treated. This affects a woman's ability to seek health care. Studies have shown that women only approach healthcare in extremis, rather than in the early stages of HIV/AIDS, and only after their husbands have been diagnosed (Majumdar, 2004; Pradhan and Sundar, 2006); or as a consequence of their husband's condition (Tarakeshwar et al., 2006). Women have more difficulty finding doctors who will treat them, and there may be stigma attached to attending an STD clinic, which will prevent them from receiving care and preventative measures (Marcus, 1993).

6.4 Belief systems

Another area which will affect the vulnerability of women is what they believe about health, their destiny, sex and systems of treatment. Abrums (2000) conducted a study of poor working class African-American women in USA, and found that it is vital to understand how women's belief systems can help maintain a powerful subjectivity in the face of the dominant health care system, which results in their opinions and beliefs overcoming preventative health measures.

6.4.1 Pollution and purification

Pollution and purity are central to Indians' belief system. Whereas attention to cleanliness may be related to scientific understanding and aesthetics, Hindu beliefs are rooted in religion's central ideas of sacred contagion, and the dread of pollution. In this belief system, personal hygiene and practices of washing are outward signs of a much deeper system of handling pollution. Thus, people who have more contact with 'pollutants' determine their position in the caste hierarchy. This may be considered permanent, if it is of sufficient intensity. A person may remain in this state throughout his/her life, and even transmit this pollution to his/her children. It may be collective and materialises in the lower castes, whereby occupations such as barbers, launderers, sweepers and funeral attendants are considered lower-caste as well as leather-makers because they use parts of the sacred cow (Lannoy, 1971).

Every day, great attention is paid to dealing with pollution. For example, a man or woman is impure on waking, becomes acutely vulnerable to pollution during excretion, eating, and sexual relations, is at a state of maximum purity after a bath, purer before eating, than after a meal, and must wash after eating lest he/she pollute others. S/he will be more vulnerable to pollution during work and social interaction and may be polluted by certain articles. Forms of temporary pollution are overcome by purifying rituals such as sprinkling water, baths, temple rites, a penance, or ingestion of purifying substances. At the same time, beyond the individual, are the permanent polluting differences between castes – the differences between a Brahmin and a Dalit (being the lowest caste) being most obvious. Within the caste, there is a sense of unity through purity compared to the pollution outside the caste (Lannoy, 1971). There are also complex rules to do with food, also, according to purity and pollution (Lannoy, 1971). Pollution is so dangerous to social wellbeing that eliminating it can only be undertaken by certain people – i.e. 'Untouchables'. This is essential in keeping the boundaries of the caste system. In the context of HIV/AIDS, Indian society still considers women as sources of infection, and the vectors of prenatal transmission (Majumdar, 2004).

6.4.2 The Concept of *Karma*

The Jain belief associated *karma* with women. *Karma* is always bad, therefore women were considered bad/sinful by association, because they had to undergo

painful and “dirty” (however normal) situations such as menstruation and childbirth. Hindus believe that there is a causal relationship between previous deeds and future destiny. Bhattacharya (2004a) explains that South Asians may believe that an individual must endure the sufferings of HIV/AIDS to pay for sins in an earlier life, or that the person contracted HIV/AIDS because of misdeeds in a previous life. Having this fatalistic belief means that the person does not try to change or modify risky behaviour, and death is seen as a natural process, and so people endure suffering without necessarily seeking treatment. Understanding such beliefs may help to implement strategies which encourage behavioural change and motives in relation to HIV/AIDS.

6.4.3 Beliefs regarding sex

There are still taboos regarding the discussion of sexual matters, and differences between male and female attitudes to sex. For example, Bhugra (2007) found differences between men and women’s perception of extramarital sex, in a recent study. Men believed that if they were not satisfied within a marriage, they could have sex outside the relationship, whereas women had no option but to endure the situation. Extramarital sex was seen as understandable and acceptable for men, but a punishable act for women. A number of studies have shown that Indian males are more concerned with sexual health as it relates to performance, rather than HIV or sexually transmitted infection (Schensul, Mekki-Barrada, Nastasi, Sagguru and Verma, 2006a; Schensul, Mekki-Barrada, Nastasi, Singh, Burleson and Bojko, 2006b). Indian women are believed to have greater need for sex satisfaction, and therefore there are many restrictions on her succumbing to lust, according to Lannoy (1971). Women may also see men as protectors of family health, leading them to believe that they cannot get HIV/AIDS from their husbands. The fact that wives contract HIV/AIDS from the person who should protect the family’s health leads to feelings of double betrayal (D’Cruz, 2004).

6.4.4 Myths and misconceptions regarding HIV/AIDS

There are myths and misconceptions about HIV/AIDS which affect women, such as that sex with a virgin will cure the infection (Mukhopadhyay, Nandi, Nundy and Sivaramayya, 2001), married people do not have extramarital sex, prostitutes are only from lower classes, children are unlikely to be infected, and it is good to marry

off children so they have a partner in adulthood. Lorry drivers believe that heat generated from the engine enters the body, and safe driving is only possible if they let the heat out of the body at frequent intervals by having sex (Gaitonde, 2001). Younger women are believed to be less likely to carry infection (Mukhopadhyay et al., 2001). Bhattacharya (2004) adds that men may believe that condom use will make them ill, or waste body power. Indian women may believe that men need to relieve stress by sex. Women may believe that a white discharge is the effect of body heat or overwork. Beliefs such as these will not alert women to seek medical advice (Majumdar, 2002). Bhugra, Mehra, de Silva and Bhintade (2007) found that married women felt safe and protected from HIV/AIDS, because they did not have sex with anyone else except their husbands.

Schaffer and Mitra (2004) conducted a survey and found that 60% of the respondents believed they could contract AIDS from a mosquito bite, or by sharing a meal, or shaking hands with someone with HIV/AIDS. Urban Indian women are reported as not liking condoms because of the fear that if the condom fell off within the vagina it could get lost, and perhaps travel to the throat, or other parts of the body (Gupta, 2002); and that condoms are associated with CSWs (Bhattacharya, 2004).

Risk assessment is culturally constructed, according to Bailey and Hutter (2007), who found that men used physical markers, (such as a healthy complexion), to determine if a CSW was healthy. They stereotyped women as 'normal' versus 'other', and ascribed certain behaviour to these women. Another belief was that if a wife did not talk to strangers, she was trustworthy. Such beliefs can have devastating effects on assessing the risk of contracting HIV. Tarakeshwar et al. (2006) found that HIV- positive women blamed the infection on their fate, or God, even though it was caused through their husbands. The men, on the other hand, understood that they had been responsible for the infection, and regarded the infection of HIV as a punishment for transgressions.

6.4.5 The role of alternative health treatments

Many Indians may seek out alternatives before Western medicine because of existing health beliefs, culture and religion. Schensul et al. (2006a) suggest that as males are more likely to visit private non-allopaths, therefore they could be a target to educate

about HIV/AIDS. The systems of Ayurveda, Yoga, Naturopathy, Unani, Siddha and Homeopathy are highly respected and used in India. These specialties exist alongside allopathic medicine, and require years of training. The Ministry of Health and Family Welfare have a department which accepts and includes all these named the Department of Ayurveda, Yoga & Naturopathy, Unani, Siddha & Homeopathy (AYUSH) (Government of India, 2008).

Ayurveda is one such approach that regards HIV/AIDS as an imbalance in the body. Ayurvedic principles emphasise that a healthy person is in balance with the elements of Nature such as fire, earth, water, air, metal and the heavenly bodies (earth, moon and stars) (Bhattacharya, 2004a). Today, more Westernised Indians may not believe in such concepts. However, Hindus, Jains and Sikhs may still be affected by these deeply held beliefs. The details may alter from region to region. Even within a city such as Mumbai, different levels of education will play a part. Advantages for poor people are the lower cost, greater availability, familiarity and belief in these systems. HIV/AIDS care can lengthen life but does not cure HIV/AIDS at present, so Western medicine may not be considered any more efficacious than these systems. More research is suggested to evaluate any claims of success.

6.5 Acquisition of HIV/AIDS

6.5.1 More stigma and discrimination

The effect of HIV/AIDS on Indian women is particularly damaging. In addition to the areas of stigma and discrimination in Table 2, Indian women face further discrimination when they contract HIV/AIDS. Divorce-related stigma may keep women in unsafe marriages, and married women may believe that marriage protects them from HIV/AIDS (Bhattacharya, 2004b). Women may be afraid of the consequences of even raising the possibility of AIDS, so they do not take measures to protect themselves, lest they be accused of immorality or spreading the virus themselves (Schaffer and Mitra, 2004). Whereas a man with HIV/AIDS is more likely to be accepted by family, cared for, and protected from shame and stigma by the female members of his family (Bharat and Aggleton, 1999); an IWLWA is more likely to be shunned by the family, particularly by her in-laws (Arunkumar et al., 2002). She may even be turned out of home, without any rights to property (Sridhar,

2002; Bharat and Aggleton, 1999). She may be forced to return to her parental home; or live where offered shelter, or forced to live alone after her husband's death (Bharat and Aggleton, 1999).

6.5.2 Personal effects

Anger, fear, depression and suicidal thoughts, self-harming, isolation and denial are common initial reactions after diagnosis (UNAIDS, 2007b). Chandra, Ravi, Desai and Subbakrishna (1998) found depression was present in 40%, and anxiety in 36%, with associated suicidal intent in 14% of their sample of 51 HIV-positive male and females. These reactions/feelings are accentuated if the woman is pregnant, as she will have the added strain of worrying about her unborn child. There is little in the way of counselling or support for women, because there are more pressing needs in areas such as medical care, shelter and nutrition. Researchers point out the lack of available literature with regard to women, and their special needs (UNDP/UNFA/WHO/World Bank, 2003).

Men make the financial decisions in a household, which prioritises their needs (Ashraf and Godwin, 1998). Five times as many men receive health services generally as women (Ashraf and Godwin, 1998; Bharat and Aggleton, 1999). Women have more difficulty finding doctors who will treat them (Ratnathicam, 2001; Sridhar, 2002). Women are more affected physically because their immune system is less protective; they have more concomitant conditions, and suffer stronger side effects from AIDS medication (UNAIDS, 2004a; Ashraf and Godwin, 1998).

6.5.3 More care giving duties

In addition to suffering from HIV/AIDS, Indian women struggle to provide care for members of the household affected by the condition. In India, women provide the overwhelming amount of care - approximately 90%, according to a study by Pradhan, Sundar and Singh (2006). D'Cruz (2004) found in a study that 86 women were sole caregivers, and a further 8 were joint caregivers. Orner (2006) asserts that the issues relevant to HIV/AIDS and care giving are stigma and prejudice, sexuality and confidentiality. Gender plays a major role, as most caregivers are female, not only in Africa, but elsewhere in the world. Orner (2006) also found that the caregiving process placed great demands on carers, and had an impact on their

mental health. There was both a lack of support, and a lack of knowledge about support, probably because these are traditionally female occupations. Women were expected to shoulder the responsibilities with very little support or acknowledgement.

6.5.4 Caregiver stress

The stresses of a life-threatening disease such as HIV/AIDS are undeniable, and caregiver stress is well-documented (Flaskerud and Tabora, 1998). These researchers noted an increase of physical and mental problems such as loneliness, anger and isolation. In recent years, with more research on women, it has been found that women release oxytocin with female reproductive hormones, and endogenous opioid peptide mechanisms, leading to a “tend and befriend” response. This means that women under stress want to affiliate with others in the form of social support. They are more adept in forming social networks than men, and the groups they form have socio-emotional bonding at their core. When women are prevented from the benefit of such groups through non-disclosure of the presence of AIDS in their families, it has a devastating effect (Taylor, Klein, Lewis, Grunewald, Gurung and Updegraff, 2000).

6.5.5 Financial burdens

The loss of the male head of household’s income impacts severely on women and children, particularly in poor households. However, according to Ashraf and Godwin (1998), household welfare depends more on women than men. Because the woman takes on the caring role, it may prevent her from bringing in money, leading to even more poverty. The lack of income may be one of the “shocks” which shifts families who were previously managing, into poverty (Mehta and Gupta, 2007, p.8).

6.5.6 The vulnerability of children

Children are affected by the stigma and discrimination which accompanies women. Mothers have an added burden in seeing their children affected by stigma, and various forms of discrimination such as not being allowed to play with other children, or being withdrawn from school (Indian NGOs 2005). It is noted that an Indian woman may be both caregiver to husband and child, and suffer from HIV/AIDS herself. As HIV/AIDS places increasingly more financial burdens on

households, choices have to be prioritised, and so children's nutrition, education and well-being are compromised, creating a major source of worry for mothers (Bharat and Aggleton, 1999).

The horrible dilemma for HIV-positive mothers in deciding whether to breast feed their babies is described by Shankar, Sastry, Erande and Joshi (2005). Physical separation may be enforced, which is felt keenly by women (Bharat and Aggleton, 1999). Bennetts, Schaffer, Manopaiboon, Sorapipitana, Yuwaseevee, Jalanchavanapate and Clark (1999) cite high levels of worry of Thai women who have recently given birth to HIV-infected babies. Women may also worry about the future, if they are infected as well as their husbands (D'Cruz, 2005). They have no real choices as ART is or other prophylaxis is unavailable. Neither do they have safe and affordable alternatives to breastfeeding. They may also choose to breastfeed rather than stigma and discrimination (UNDP/UNFPA/WHP/World Bank, 2003).

Children are especially vulnerable to HIV/AIDS. At this time, there are 10.4 million children who have lost their parents to AIDS; 2.3 million alone in 2000, one third of who are less than 5 years old (UNAIDS, 2007a). Babies can be infected through mother-to-child transmission, because of the mother's lack of knowledge, or because she is already pregnant when she discovers her positive status. Women can die from AIDS in the prime of their lives, leaving behind young children in precarious situations. These children have already witnessed their parents' deaths, which can lead to psychological problems, and may already be infected themselves. Without parents and protectors, they are vulnerable to exploitation and sexual abuse. Half of all new infections – 7,000 daily, are young people throughout the world (UNAIDS, 2007a), with newly infected children below the age of 15 years being 0.35-0.54 million (UNAIDS/WHO, 2007).

If they have no relatives to care for them, they become street children, at great risk of unprotected sex, in return for food or shelter. Because they are marginalized, they can be exposed to substance abuse with all its risks, and often lack knowledge and awareness of HIV. Forced sex is another mode of contracting HIV, and discrimination leads to secrecy. Often health centers are not children friendly, and insensitive staff and lack of confidentiality means they are less likely to seek

treatment (UNAIDS, 2007a). This is evidenced among homeless youth and children in Russia and the Ukraine. It is one of the saddest aspects of HIV/AIDS that these children are so neglected, and strong advocacy is needed to support families, and especially extended family members, who take on the role of caring and bringing up orphans.

6.5.8 Families and HIV/AIDS

An Indian family is traditionally a source of strength and support, especially in sickness and need (Bharat and Aggleton, 1999). The infection of HIV/AIDS is no different, and the family remains essential in providing both physical and emotional care, particularly amongst the poor and underprivileged. Lack of proper toilets and/or water supply places an even greater burden on such families, who are expected to assist in the care by accompanying the person to distant toilets, to hospital, meeting doctors and counsellors, collecting and administering medicines, providing adequate health and nutrition, helping with supportive services. The person with HIV/AIDS may need extra food and coaxing to eat, which has to be attended to by the family.

Women in this situation often neglect their own needs, in order to provide for the family (Bharat and Aggleton, 1999). Interventions which help are financial aid, with medication, medical care and household income, and advice and support for families in proper care and support. Ongoing counselling beyond pre- and post-testing, and provided by properly trained people is essential. It is noted that this is particularly important for women, as men appear to have their needs met by female members of the household (Bharat and Aggleton, 1999). In minority groups, culturally sensitive information and communication on HIV/AIDS needs to be encouraged within the family, in order to reduce the vulnerability (Thomas and Bandyopadhyay, 1999). Although the family is considered integral to any consideration of Indian culture, it may not provide the expected safety net. Some groups will not be served well such as street children, and women may be cast out by extended families to fend on their own (Bharat and Aggleton, 1999).

Bharat and Aggleton (1999) conducted a study which explored the support families provide. They found that men were protected from shame by other family members,

and their errant behaviour was excused on the grounds that it was normal for a male to act in such a manner. Double standards mean that women, on the other hand, are expected to uphold the moral standards, and the presence of HIV is evidence that they have failed in their duty (Ogden and Nyblade, 2005). Men's needs were more or less met, but women's needs were largely unmet. In addition, women are regarded with more hostility and are treated more harshly than men (Aggleton, 2000). They were expected to provide care but were not assured of it themselves.

In my study, I found examples of disruption to the tradition that girls leave their family home to be part of another household. When HIV/AIDS intervenes, girls may be sent home to their mothers (Nabar, 1995). D'Cruz (2005) describes the devastating impacts on family life, with complex changes affecting spousal relationships, family roles and responsibilities. In her study of HIV-affected families in Mumbai, the women participants stated that, despite some anger and frustration, there was no change in their respect for their husbands, indicative of the extent to which the revered position of the husband in the life of a woman was ingrained in the respondents: "If there is no man, a woman is afraid" (D'Cruz, 2005, p. 6).

D'Cruz's (2005) study of concordant and discordant couples (concordance is where the partner is affected, and discordant where only one person is infected) found that women who were infected by their husbands were just as angry as those not, because of the effect that HIV/AIDS has on the whole family. They had been prepared to tolerate the husband's misdemeanours except when it brought the disease into the family. Yet only one wife communicated her anger directly to her husband. The presence of a sexual relationship was not related to concordance or discordance, and was an individual decision. Men stated that the reason for abstaining from sex was from poor health rather than consideration for the wife (D'Cruz, 2005).

Explanations for this kind of reaction lie in how women are socialised into roles of 'good women' with virtues such as "submission and docility, skill and grace in household tasks, self-effacement and self-sacrifice". To be a good wife is by definition is to be a good woman. Wives have to "restrain their senses and keep their hearts under control. She must venerate her husband, even if he is useless and seeks pleasure elsewhere. If she does not, then she is disgraced in this world and

“tormented in the next” (Kakar cited in D’Cruz, p.273). However Indian women may not see their position as being oppressed. Because of the rigid hierarchies such as age, sex, position in the family, caste and wealth women learn to limit their freedom, suppress their needs, silence their senses and sublimate themselves into a philosophy of self denial, self effacement and service (D’Cruz, 2005).

6.5.9 The position for widows

There is a worrying trend of women in their prime and most productive years becoming widowed through the loss of their husbands through HIV/AIDS (Pradhan and Sundar, 2006). They found that nearly 60% of their large sample of 2,068 women were under 30 years. This has enormous impact on the composition of families, and how these young women survive. The status of a widow in the community slums is a dismal one. For example, they found 30% of the participants were illiterate, and their ability to mobilize help was greatly affected. Their annual income was less, and more were below the poverty line. They were also at a greater risk if their property rights were not protected.

These young widows had less of everything – less assets such as land, and valuables, as these had been disposed of in order to pay for medical expenses. They also had less consumer durables such as fans, TVs, telephones, and less expenditure on basic food and amenities. Moreover Paxton (2004) found that 42% of those women who tested positive in pregnancy were now widowed. In addition, widows face a double burden of stigma. Pradhan and Sundar (2006) found that although 40% of the young widows were living alone, almost none of them were living with their natal family; however they were receiving some financial support from their families of origin, whereas only 9% were getting support from their in-laws. They faced discrimination, and refusal to acknowledge transferal of property rights on the death of their husbands. There was anecdotal evidence that some widows are forced to beg and become very impoverished.

Dwivedi, Princess of Madanpur says:

“At all cost women must show the world that they are not widows. They wear their bangles and their mangalsutra ...proudly and conspicuously. Even if their

marriage is unhappy they wear them, because the worst fate that can befall a woman is widowhood.” (Dwivedi and Holkar, 2005)

She adds that she has done well to move to Bombay (Mumbai) where life is freer and she does not have to think of herself as a widow. That freedom does not exist for the women in the slums.

6.6 Summary of the chapter

The factors which make Indian women with lower socio-economic backgrounds particularly vulnerable are outlined in this chapter. These factors include issues pertaining to all women, because of female biology and areas like sexual violence. There are specific areas for Indian women such as poverty, and deficits in nutrition, decision-making, education, and awareness. Some factors arise from the highly mobile population, and healthcare discrimination. Beliefs regarding destiny, pollution, sex, HIV/AIDS and healthcare treatments have been discussed.

I have shown that the acquisition of HIV/AIDS increases the burden and stress for women by increasing caregiving, financial burdens, and worries about their children. The position for widows resulting from HIV/AIDS is particularly grave, as all the above factors are doubly increased, but without a breadwinner and protector, women are again made vulnerable. Having set the background from reviewing the available literature regarding women, I now commence the data analysis in Chapter 7.

CHAPTER 7

A SOCIO-DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

“Stemming the epidemic of HIV/AIDS requires speaking the unspoken. It requires challenging the values, that at least, marginalize, (and at worst, kill) people infected and affected by HIV/AIDS.”(Audrey Swift, Concern Worldwide, Cambodia, cited in Health & Development Networks, 2007, p.50).

7.0 Introduction to the chapter

The data analysis commences with this chapter, and continues through the next seven chapters, consisting of demographic details of the participants, in-depth interviews, documentary data, narratives, and a perceptive diary of the researcher. The demographic data discussed in this chapter was considered an integral part of the data collection, in order to contextualise the participants. Preceding chapters have discussed the diversity of women in India, from urban to rural, and in a range of socio-economic situations. It was essential that the participants in this study were defined by their particular living conditions, socio-economic status and education.

Demographic data was collected through the interview process. Questions were asked regarding the participants’ language, age, birthplace, religion, marital status and caste. The participants were asked where they were born, and how long they had lived in Mumbai. These questions were asked in order to support literature which states that Mumbai has a highly mobile and fluctuating migrant population, and that this factor is one of the vulnerabilities to HIV/AIDS.

The question: “Why did you choose to come here?” was intended to elicit information on whether women have choice in the decisions which affect their lives. Questions about caste and class were intended to investigate the relationship between these factors, and socio-economic status. Information on education such as attendance at school, level of education and literacy was collected. The question “Did other members of your family go to school?” was intended to ascertain whether the boys in the family had preferential treatment as regards school or whether at the present time, these families were able to continue to send their daughters to school.

Economic data such as the level of income and number of people in a household, and number of children was collected by asking questions such as “What do you live on?” “Do you earn money?” “How many people live in your household?” and “Who are they?” These questions provided detailed information about households. The selection criterion set by the SAHAS programme was Rs4,000 per month (AUD\$107). This standard was used by the programme to define poverty, and therefore the participants who were clients of the programme had incomes below that figure. It was important to ascertain the level of poverty; and how the family was coping with the financial strains imposed by HIV/AIDS

Data collected on the participants’ knowledge and awareness is important in judging the effectiveness of such programmes, and how they could be improved for this group of women. Questions such as: “When did you first hear of HIV/AIDS?” and “Who told you about it?” “What did they tell you?” and “What does the word HIV/AIDS mean to you?” “What did you know about it before the infection?” sought to determine the knowledge and awareness base of the women, before the infection of HIV/AIDS became known.

The effect of HIV/AIDS on a household was examined by asking the participants whether they were infected, or affected by HIV/AIDS, to determine the burden of this disease on the household. To be infected, as well as caring for household members, adds significant physical and emotional stress to a woman who may not be well herself. Researchers have noted the young age of widows, which is so damaging to the composition of the household. This was revealed by asking the marital status of the participants. Likewise, the number of children adds another dimension of

caring, which becomes increasingly difficult for the mother to sustain, if she is also ill. These characteristics are displayed in the following 15 figures, in bar and pie graphs which provide accessible and simple information.

7.2 Population characteristics

7.2.1 Age

All 45 participants were either infected by HIV/AIDS, or were carers of family members who had HIV/AIDS. The highest number of women (28.8%, n=13) were in the age group 30-35 years, with smaller numbers aged 19-23 years (20%, n=9), and over 66 years (both 4.4%, n=2). The age eligibility criterion for this study was that participants must be aged 18 years or more.

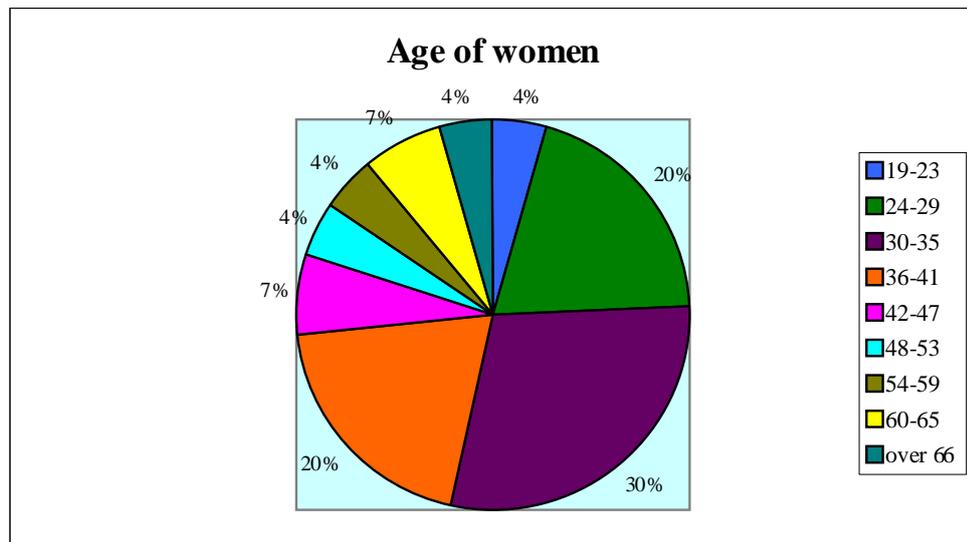


Figure 6: Age of women

The older women had been widowed. Their husbands had been infected, but fortunately these women were not infected. In some cases, the women had nursed their sons who had died from HIV/AIDS. Of the women interviewed, 84% fall into the categories from 19 years to 41 years. These are the important reproductive years, and if they are infected, the ability to have children is compromised. In addition to rearing children, these women are faced with the burdens of coping with family members who have HIV/AIDS, or in taking on family members orphaned by the disease.

7.2.2 Marital status

There were no divorced women, and very few single women in this group (0.4%, n=2). The number of married and widowed women was almost equal (46.6%, n=21 (married, and 48.8%, n=22 widowed). The number of young women widowed in this group (48.8%) is notable, because they have lost their husbands at a much earlier age than expected. Indian life expectancy was estimated in 2001 at 62 years for males and 64 years for females (World Health Organisation, 2007). Without the advent of HIV/AIDS, many of the 48.8% of women in this study would be still married.

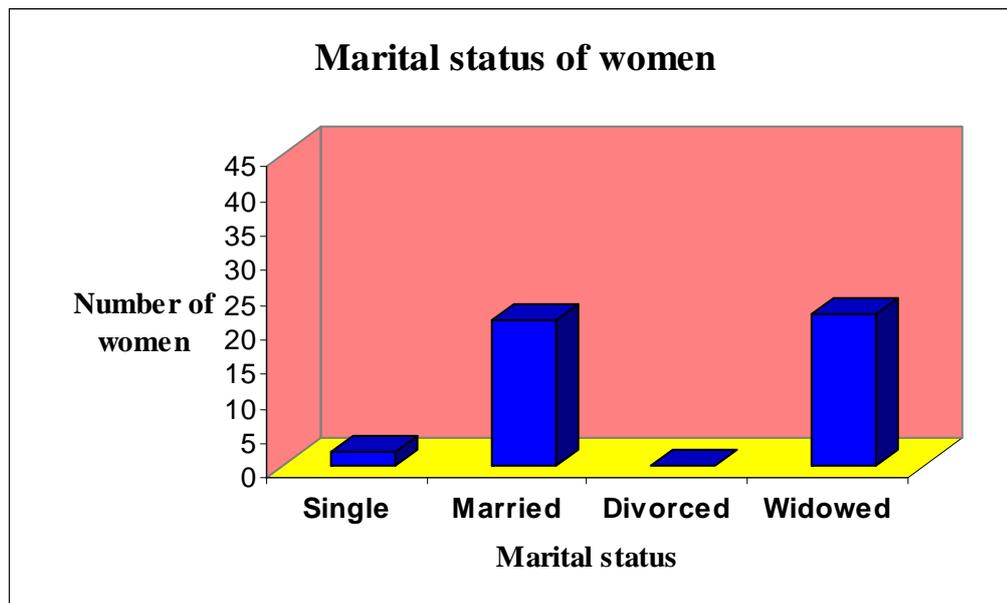


Figure 7: Marital status of participants

At a time of child rearing and caring for the family, these women had extra burdens of the loss of the breadwinner and their own failing health. The lack of divorced women, and 0.44%, n=2 single women in this sample reflects cultural values, i.e. that divorce is still rare, and also the fact that their husbands had died early. All but three of the widowed women had children to support. This has significant economic and social implications for the both the mother and children. One woman said that women did not have a choice if they wanted to marry or not, nor did they have a choice in the selection of their husbands.

7.2.3 Number of children

22.2%, (n=10) of the participants had no children at all. This may be because their husband had died before they could conceive, or because their children had died due to HIV/AIDS. 22.2% (n=10) had one child, and 24.4% (n=11) had two children. This represents 68.8% (n=21) of the sample. There were no families with more than five children. The small number of children corresponds with the national figures. Family planning education in India has been successful in that knowledge of contraception is widespread – 99% according to (National Family Health Survey, 2005), with 60% women report having seen programmes on TV. The number of children per woman has dropped from 3.4 children to just over 2 children.

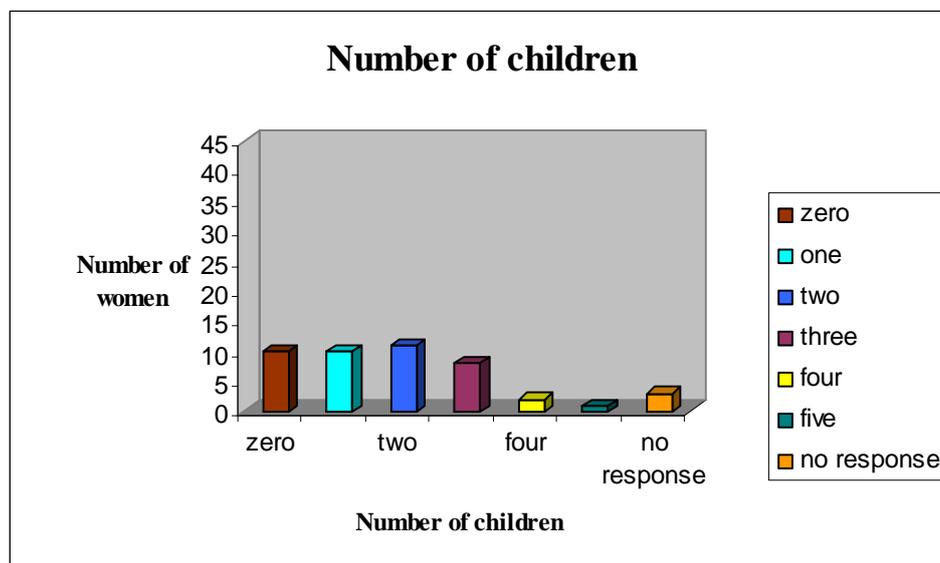


Figure 8: Number of children

Women generally marry at the young ages of 16-19 years (76%), have their first child soon after, and are sterilised after 2-3 children in their 20's. Child mortality is still high in India at 68, and under five years mortality is 96 per 100,000 (Bajpai and Goyal, 2004). In this sample, there were older women, who had adult children who were not living with them, or who had died from HIV/AIDS. The small number of children per family may be due to the success of family planning, or the number of children who are dying through HIV/AIDS. Further research would be needed to attribute the reason for smaller families. The data also shows the relationship

between caste and socio-economic conditions. Lower caste is associated with less ability to earn and poorer health outcomes. This has been discussed in previous chapters.

7.2.4 Number of people in each household

53.3% (n=24) households had one to four family members and 35.5% (n=16) had four to eight members. Three households (6.6%) had eight members. Severe overcrowding exists in slum communities. In Mumbai, it was reported that 6.5 million people live in areas where there are problems with sanitation, with one shared toilet for every 50 people, and 80% not fit for use (*Indian Express*, 18 November 2005, p.15). Water is not readily available in most households. The municipal water supply was pumped into houses for certain periods of time, i.e. for an hour or two at 3.00am. The dwellings that I saw consisted of one room in many cases for the whole family, with a small alcove for washing. There were no windows and the rooms could only fit in one bed sideways, and many did not have bathrooms. There was little provision for hot or cold weather, and when there were floods in Mumbai, many people in these areas were flooded out, and left with no belongings. It is estimated that in Mumbai, 54.1% live in dwellings unfit for human habitation (Chakrawerti, 2005).

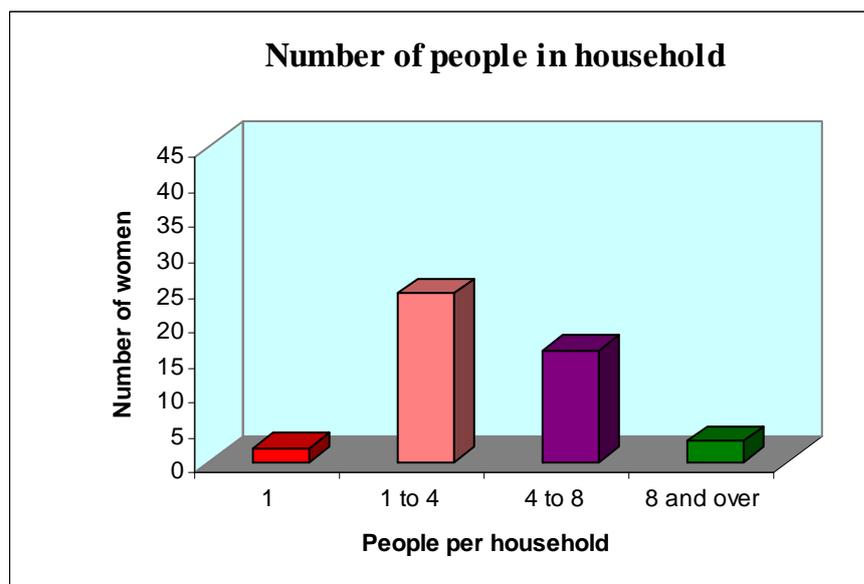


Figure 9: Number of people in the household

In other communities which I visited, the women were in apartment blocks with one bedroom and an inside bathroom, but still extremely small by Australian standards. Housing is extremely difficult to obtain and leads to larger numbers of people living in cramped, illegal dwellings. When HIV/AIDS affects a family and members die, the remaining family may have to house orphaned children, thus creating more pressures from more people in that dwelling. The overcrowding and unsanitary conditions lead to communicable diseases, and illness is rife. In Mumbai in 2006, there were 27,682 cases of jaundice, typhoid, gastro-enteritis, dengue and malaria. (Baria, 2006), and after the floods in August 2005, there was an increase in water-borne disease, and 100 people drowned (Kshirsage, Shinde and Mehta, 2006). HIV/AIDS takes its toll, and is associated with lower immune response from concomitant diseases such as tuberculosis.

7.2.5 Age of widows

The number of women widowed at an unexpectedly young age is shown in Figure 9. Highlighted is the fact that 37% (n=17) were widowed by the age of 45.

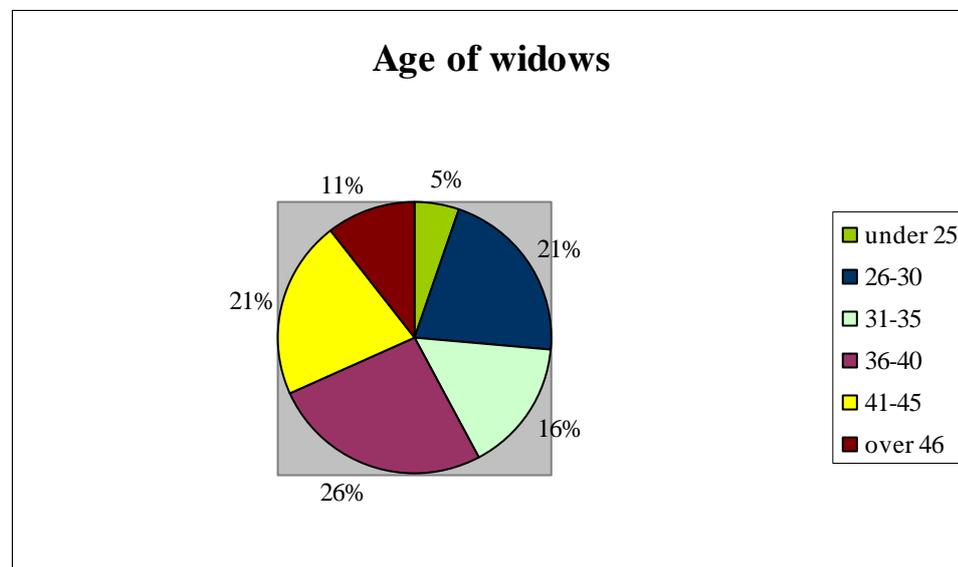


Figure 10: Age of widows

The data shows the number of women widowed in the prime time of their life, and also the number of women who are both affected and infected, thus imposing burdens of their own illness with caregiving for the family.

7.3 Religion and caste characteristics

7.3.1 Birthplace

It was expected that because of Mumbai's highly mobile population, particularly in the slum communities, that there would be a large number of women from other states who had migrated to the city as their husbands sought work. The majority (53%, n=24) of women were born in the state of Maharashtra, and (16%, n=8) were born in Uttar Pradesh. The remainder of the participants (46%, n=20) came from other parts of India, such as Bengal, Rajasthan, South India and Punjab.

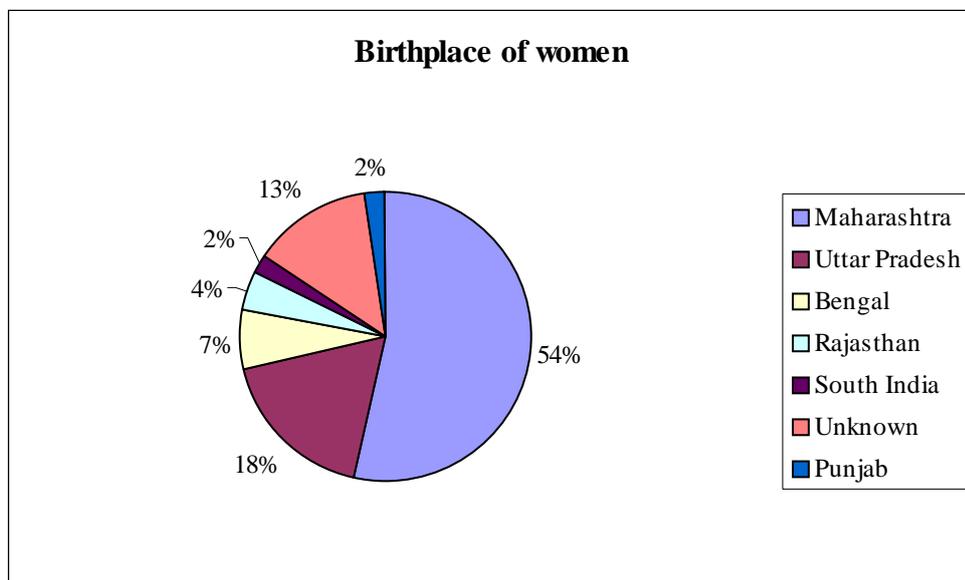


Figure 11: Birthplace of women

In times of hardship, people migrate from rural areas, adding to the highly mobile populations in Mumbai. There were 22% (n=10) women who could not speak Hindi. Migrant women coming to Mumbai from other Indian states are often unable to speak Hindi or English, and are therefore unable to access written and oral information about HIV/AIDS in those languages. The Somaiya Hospital initiated a programme of street plays to address this problem, and to inform the community about HIV/AIDS.

The women who were born and brought up in Mumbai, were more likely to know about HIV/AIDS according to research which noted lower levels of awareness in rural India. For example, Balk and Lahiri (1997) noted 8% of rural women

compared with 33% urban women had heard of HIV/AIDS. People migrate to Mumbai in search of employment, and the hope of a new life, but unfortunately, finding employment is not easy for illiterate, unskilled, farm labourers. This means gravitating to the slum areas, unlicensed dwellings, and often exploitation in employment and rent. The women in this study, who had been born outside Mumbai, were either brought to the city by either their parents, or by their husbands at the time of their marriage.

For those women who have come to Mumbai from another state, there are adjustment difficulties in language, religion, as well as being a long distance from their place of birth. They demonstrate great resilience, and coping abilities, while adjusting to their new and harder lives. When the catastrophe of HIV/AIDS hits a household, it may be necessary to send children to grandparents who live in rural areas, a long way from Mumbai. This happened to some participants who, unable to keep their children with them, elected to send the children to the maternal grand parents.

7.3.2 Religion

75.5%, (n=34) of the women were Hindu in their religion and practice, with 13.3% (n=6) Buddhist, 6.6% (n=3) Muslim, and 2.2% (n=1) Christian.

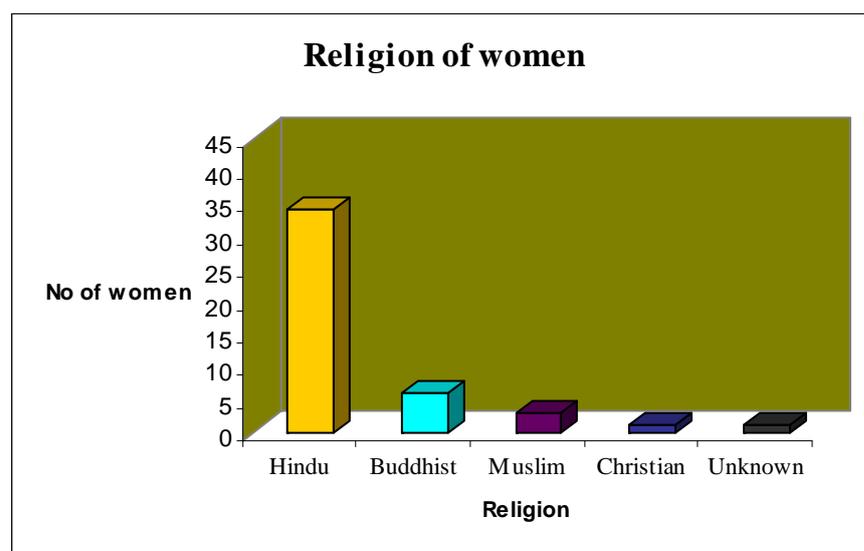


Figure 12: Religion of participants

These figures are to be expected in a mainly Marathi population, which is Hindu in religion. National figures show 82% of households are Hindu, but this varies from state to state. Buddhism is a way of lower-caste populations escaping the restrictions of their caste. The greater proportion of Hindu women in the sample prompted scrutiny of Hindu beliefs and health practices (see Chapter 6). I was able to observe some religious celebrations and observances of this community. The 2 occasions of Haldi kumkum day and Dr Ambedkar's birthday that I observed were celebrations of life in that community. For example, Haldi Kumkum was celebrated during my stay. This is not a religious festival in itself, but is held in conjunction with religious festivals throughout the year. Traditionally, it is a time for a woman to invite friends and family together to have fun, and exchange small gifts. In the slum community, the Marathi women dressed up in their beautiful saris with their wedding jewellery, and five older women honored me by anointing me with haldi and kum kum (red, yellow and white colours).

There was a celebration in honor of Dr Ambedkar who championed the cause of the 'untouchables' (*dalits*), on another day at the hospital. On this day, it was transformed into a shrine with a figure of Ganesh, with streamers of marigolds, and coloured lights flashing. I queued with hospital staff and patients for a blessing from the priest, and I was given a red tikka (red spot on the forehead), a flower and a small metal dish. Similarly, World AIDS Day was celebrated like a religious ceremony with *rangoli* - circular decorations on the floor in coloured chalk and flowers. These have a symbolic or auspicious design. In a room crowded with nurses, doctors and hospital staff, the dignitaries lit candles, made a pledge to "keep the promise to strive towards lifting the scourge of AIDS from the community."

It seemed religion was never far away from the people. Even in the poorest community, there was at least one easily accessible, small shrine where people could stop in their busy day, and pray. On my first walk through the community, the priest came out and welcomed me. I noticed reverence for trees, particularly the *tulsi* plant and *neem* tree, in everyday life. Trees are regarded as the living symbols of a divine presence. Along busy highways, trees are garlanded with marigolds, or chalk or tinsel, and when one had to be cut down in the suburb where I lived, there was an

instant outcry. Branches of the neem tree are often sold at roadside stalls for medicinal use.

7.3.3 Caste of participants

In this study, 36% (n=16) women were from the state of Maharashtra, and Marathas in caste. The next largest group were migrants from other states (13%, n=6), reflecting the movement of people from rural areas, in search of a better life. When the Marathas, Scheduled Caste and Buddhist groups (i.e. lower castes) are added together, it can be seen that the percentage of lower castes in this group was 65%.

It was expected that there would be low numbers of Brahmin women, as this is the highest caste, and that most would be either Maratha (i.e. from the state of Maharashtra) or from lower castes such as SC (scheduled caste), or BC (backward caste), because the study setting was in a poor socio-economic area. Members of scheduled castes and tribes have much poorer health than those who belong to the upper castes (Bajpal and Goyal, 2004).

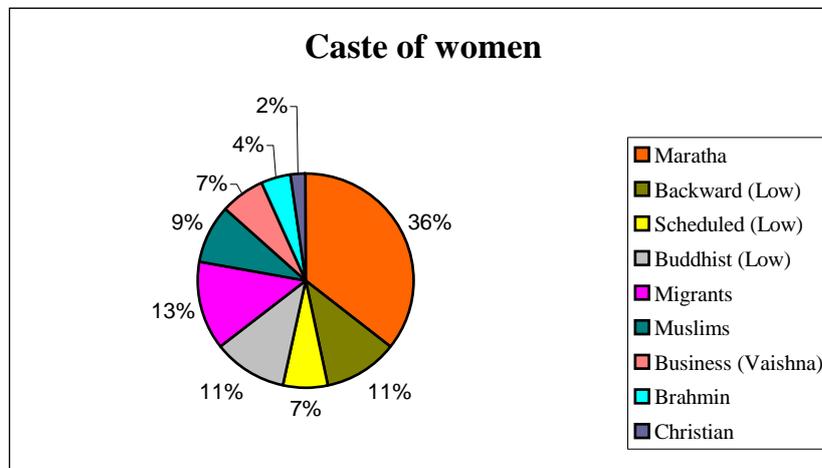


Figure 13: Caste of participants

The concepts of caste and its hierarchy still are extremely important in India. Everyone is conscious of their own caste and therefore their ranking in society, and can place every other person into an exact position in the hierarchy. Rural villages are more tightly held in the clasp of caste, whereas in cities, there is the possibility to escape into anonymity. Originally, caste was associated with occupations, and could

be likened to the guilds of feudal Britain. *Brahmins* had the highest rank and were associated with the priests and spiritual guidance, teaching and the law. *Kshatriya* was the noble class of warriors and kings, *Vaishya* were agriculturalists and merchants; *shudra* performed service by manual work and trades. The fifth group were the *untouchables* renamed by Gandhi as *harijan* (or *the people of God*). These people are now called *dalits*. The *malecha*, (outsiders or foreigners) came from elsewhere as invaders (Caste system in India, 2006). Scheduled castes (SC) and backward castes (BC) are groups which were nominated for affirmative action, but this has had some backlash on them. Old traditions die hard, and, in reality, the lower the caste the more likely the person will be in a lower socio-economic position, without much chance of changing the caste they were born into. The complex caste system is explained more fully in Chapter 5.

7.4. Language and literacy

7.4.1 Language of the participants

The majority of women, 82.2% (n=36), spoke Hindi which is the national language. However, there were women who spoke Hindi and Marathi (48.8%, n=22). Some women did not speak Hindi or Marathi 20% (n=9) and none of the women spoke English. Other languages spoken included Bengali (2), Hekam and Sindhi (1)

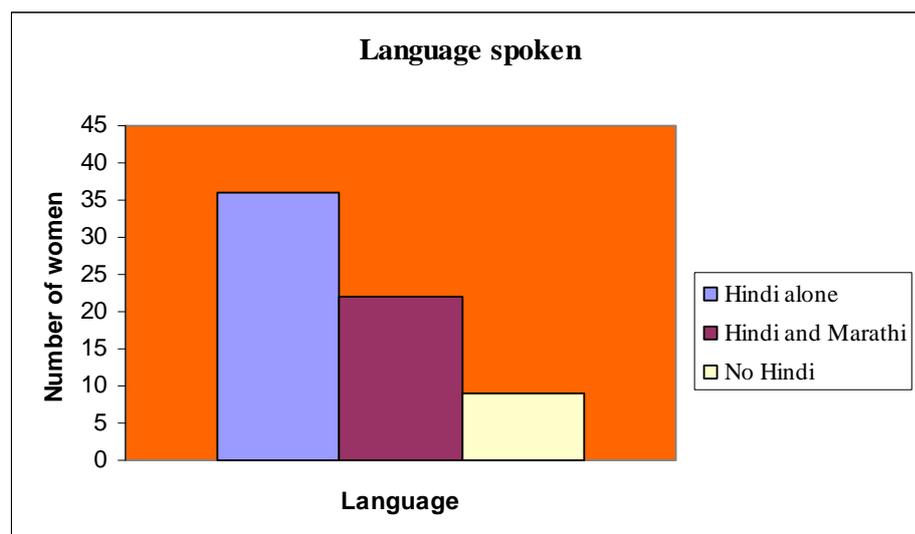


Figure 14: Language spoken by participants

The research was undertaken in the community slums near to the KJ Somaiya Hospital. One would expect that, because these communities were predominantly Marathi (or from the state of Maharashtra), the number of women speaking Marathi would be higher. The number of women speaking Hindi reflects the fact that it is the national language. Free government education in India is carried out in Hindi, so it is widely spoken, and used as a common language, when people come together from different language groups. Some participants, who were born in Maharashtra, speak the language of their parents who migrated to Mumbai from other states such as Gujarat. There are 428 listed languages and dialects in India reflecting the incredible diversity of India (Languages of India, 2008). Three quarters of the population speak languages derived from Sanskrit. These include Hindi, Bengali, Gujarati, and Marathi among others. The remaining languages, such as Tamil and Telugu are drawn from the Dravidian language group (Caste system in India, 2006).

I observed that all the dwellings of the participants had electricity, a fan, and also TV. The national figures estimate that 60% of households have electricity, according to a WHO report (World Health Organization, 2004). The same report estimated the number of urban dwellings with TV to be higher than rural dwellings. That report stated that 46% of Indians were said to watch TV at least once every week, and 79% of women who knew about HIV/AIDS learned about it from TV.

Pallikadavath, Sreedharan and Stones (2006) found in a large household survey of married women, that 33% of rural women learned about HIV/AIDS from family and friends. The second most important, and only disseminator of information, was television (27%). If the women did not speak Hindi, English or Marathi, that medium was a limited source of information. In addition, the information given by the popular media may not be correct, as there is no concerted effort to educate journalists about stigma and discrimination. Pallikadavath, Sreedharan and Stones (2006) found in their study that health messages delivered by radio or print to be less effective than TV.

7.4.2 Level of education and attendance at school

35.5% (n=16) women had received primary education, another 37.7% (n=17) secondary education and a very small number (8% n=4) had been able to achieve tertiary education.

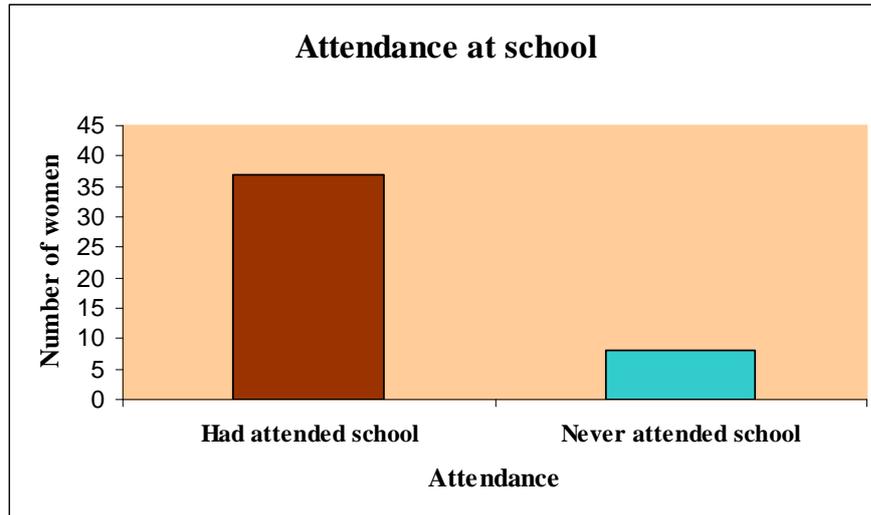


Figure 15: Attendance at school

Some women and girls were withdrawn from school in households affected by HIV/AIDS, so that mothers could go out to work; and in other households, widows were forced to withdraw their children from school, thus limiting girls' education.

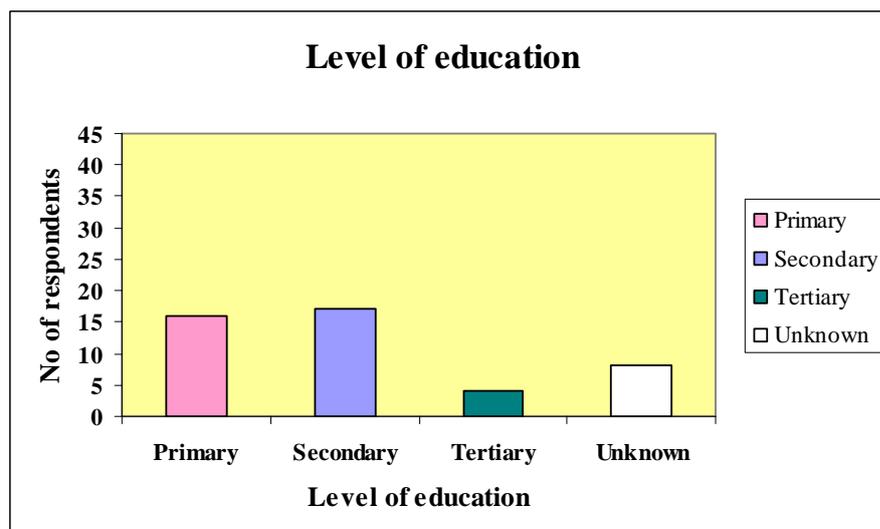


Figure 16: Level of education of participants

One participant really regretted the fact that her mother's death had disrupted her education. 82.3% (n=37) of women had attended school and 17.7% (n=8) had not attended school at all. The high number of women who had attended school was interesting, given the low socio-economic standing of the group. Most of the participants had experienced some level of schooling.

The presence at school may not necessarily translate into functional literacy. Girls are withdrawn from school so that they can help at home when there are extra burdens on the household such as the illness of HIV/AIDS. This means they may not be able to keep up at school, and this impacted further study. An example is the young girl in the study who had to give up college because of her mother's illness. Illiteracy is one of the factors which affect the effectiveness of transmission of health information, particularly related to HIV/AIDS. 76% of the women had little or no knowledge of the disease until after their own diagnosis, or that of their husband.

7.4.4 Literacy of participants

There was evidence of attendance at school, and some participants had secondary education, however 62% (n=28) of women said they could read and write, whilst 37.7% (n=17) could not. As discussed above, the disparity between attendance at school and literacy may lie in girls' education not being emphasised in poorer areas, as their help is often needed at households affected by HIV/AIDS.

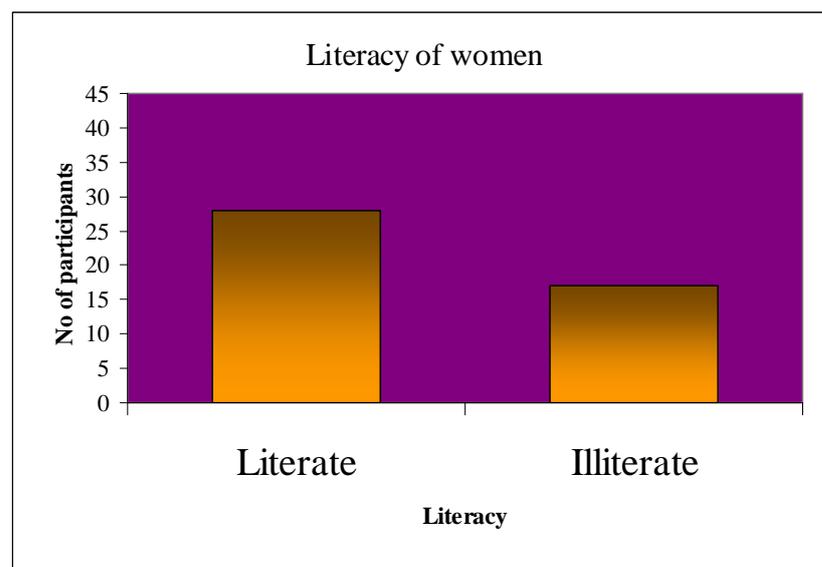


Figure 17: Level of literacy

Given the numbers in Figure 16 who attended Years 1-5, it was expected that literacy would be higher. Literacy rates are an important gauge of health, and are considered more important than per capita incomes (Bajpai and Goyal, 2004), because women who are illiterate are less likely to know what health services are available, and to be able to access them (National Family Health Survey, 2005). While figures from the latest National Census of India of 2001 claim a 54.16% literacy rate for women, (National Family Health Survey, 2005), however the details of how literacy is measured in those statistics are unclear. I was interested in whether women could read in order to access literature which could help them avoid HIV/AIDS, and therefore access services. Lack of education, and language difficulties, resulted in these women being unable to access appropriate health information.

7.5 Income characteristics

13 participants did not specify their income, but as they are clients of the SAHAS, their income had been assessed as under 4,000 rupees per month per individual. In one case, the husband was a social worker and earned 25,000 rupees per month. The remainder of the women had a family income of under 5,000 rupees a month, about AUD\$120.

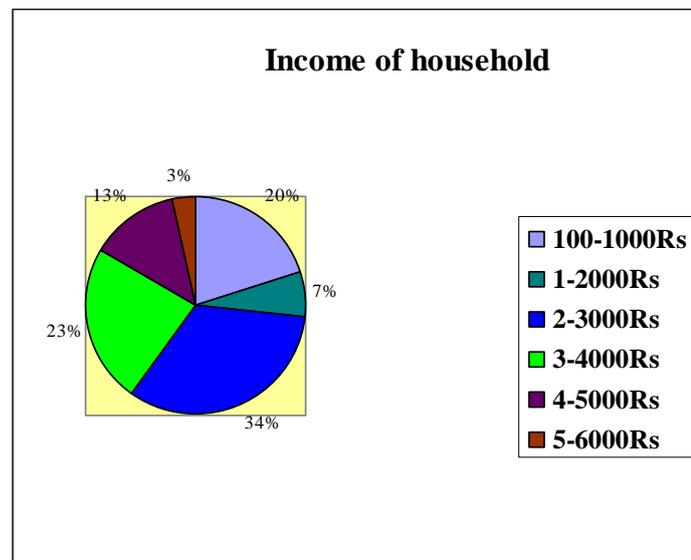


Figure 18: Income of household

In some cases, the income was so low as to be unsustainable, and nutrition was subsidised by SAHAS if the household was seen to be at risk for a restricted time of six months (SAHAS Co-ordinator). Women are particularly at risk in households with so little income as they put themselves last in nutrition and needs. Poverty is associated with higher infant mortality rates, and the poor are much more likely to suffer ill-health (Bajpai and Goyal, 2004). Poorer women are unlikely to access health care and only 13% of women receive adequate care according to Bajpai and Goyal (2004). Researchers Pradhan, Sundar and Singh (2006) found that households affected by HIV and AIDS have lower assets and savings. They have reduced spending on essentials such as food, because of increased medical expenditure, which may be four times more than non-HIV households. They may have to borrow money, and are therefore prey to moneylenders.

The official estimate of people living below the poverty line has declined in India from 54.88% in 1973-4 to 26.10% in 1999-2000. People are considered below poverty line (BPL) if their family income is less than 1,500 rupees per month (AUD \$26). All conversions which follow are rupees to Australian dollars. People with family incomes between Rs 1500 (\$40) and Rs 3000 (\$80) are considered poor but are above the poverty line (APL) (Bailey and Hutter, 2007). Although the national figures for poverty have reduced, the pressures on cities such as Mumbai result in overcrowding and unsanitary conditions for families. The SAHAS programme used a benchmark of Rs 4,000 (\$106) per month as a criterion of inclusion.

Families are further compromised by taking on orphaned children, or other family members. In some households, the family group was composed of remaining members who had been orphaned through HIV/AIDS, or fractured family groups, such as brothers or sisters caring for younger children. This led to problems because parents were missing, and the accepted social structure of the family was lost.

7.6 HIV/AIDS characteristics

7.6.1 Knowledge of HIV/AIDS before diagnosis

Many women (76%, n=34) had little or no knowledge of the disease before their own diagnosis, or that of a family member. Only two women said they knew about

HIV/AIDS beforehand. Some women (20% n=9) did not respond to this question. Despite extensive awareness campaigns about HIV/AIDS, the women in this group had little knowledge of the disease, and said that they were surprised with the diagnosis. This data showed that only two women in the study had knowledge of HIV/AIDS before diagnosis. Balk and Lahiri (1997) found an average of only 17% women knew about HIV/AIDS in their study in 13 Indian states. The Behavioural Surveillance Survey carried out in 2001 found that knowledge and awareness regarding HIV/AIDS was particularly low in rural women in Bihar, Gujarat and Uttar Pradesh (NACO, cited in Pradhan and Sundar, 2006, p. xx).

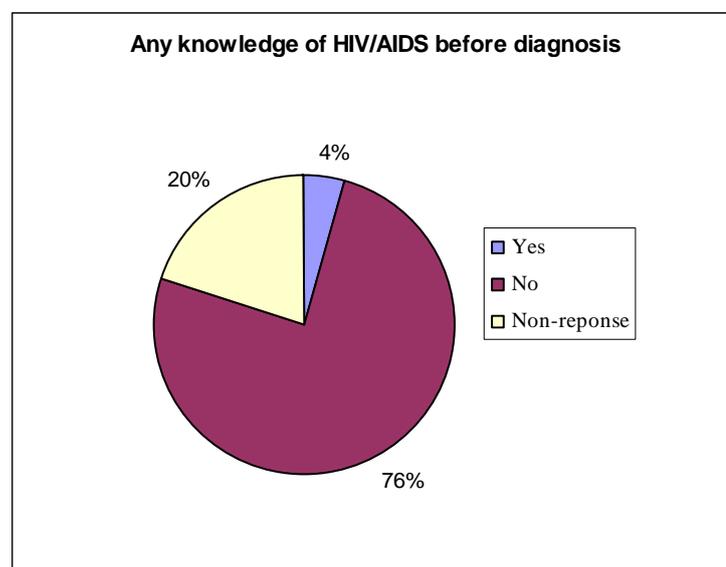


Figure 19: Knowledge of HIV/AIDS before diagnosis

Researchers have suggested that women are particularly vulnerable because of low education, and therefore awareness to health messages about HIV/AIDS. If women cannot read, or the language used is not their own, the likelihood of them accessing information is much less, therefore the participants were asked what languages they could speak and understand. Pradhan and Sundar (2006) demonstrated that a mere knowledge of the existence of HIV/AIDS is not sufficient. Indian women have less knowledge than men in the areas of prevention factors, where to go for testing, and the modes of transmission. Education becomes a luxury in households where HIV/AIDS is present, because of the reduction in family income, or increased expenditure for medicines or treatment.

One factor suggested by these researchers is that PLWHA may consider that it is not worthwhile to educate their children, if the parents are not going to reap the benefits, as they will die early. Girls are withdrawn from school to help in caring for members of the family affected, or to supplement the family income. Knowledge and awareness programmes are considered pivotal in the prevention and spread of HIV/AIDS. Even more important is knowledge about modes of transmission, so that women can be protected. The Indian government has undertaken awareness programmes for twenty years, but they can be sabotaged by cultural taboos, and denial of the disease (Chatterjee, 2003). Earlier studies show that so many women only hear about HIV/AIDS from a health worker. Discussion of sexual matters remains taboo subjects for women. The women reported that their husbands did not admit to having HIV/AIDS, and it was only disclosed at the time of diagnosis by doctors making the women aware of the risks. Stigma related to contracting the disease occurs in all societies, as mentioned in Chapter 3. Non-disclosure by partners places these women at further risk, when they are not engaging in high-risk occupations such as commercial sex work.

7.6.2 Infected and affected women

All the women in this sample were affected by HIV/AIDS, (i.e. Living with a family member with HIV/AIDS) and 46.6%, (n=21) were also infected with the disease.

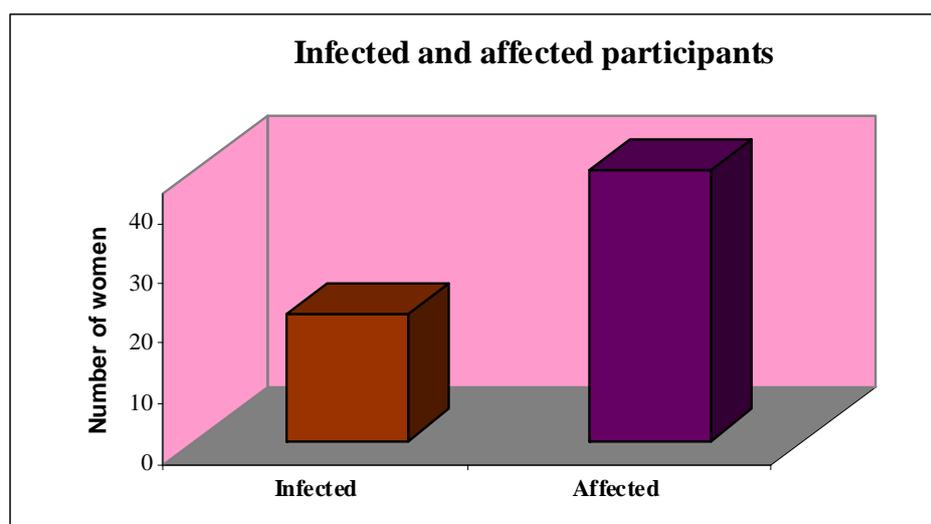


Figure 20: Infected and affected participants

Almost half (46.6%, n=21) of the women had a double burden. They had to care for family members, who were infected. This increased their workload, responsibilities, and pressure to earn money. At the same time, this group were also struggling with their own health problems. Women put their family's needs before their own, and miss out on vital health services. Decisions about health care are also taken by the males of the household and this may prevent women from accessing health care.

7.7 Summary of the Chapter

The demographic data reveals the low standard of living which I observed in these community slums. Household incomes were below the poverty line, indicating the economic effect of HIV/AIDS, as well as low incomes beforehand. Half of the women were residents of Mumbai from birth, but half had come from other states reflecting the high migration to the city. The women had mostly come at the time of their marriage, and therefore did not come independently. Their religious status was mostly Hindu (75%). The lower castes were prominent in the figures reflecting the lower socio-economic status of these women.

All of the participants were affected by HIV/AIDS in that they had cared for, or were continuing to care for members of their family. Half of that number were also infected, which showed the double burdens of caring. Although women had attended school, levels of female literacy were lower than male; and 76% had no knowledge of HIV/AIDS before their own diagnosis or a family member's positive status. As 22% did not speak Hindi, and this is the predominant language used, health messages are not reaching these women because of language, literacy levels and opportunity.

The numbers of women widowed at a young age, and in their prime child-bearing years, i.e. 84%, is disturbing. There are few supporting mechanisms for these young women. The number of children per household was low. More research is indicated to determine whether this may be due to the success of family planning, or that children of infected mothers were sent to relatives, or that women had lost their husbands before they had been able to bear more children. In Chapter 8, 9 and 10 additional data obtained from the interviews with the participants is examined.

CHAPTER 8

ENVIRONMENTAL, ECONOMIC & CULTURAL RESOURCES

Analysis of in-depth interviews

“Stigma hides in cultural norms, in laws to ‘protect Society’, in the human imperative to distinguish between us and them.” (Sam Friedman, National Development and Research Initiative, USA, cited in Health & Development Networks, 2007, p.50).

8.0 Introduction

Chapters 8, 9 and 10 are the crux of the analysis of the 45 in-depth interviews. The chapters have been divided into the domains of environmental, economic and cultural resources, social ecology, and human capacity, as presented in the psychosocial framework in Chapter 4. Chapter 8 is an analysis of the environmental, economic and cultural resources available to the participants. Chapter 9 is the analysis of the social factors that affect women, and Chapter 10 analyses the human capacity domains in the lives of the women. The aims outlined in Chapter 1 and Chapter 4, were achieved using the psychosocial framework as an underpinning to the interview analysis and are detailed and described in Chapters 8, 9 & 10.

The psychosocial framework outlined in Chapter 4 is a useful tool to examine the influences on human lives, particularly in crisis situations. I have modified the framework further, to highlight both threats and strengths in the dimensions of environmental, economic and cultural resources, social ecology and human capacity. The threats and strengths which affect women’s resilience are noted. This permits deeper analysis and a practical format in which to examine the threats which impact on women’s capacity to manage. There may not be a corresponding strength to offset

the threats, which highlights the gaps in supports, where interventions can be suggested.

In the area of cultural influences, the diversity of responses indicates the range of experience for these women. Religion was a source of comfort to some, but not to others. The lack of status and decision-making is offset by the strength of those women, who ignored the dictates of their culture, and stepped in to support their daughters or other members of their family. It is impossible to examine the influence of HIV/AIDS on women in these communities, without acknowledging the influence of their living environment, their economic situation, their poor health and their cultural beliefs. Their deprived living conditions and overcrowding facilitates disease, and makes the likelihood of concomitant illnesses even greater.

I wanted everything the women said to be recorded and documented throughout this analysis, so that they know I value their words. I have assigned pseudonyms, so that each woman is represented, and can trace her voice throughout the document. There was a wide diversity of opinion expressed, which demonstrated how comfortable the participants felt with the interpreter and the CHWs.

The threats have been expressed by the women themselves. For infected women, there was a lack of the necessary comforts to make life easier. The illness of family members inevitably led to more work, and added to the burdens of HIV/AIDS exacerbating and worsening the situation. There was trauma and powerlessness watching their husbands or children become ill, and finally die. This process took up to five years in some cases. The loss of the breadwinner, and women's selflessness, led to malnutrition and fatigue of women. To some degree, the women were hampered by the gender differences in decision making and priorities. The changes wrought by the disease altered family composition and traditions.

I have commenced the analysis of the interviews by selecting the dimension of environmental resources, because a description of the lived environment is crucial to understanding how these women live, and the difficulties they face with regard to economical and physical resources. The women did not directly describe their environment, but it was evident that they were affected by it. The conclusions about

their environment has been gained both from the demographic data described in Chapter 7, detailing the number of people in a household, and their economic situation. In addition, the following section contains my observations as I moved in these communities, over the period of field research.

8.1 Environmental resources

Box 1 summarises the threats which I perceived were experienced by the women in their environment. This data was collected by analysis of the interviews.

Box 1: Environmental Resources

Threats	Strengths
1. Overcrowding 2. Poor sanitation 3. Communicable diseases	No corresponding strengths unless present conditions are improved

Threat 1: Overcrowding

I visited several slum communities whilst interviewing the participants. These communities were in the catchment areas around the KJ Somaiya Hospital. Firstly, there was the community which had grown up around the hospital. It took me one and a half hours to walk from one end to the other, so it was extensive. The unmade main street was deeply rutted, and only auto-rickshaws could drive along it. Many of the dwellings had no inside toilet, and a very small space for living. The participants sat on mats on the floor for eating and rolled out beds at night. There were outside toilets shared amongst several families.

There was another community of much older slums with damp, dank, airless dwellings alongside a foetid, evil-smelling drain. Chembur, a suburb of Mumbai, contained an even older slum, where shoes and sandals are made. The narrow, oppressive alleyways have central drains filled with the residue of glue, tanning agents and dyes. In another area, there were some families living in high-rise apartment buildings with no lifts. This was the best accommodation I saw. They had indoor toilets and more space.

Drawn by promises of a better life, it is estimated that 200,000 people migrate to Mumbai every year (Joshi, 2006). Unfortunately only 20,000 houses are being built instead of the 40,000 required (Chakrawerti, 2005). Added to the dilemma of scarce available accommodation are the rapacious landlords who charge exorbitant rents for the most miserable of inadequate dwellings. I saw one woman's dwelling, accessible only by ladder, which was very small, dank and airless. Many dwellings are illegal, and constructed on 'borrowed' land, which makes ongoing tenancy very uncertain. Whole suburbs were created by the incredible influx of people after Partition in 1947, when dwellings were hastily and unsafely erected. When I was in Mumbai, the government was endeavouring to demolish and rebuild one of these suburbs. The landlords protested that demolishing the dwellings would only add to the housing shortage, and so the proposed demolitions did not proceed.

I observed the daily battle between the road builders who demolished illegal houses. They had to be extremely fast to start road building otherwise other 'squatters' appeared overnight to build again. It seemed inhuman to expect the number of people to be living in such small dwellings under constant threat of demolition. I noted in the areas threatened with demolition, signs would appear and crowds gather, but the inexorable breaking down of houses would continue.

Threat 2: Poor sanitation

Poor sanitation leads to communicable diseases. Some of the participants had to share a communal toilet, which was difficult if they were ill. In squatter communities, sanitation is often not provided, and people have to use open spaces. Children played in these areas, and obviously were at risk of disease.

Threat 3: Communicable diseases

It has to be remembered that many of these HIV-positive people have concomitant diseases such as TB, and because their immune systems are severely compromised, they are more liable to pneumonia. In such overcrowded spaces as the slums, disease is rampant. For example, 27,682 cases of jaundice, typhoid, gastro-enteritis, dengue and malaria were reported in 2005 in Mumbai (Baria, 2006). In August 2005, Mumbai received the most monsoonal rain in 90 years. This led to large numbers of

people having to stand in polluted water for periods. The Health Department noted greatly increased numbers of people reporting leptospirosis, malaria, dengue and gastro-enteritis. In fact 35, 000 people were treated for fever and there were 27 deaths from leptospirosis because of the infestation by rats in the slum communities (Kshirsage, Shinde and Mehta, 2006).

The pollution of Mumbai does not help matters. A visible pall of blue haze surrounded the hospital and the community slums. There has been a 30-40% rise in children suffering from polluted-related illnesses over the past few years, and the pollution in Mumbai is three times the safe level for humans (Ali, 2006a). Anecdotal evidence during conversations with the community elder revealed that the threats to health observable in the slum communities were not being addressed by the municipal or government authorities, despite frequent requests from the community leader, regarding sanitation or rubbish removal. The poor living conditions associated with overcrowding and lack of resources renders these women even more vulnerable to communicable diseases. Daily living is very difficult without running water, washing facilities, and toilet amenities. Added to that, is the uncertainty of tenure in slum communities. Women who lose their husbands are even more vulnerable.

8.2 Physical resources

This refers to the decrease in physical resources, for example, manpower or earning capacity when the husband is ill or dies, and the consequential increase in workload and financial strain for women.

Jwala said:

“A person is a great support, whether he earns or not. If he would have stayed home, I could go out and earn money. I find his absence terribly unsettling.”

Box 2 is a summary of the physical threats and strengths in the physical area as demonstrated through analysis of the interviews.

Box 2: Physical Resources

Threats	Strengths
1. Increase in workload 2. Illness – self 3. Illness of other family members	1. No corresponding strength 2. Somaiya Hospital medical services 3. No corresponding strength

Threat 1: Increase in workload

The women in general were selfless in their approach to taking on more work. However, the deteriorating condition of the person with HIV/AIDS increases the already heavy load of daily household tasks. This is further described in the Narratives section. The loss of their husbands as breadwinners forced women who had not worked previously to seek work even when they were not fit.

Bidya said her illness made her so tired:

“Sometimes, the workload takes its toll”.

Pooja admitted:

“There is a lot of pressure of work on me.”

Priya has taken on the care of a very sick little sister:

“There is a lot of increase in household work.”

Neela said:

“I cannot run everywhere. I get tired very easily. I have to get my children from school, look after my health, cook for them and so on.”

Threat 2: Illness – self

Some women had unrealistic hopes of recovery because they had taken some medication, which may be for a co-existing illness, or they had been given food and were feeling better. They were not on a programme which provided ART, so survival over a long period of time was unlikely.

Reema said:

“I am being treated for TB.”

Neela could only work when she felt better, but still tried whenever she was able.

She said:

“I have fever, cough and cold.”

Abha said:

“I don’t feel hungry and there is a lot of breathlessness and weakness. My sister-in-law cooks food but I eat very less.”

She had to be helped by her sister and family.

The women commented on symptoms such as vomiting and diarrhoea, but there was not only an acceptance of illness, there was also a lack of awareness of the symptoms connected to HIV/AIDS.

As Leela said:

“I am not well today. I have fever, cough and cold.”

The women also made light of their condition. Kavita said:

“We are happy and healthy the way we are – as long as our family supports us, we have no worries.”

The women suffered from the effects of HIV/AIDS, and co-existing illnesses, often felt tired, but struggled on with caring for children, and other household duties. Whilst housework is onerous and labour intense, the women seemed to pace themselves – if they could not work one day, they would try the next.

In Fatima’s family seven people were suffering from HIV/AIDS. She related how their children are HIV negative, except the youngest daughter:

“Even the slightest sign of illness and we go to the doctor, in my family, my sister-in-law and her husband were infected much later after my detection, but he (the brother-in-law) died within a year.”

“We take care of each other and make each other understand. My son is negative so he is with his grandmother. He is 11 years old. My daughter is 9 years old. She is well now and goes to school. She is in 6th standard.”

Threat 3: Illness of members of the family

The women described graphically the progressive disease of their family members. The opportunistic, or co-existing illnesses such as TB and hepatitis, were evident in

their narratives. They sought treatment for an illness as it happened; and did not always understand the nature of HIV/AIDS. The stages in the disease took place over up to five years, and imposed a substantial burden of caring.

Rekha related:

“My brother used to fall sick very often. I used to bring him here to Somaiya. Once he would start medication, he would be fit and fine. He was alright for almost three years but his condition is deteriorating again.”

Veena had similar experiences caring for her sister.

“She would only get better for a few days and again fall ill”.

Suruchi also said:

“My husband used to fall sick often. He would always get fever.”

Sita related the story of her son:

“My son was sick for five years. He was diagnosed with TB and was under treatment for three years from Sion Hospital. Then he was well for some time. Once he was well, he started work again. He used to eat outside a lot, so he fell sick again. He would get fever and vomit a lot. I took him to the hospital where he was again diagnosed with TB, so the doctor repeated his treatment. For nearly four years we took that treatment from Sion Hospital, then in the fifth year I took him again for a check up at Somaiya Hospital.

He was again well for 15 days, but after that he was vomiting continuously. Then his medicines were changed. He felt better and we took him to our native place. The doctors had told him to stay indoors but he didn't listen. Immediately his vomiting began. Then he was very critical so we brought him back to Somaiya Hospital, but the doctors told me there was no hope. I was adamant. I took him to Sion Hospital. He died there the next day.”

Saras's husband was suffering from cold and cough.

“He used to not eat food. When he used to work, he would feel very weak after coming home. Then he took 14 pills in order to commit suicide, and he started getting splitting headaches and fits. Day in and day out he used to ask me to press his head.”

In Irfa's case, her mother's '*paralytic attack*' (stroke) took precedence over HIV/AIDS. For an 18 year old, it was a harrowing experience, nursing her mother at home, and watching her deteriorate.

“I took all the care I could but as there is no cure to this, I think she would have to go sooner or later. Her left side was paralysed, so she couldn’t move on her own. Slowly she stopped eating as she couldn’t digest the food. By the end she stopped recognising us.”

Pooja related that her husband’s only difficulty

“is that he gets a lot of cough and colds. He vomits a lot. In that case I have to admit him to the hospital. He doesn’t fall critically ill. Some small things go wrong with him, like food poisoning or fever or cough. Nothing major.”

Ritu said:

“My husband was infected. He got four to five infections at a time. I had to take him to Somaiya. He had TB and something else”

Aisha said:

“After my husband came to know about his infection, he was fit and fine for five years. He was sick for only a year. He did not suffer much. He had malaria and jaundice once.”

Fatima is receiving treatment for TB. Munira related her experience with her husband’s illness as:

“My husband suffered a lot. By the end he was suffering from pneumonia, TB and something else. He was under medication for two years in Somaiya Hospital. He died there. I took a lot of care of him.”

Keya told how scared she was when her husband “died very suddenly.” She thought she was safe but she had contracted HIV/AIDS. Seema’s husband was being treated for TB when the doctor came to know he was infected.

It is obvious from these women’s narratives, that the level of understanding of the illness associated with HIV/AIDS is not high. This may be related to their inability to understand health messages, because of language difficulties, and lack of education.

Strength 2: KJ Somaiya Hospital medical services

The medical help, well received in most cases, involved more than prescribing medicines. Sometimes it included normalisation of the disease.

Lina said:

“The doctors told me how to take care of him (her husband), how to give him medicines on time, food and other things.” Shamla said: “After medication and treatment, I now feel I am infected by just another disease.” And Shobha being treated for TB, reported: “I am feeling better now.”

The doctors also minimised the illness. Arwa said:

“The doctors told me and made me understand that good food, safe sex, use of contraceptives will be the things I should be doing.”

As she was already HIV positive, this information was too late for her, but may prevent further transmission.

“It’s a small illness which has been hyped up a lot. Now I feel it’s just another disease. It’s not as terrible as we make it sound.”

Sita said:

“The Somaiya people helped a lot. They gave him (her husband) medicines, food and tonics”.

Seema was able to discuss her infection with the doctors. Rita and Shobha reported they had received treatment for TB. Both brother and sister-in-law had HIV/AIDS and TB. Keya reveals:

“I am on medication for TB. I cannot take any other medicines.”

One woman looked after her husband and her sister, both of whom were HIV positive. She greatly appreciated that the social worker at the Somaiya Hospital had arranged for a nurse to visit, and give personal care, and medications. Mina, Rupa, Nirmala, Irfa and Sheela related how unspecified help and support was provided by the hospital .

It is worth noting that there have been improvements in care, since the earlier cases of HIV/AIDS. Kamla and Vijaya have horrific stories to tell about healthcare which have been related in the stigma and discrimination section in Chapter 10. Later, Kamla revealed:

“A person in my neighbourhood got infected. He wanted to go abroad, so he went for blood tests and came to know about the infection. He was so scared he locked himself in for three days. Then he came to see me. I told him there was nothing to be afraid of. I took him to Somaiya Hospital for tests and to the counsellors regularly. His wife and children were also tested and they were

negative. He takes medicines regularly and is fine now. Then I went to CIPA (Centre for International Programmes Abroad) personally and got medical aid. There are about 4-5 cases in my locality who come to me when anything happens. I have created a lot of awareness of HIV/AIDS in my locality because I felt very bad about my family experience.”

Of the women in the study, 48% (n=22) were infected with HIV/AIDS, in addition to having members of the family to care for. They seemed to accept their illnesses, and this may be because there is a high incidence of illness in these communities. For example, Kshirsage, Shinde and Mehta (2006) state that 35-45 % of families in the slums, and more than 50% of pavement-dwellers, have at least one person ill in the family. The women were selfless in their care for their family. These duties were taken very seriously, and they did not express anger in this regard.

8.3 Economic resources

As revealed through interview analysis, Box 3 provides a summary of the key economic factors, which help or hinder women at this time of added financial burden and stress. HIV/AIDS is sometimes the factor which tips people who have previously managed into poverty. Where a family is below the poverty line, HIV/AIDS can place intolerable burdens on the family.

Box 3: Economic Resources

Threats	Strengths
1. Poverty	1.a. Strong family values b. Resilience of women
2. Finances	2. Employment
3. Malnutrition	3. Somaiya Nutrition Programme
4. Lack of medicines	4. Somaiya Hospital

Threat 1: Poverty

HIV/AIDS places a double financial burden on poor families, who are least able to absorb the costs. The male breadwinner is often forced to reduce working time through illness, or a household may lose the breadwinner through death. At the same

time, the cost of healthcare as well as transport costs to health services increases. This situation causes an intolerable burden when there is no money to spare. The financial situation may be solved temporarily, but the impact is felt long afterwards. Nirmala spoke of the debts and the dissension it had caused in her household:

“There is a lot of debt to be cleared. The money was spent over my son’s medicines. We are still repaying that. There are a lot of fights over that. Thankfully, the house is still on my husband’s name, so my other son cannot drive them out of the house. They (her family) fight a lot, but they are bearing all of it and staying here, because this is Mumbai and everyone can earn at least their daily bread here.”

Neela was destitute as her husband had died and her mother-in-law had taken her in. She was living under a bed with her two children. She said:

“There is no permanent source of income. During the July floods I got food and clothing from Somaiya Hospital”

In Nirmala’s case, the mother-in-law understood the plight of her daughter-in-law:

“No-one helps a person like that. Some relative from the native place leaves some money behind. The Madam here (the Co-ordinator) here also gives clothes for her two daughters.”

Threat 2: Finances

The loans incurred by families due to ill-health may take many years to repay, and the family’s assets are heavily mortgaged into the future. Widows may lose all household assets following their husbands’ deaths. Moneylenders demand high interest, and place pressure on families to repay. Rekha said:

“I have spent so much money on my brother’s health and medication that I am completely bankrupt now.”

Ritu spoke of the worries in her family:

“We had just taken out a loan and had to repay it soon. One of my daughters was sent home by her in-laws so we were very worried.”

Widows with young children were particularly vulnerable, as Anju who was infected, and so was her youngest son. She only earned Rs 700 (\$18) per month, (AUD\$20.50) doing household chores as a domestic. She was forced to get

nutritional help and faced an uncertain future. Sick women are forced to work, as they cannot afford to take time off work without loss of income.

Veena and her husband:

“Spent a lot of money on her (sister’s) treatment”

Children compound the insecurity of a widow. Arwa said:

“Now I have to shoulder the responsibility of my children all alone.”

Some families claimed that they had enough money to bear the financial burden created by HIV/AIDS, for the present. When the future is considered, plus the extra commitments of raising orphaned children, the burden is severe. Kamla had the income from herself and her brother-in-law, and says:

“So money matters were taken care of”

After her husband’s death, she had to assume responsibility for her three sisters, and three orphaned children. Usha received some financial help from KJ Somaiya Hospital, Rs 3000 (\$80) per month, and supplemented the remaining expenses for medications, Rs1000 per month (\$27), from her savings.

By caring for her unmarried brother, Rekha was compromising her own son’s education and future. She said:

“I don’t have money to send him to college. You can’t get a good job unless you are 12th pass. I have spent so much money on my brother’s health and medication I am completely bankrupt now.”

Three males earned money in Seema’s household - her husband, brother-in-law and father-in-law. As her husband was HIV positive, her position may change if she is widowed. Families send money home to their relatives in their native place, so the income is often compromised. Veena’s husband earns Rs3000 (\$80) a month but

“We have to send money to my in-laws in the village also.”

When there are members of the family affected by HIV/AIDS, the family savings can be used on the first person to need care. In these cases, that is usually the

husband, and so it can be difficult to find any more money for treatment for subsequent persons affected, as in Neela's case because she is widowed, and dependent on extended family for her accommodation and food.

Strength 1a: Strong family values

The duty of caring for ill relatives superseded the financial position. For example, Veena cared for her sister.

“She is family, and we don't leave our family just like that.”

Pushpa said:

“I coped with it because she was my mother. I wouldn't have done it for anyone else.”

Anju, who is infected herself, with an infected son, was fortunate to have her mother and sister helping her to care for her children. Suruchi relied on her brothers to support her and her two children.

There is trust in Rukhsana's statement:

“My children support me emotionally. They will take care of me and their father.”

Strength 1b: Resourcefulness of women

Women have to be resourceful, and often have to draw on their only valuable possessions – the mangal sutra (wedding necklace). Veena said:

“Right now I didn't have enough money so I kept my necklace with a moneylender and got the money’,

and Vijaya who sold her jewellery :

“To get money to pay the hospital bills”.

The jewellery has much more than monetary value. It is the symbol of a married woman and much treasured. The situation has to be desperate for a woman to give up her only asset. Jwala said:

“If my husband was alive he could have stayed home and I could go out and earn money.”

Aisha said:

“In his last year, I took a loan to meet all the medical expenses (of her husband).”

Sarita stated that she is the only money-earner in the household, and:

“has given up part of my house and has also a small shop on rent that solves my money problem.”

Some women were able to supplement the family income with casual work at home, despite the fact that they were infected. Anju did household chores earning Rs 700 (\$19) per month, and Reema, whose husband could no longer work because of illness, revealed:

“I stitch clothes whenever I get time. I have never counted my earnings but not a penny is saved.”

Aisha has become the breadwinner for her family. When her husband was alive, they had a shop,

“but after his death, I shut the shop and now work at home. I can earn up to Rs 4000 (\$107) per month if I get enough work, however my problem is chronic tension...If I am not well mentally, I cannot work which affects my monthly income. I can work only when I am completely relaxed.”

Neela knotted the ends of dupattas (the wide scarf which is worn over salwar kameez) from her living quarters under a bed.

Strength 2: Employment

For unskilled and illiterate women from the community slums, there are few opportunities for work, apart from domestic work, or the demeaning and disgusting work of ragpicking, and plastic collection. SAHAS has started a sewing programme for women. They acquired six sewing machines, and women have been recruited to learn embroidery and sewing in a joint project. Whilst I was there, the hospital had placed orders for hospital gowns and blankets. This is such an important project. I watched the women as they learned, and would return with a garment they had made with such pride. The training scheme aims to broaden the scope to teaching file-making and other income-generating activities.

Arwa, only breadwinner in her household, earned Rs 400 (\$11) per month for herself, her husband and three children, and Rekha earned Rs 350 (\$9) per month “at an old lady’s house” to supplement her husband’s income of Rs 2500 (\$67) per month as a watchman. Rupa earned Rs 2500 (\$67) per month as a *peon* (office person) for herself, mother-in-law and two children. Shobha and her husband are both HIV-positive. The husband is still earning at present but their future is uncertain.

The money earned can be uncertain too. The income, which Munira’s brother earned from selling sandals, could not be relied on. Keya who has HIV/AIDS, works as a rag-picker earning Rs 10-20 (27-56 cents) per day. At least, in her case, her brother and wife are earning money and she said:

“If I am not well, they give me money.”

In Irfa’s household, her three brothers had to leave school. One is earning money, while the other two “are learning the ropes of the job” (as mechanics), and together they earned only Rs 1500 (\$40) in total to support six people.

There can be different allocations of finance in one family group. For instance, 50 year old Nirmala, was living with her retired husband. Her son earned Rs 3000 (\$80) per month but this only supported him and his wife. The remainder of the family included the two older people, a HIV positive, widowed daughter-in-law, and her 11 year old, HIV positive daughter. They lived on the earnings of Nirmala, who did household chores for Rs300 (\$8) per month, and the daughter-in-law who made dupattas when she was well enough and earned Rs200 (\$5) per month. The relationships were tenuous, and threatened to break down. Kavita was more fortunate, as she and her husband were able to work. She said:

“Both of us are healthy and work every day”.

Threat 3: Malnutrition

Without a system of government social support, women are usually left destitute when their husbands die. The KJ Somaiya Hospital’s nutrition programme complements the home-based care programme. Nine of the women interviewed had received food from this source. Apathy can result from malnutrition, so that it is

very difficult for these women to make decisions, even when they have the freedom to do so.

Strength 3: Nutritional help from KJ Somaiya Hospital

There is little doubt that if some women had not received nutritional support, they would have died. It is a sad fact that basic needs such as nutrition have to be addressed first in these communities. Several women said they had improved with better food. Bidya “takes vitamin and calcium tablets.” Sita said:

“Somaiya people helped a lot (with her son). They gave him medicine, food and tonics.”

Shamla said:

“I was so thin that people used to ask me if anything was wrong. Doctors told me to eat whatever I felt like. Food should be healthy like bananas, groundnuts, leafy vegetables and so on. I got food from here for almost a year.”

Threat 4: Lack of medicines

There was a small charge made at the KJ Somaiya Hospital for medicines and treatment. As women are the last in priority, it is not surprising that they would not be able to afford medical treatment particularly if their husbands or children needed treatment.

The women spoke of medicines provided by the hospital, but these were not specified. An essential criteria for being on the KJ Somaiya Hospital programme, and irrespective of the medications provided, was that the participants did not receive ART. I was unable to ascertain the reason for the lack of provision of such medication which would have lengthened their lives. The plight of watching a sick child is emphasised by Shobha, who said:

“My daughter has been sick since birth. She has been on medication almost all the time. But now we cannot afford that also”

Shamla said:

“It’s been 6-7 months since my medication has stopped, and I still feel good.”

Abha and Bidya get medical help from Somaiya. Veena said:

“Even though we cannot afford, I have kept a nurse (for her sister). She gives a bath and gives her medicines on time. I had to do this because I have to look after my husband also. We are getting help from Somaiya Hospital. The social worker is helping us with the expenses.”

Doctors, not specified whether at KJ Somaiya Hospital or elsewhere, told Nirmala:

“There are some new drugs on the market because of which the infection becomes inactive. So now I will get the same medicine for my daughter-in-law and granddaughter.”

Despite the fights in her family over the money owed for her dead son’s medicines, Tara said:

“At first I couldn’t walk, but now I feel healthy and good because of the medicines I took. “I am not on medication now. The doctors (not specified) told me that they would check on my reports and then decide on medicines.”

The interviews are testimony to the fact that people in low socio-economic conditions just exist. When HIV/AIDS affects a family, it increases a family’s poverty. The KJ Somaiya Hospital had responded with their Nutrition Programme but women can only receive this help for one year. In reality, the costs and burden of medical care for surviving members of the family meant that women were always last in line for food and medicines.

8.4 Culture and values

I had a glimpse into some of the difficulties and complexities that are associated with caste and religion in India, and the consequences of stepping outside the expected norms, from Aisha’s story. She related:

“I have suffered a lot in life. I was married forcefully against my wish, my in-laws weren’t good to me, my husband was jobless. All this has influenced me mentally. This was my second marriage. My husband was a Muslim and I am a Hindu. Despite this, we got married. So no-one visited us much, but they did not discriminate. However, I think the community still does discriminate, and no-one helps.”

Box 4: Cultural Resources

Threats	Strengths
1. Lack of religious faith/belief 2. Lack of status for women 3. Lack of decision making 4. Gender differences in care 5. Return to natal families 6. No corresponding threat	1. Firm religious faith 2. No corresponding strength 3. Equal decision making 4. No corresponding strength 5. Strength and resilience 6. Self-care – dress 7. Healthy beliefs/attitudes

Threat 1: Lack of religious faith and belief

I had anticipated that, in this community, women would have strong links to their religious beliefs; and this would be a source of strength for them. However, for some women, there was a disillusionment and bitterness with regard to their religion.

Vijaya said bluntly:

“If there is a God, this would not have happened”.

Referring to the infection and death of her husband, leaving her a widow at 24 years to care for two young children has made her bitter.

Suruchi said she “does not believe in God so much.” She was widowed, HIV-positive, and had an infected child.

Abha also mentions:

“I do not believe in God. When there is nothing good in my life, why should I pray to Him and what should I thank him about.”

Sheela said:

“I don’t believe in God. If there was a God, why am I suffering so much?”

Keya too, does not believe in God and plans to take her own life once she is critically ill. Resignation was expressed by Shamla: “God will take me whenever He wants.”

Strength 1: Firm religious faith

Despite the lack of religious faith for 60% of the respondents, 40% said that their religion helped, regardless of whether they were Hindu, Muslim, Buddhist or Christian. Ritu, Saras, Jwala, Bidya, Tara, Kamla and Charu mentioned a belief in God without further comment. Where there was belief, it provided women who were otherwise isolated from other forms of support, with hope, trust and faith. The

religious beliefs did not extend to the next world. The emphasis was on how God did or did not help now.

Priya had perhaps not turned to religion before :

“I am not such a firm believer in God, but now I feel that praying to Him may help. I feel like praying for my sister who is only 7 years old.”

Saras said:

“What can I say about HIV/AIDS? Both my daughter-in-law and her child are on medicines. They have to live and have to fight. We have left the rest to God.”

For a woman who has lost her parents, her husband and her siblings at the age of 30, belief in God is all she has left. Smitha “*finds that praying to God gives me hope*” Usha’s beliefs extended God to the people around her:

“I believe that Doctor is God, medicines are God and everything around me is divine. I still trust God. I prayed to God and told Him that I couldn’t see his (her son’s) sufferings. I told God to put his soul to rest as painlessly as possible.”

Nirmala also spoke of doctors as divine beings who can do no wrong.

“They are God for us. We trust them completely. They will always do good for us.”

Neela had no-one to confide in, but said:

“I think my trust in God will not go in vain, and my condition will improve.”

Seema said:

“I have full faith in God. I tell Him every day to take care of my husband and children. I don’t mind anything happening to me but not to my husband as he is the backbone of my family and keeps my family happy.”

Gita described her sister’s faith in God, and not her own, as she battled with the aftermath of her sister’s children left behind to care for.

Pushpa’s faith in God is strong.

“My mother outlived the doctor’s prediction. That proves there is a God somewhere.”

Rekha believed in God and that

“He has saved him (her brother) many times. I have left everything in His hands.”

Spirituality, fate and religion brought hope too.

Pooja believed in God:

My faith has helped me a lot and I think he (her husband) will become better.

I have a gut feeling that something good will happen to us.”

The rituals associated with religion impart a sense of security and protection. For example, Rukhsana used prayer: “I pray to God that everything goes well”.

Shamla, who is Hindu, says:

“I believe in God. I do pooja (prayers) every day. The lamp in front of God in my house never goes out. It burns day and night.”

From another religious perspective, a Muslim woman, Fatima, described how she did the “ ‘namaz’ and the ‘rozahs’ from her belief in Islam.”

And Munira, also Muslim, whose religion sustained her, said that despite the fact she had lost her husband at the age of 27 years:

“I believe in Allah. He will do good for us.”

None of the women expected the temple to provide any health service. 80% Indians are Hindu, but their religious structures do not provide practical help or counselling. A strong belief system is an undoubted support in times of crisis, and when this disappears, there is nothing to take its place. The religious leaders do wield some political and social influence (Keller, 2005) and they could be enlisted to help with community attitudes.

Threat 2: Lack of status of women

The lack of women’s rights and status is seen in the following situation. Arwa has been infected by her husband, and yet he deflects the blame onto her, and this gives him the excuse to beat and abuse her. The husband takes away her dignity and respect, by not according her the status of wife and mother of his children, and by

encouraging the building owner to threaten her tenancy, and to give her further stress and uncertainty by legal action. The courts are overburdened, and a case like this could go on for years, which will further stress Arwa. She said:

“My husband blames me for infecting him. My husband used to beat me and verbally abuse me. He called me a cheat. I had expected his support and not his wrath and anger. He called me ‘characterless’. Now my husband is admitted in hospital. He is paralysed and has a brain tumour. My husband has told the owner of my house to sell it. He doesn’t consider me his wife nor is he bothered about the children. The building owner has gone to court and taken legal action against me. This is a problem for me”.

Threat 3: Lack of decision making

Lack of status and rights results in lack of decision-making, and is attributable to social factors within Indian society. The fact that women in this community do not always have the right to make their own health decisions is shown in the following situations. In the case of Rukhsana, the lack of ability to make decisions was obvious.

Rukhsana is a mother who says:

“My family is male dominated, so women have no opinion. My sons will decide whether I should get myself checked or not.”

Strength 3: Decision making

In Veena’s situation, she said it was a “joint decision” by her husband and herself to care for her sister.

“It was very simple really. She is family and we don’t leave our family just like that.”

This is an example of family and duty overcoming any idea of deserting a family member. It is also heartening to see that a woman could appeal to her husband, so that she could continue the care of her sister, and they could come to a common decision. Aisha was able to decide to close the shop she and her husband had run, but only after her husband’s death. Sometimes, there was a voluntary submission of will and decision making to God in a fatalistic way. As Pushpa said:

“I have left everything in His hands.”

Threat 4: Gender differences

Kamla commented on the differences between men and women from her experience, both as a carer for three of her family who have died from HIV/AIDS and also as a social worker in the community:

“I have seen in many families if the husband is infected at first, he creates a scene in such a way that it looks like the wife has infected him and not vice-versa, which is actually the case. A male child will get more attention than a female child. A wife is mostly put to blame, no matter what.”

Threat 5: Disruption of family structure: Return to natal home

Usually women leave their maternal home when they marry and expect care from their husband’s family. However, the relationship between in-laws can be fractious and tenuous. Mothers-in-law are known to throw their son’s wife out when diagnosed. Then women have no option but to return to their mothers. It would need more research to gauge the effect of this, and the disruption to social mores, which have existed for thousands of years.

Kalavati brought her sister-in law’s daughter home when her in-laws discriminated and treated her as if she was an ‘*untouchable*’. She took care of everything right from food to medicines and hygiene. Gita returned to her mother, who cared for her, from bathing to feeding her.

Strength 5: Strength and resilience of women

There were mothers and mothers-in-law who did not give in to discrimination but took in their daughters and daughters- in-law. For example, Nirmala, a 50 year old woman stood up for her daughter-in-law, and defended her against the rest of the family.

Charu is a widow who has taken on the care of her niece. She said:

“I will teach her as long as she wants to. I will get her married and have promised my sister-in-law that I will secure her daughter’s future. I wanted my sister-in-law to live as much as she wanted. I wanted her to be happy and she did live happily then.”

Sheela depended on her mother who discriminated against her, but still provided medicines and food.

“My mother discriminates a lot. She doesn’t let me sit with everyone while having lunch or dinner. My plate and glass are kept separately. My clothes and soap are used only by me”.

Gita related how her sister-in-law was badly treated by her in-laws, so her own mother took on her care.

“When she was really sick, her mother took care of her. She did everything from bathing her to feeding her.”

Sita looked after her adult son for six years. Nirmala has taken in her widowed daughter-in-law and her two children. She has fought to keep them in the family despite the family fights, and said:

“As long as we are alive, we will not let them go out of the family and ask for help.”

There was one mother, Usha, who took great care of her son, administering just the right medicines and food, and taking him to the hospital at regular intervals. She felt if she cared for him enough he would be saved:

“I did everything right from bathing him to feeding him food. It was like taking care of a small baby...I had felt he would be cured of this disease, but the doctors told me otherwise. I had a lot of hope that he would survive, but Man proposes and God disposes. He left me.”

Kamla learned from the negative experiences of her own family, went on to read and learn and study and now works in the HIV programme:

“I told everyone about this disease. My life is like an open book. I have not kept anything back. I have seen all this. I can still picture all of it in front of my eyes. I get my strength from this.”

Strength 6: Personal care (dress, washing, hair)

The women I interviewed were clean and well groomed. This impressed me greatly, as their living conditions were so impoverished, and there was often not a separate bathroom. Washing was difficult, without modern conveniences. All the interviews had been arranged prior to our arrival, so the women had some warning, and

appeared neat, and beautifully dressed in saris. I wondered whether this emphasis on cleanliness and grooming was cultural, religious, or related to a sense of self-esteem.

Dress is a way of expressing cultural identity and of belonging to a special group or region. It is also a way of defining prestige, status and position in the community (Barnes and Eicher 1992). Women easily identified subtleties of dress, which escaped me as a *firangi* (foreigner). These details place other women in caste and class. The Hindu religion has many prescripts regarding purity and pollution, and women are required to wash before prayer, and attending to any household duties. An Indian woman (Neela, personal communication, January 15, 2006) summed it up thus:

“Actually, it is our ‘sanskriti’ to wear saree. Indian women dress for themselves and for attracting their husband also. But I do not think only for attracting purpose, women dress well. Whenever we look good, we also get confidence.”

Strength 7: Healthy beliefs

Shamla described in great detail her health regime. Besides knowing about healthy food she said:

“I stay very clean at home. I wash my clothes separately first in hot water and wash my children’s clothes later. I wash all my garments in hot water as a precaution. I also wash my plate and other utensils immediately. Cleanliness helps in warding off diseases. Dirt invites diseases and germs. We should keep our houses clean. Madam has seen how clean my house is. Everything should be clean right from the curtains to the utensils to the floor. The place where we sit should be clean.”

Whether these actions follow a belief in preventing HIV/AIDS, or have been absorbed from the community health workers is unclear. It is extremely difficult to keep clean in the surroundings of slums, with constant dust and rubbish, and with the whole family in one room.

8.5 Summary of the chapter

The information gained in the interviews includes the effect of culture, social issue and environment on the women participants. Strengths, such as resilience and ability to adapt, had evolved to offset the extremely difficult environment in which they lived. The importance of family, particularly children, and religious beliefs, was demonstrated. In Chapter 9, the effects of family and community are further considered, and perceptions and feelings of the participants, follow in Chapter 10.

CHAPTER 9

SOCIAL ECOLOGY

“When a young woman who is first time pregnant is found to be HIV-positive, we ask her to call her mother-in-law. We explain the report to the mother-in-law. These patients who come here are from the low-income group, and if the girls are newly married, they are really dumb and don’t understand anything so the mother-in-law is called to explain.” (Gynaecologist in a private hospital, Mumbai, cited in Bharat, 2001, p. 24).

9.0 Introduction to the chapter

This is the second chapter which contains analysis of the in-depth interviews. In this chapter, the dimension of social ecology is examined. Social ecology, according to the Psychosocial Framework used in this study, is the social capital of a community, and refers to the relationships within the family and the networks or links to groups, religious and cultural institutions and government and political authorities (The Psychosocial Working Group, 2003). The concept of threats and strengths emanating from the social ecology dimension are examined.

HIV/AIDS differs from a disaster such as a tsunami or a terrorist bombing where the community may unite against a common enemy. In the case of HIV/AIDS, the community polarises under the strain, dividing because of stigma and discrimination. Indian women with limited education and awareness, finances, employment, power and status are very vulnerable to extra layers of stigma and discrimination. The dimension of social ecology overlaps with human capacity and cultural values. In all of the areas described below, there are threats to coping as well as the potential pool of resources or strengths.

9.1 Social Ecology

Box 5: Social Ecology

Threats	Strengths
1a. Lack of health care 1b. Negative health care experiences	1a. Access to Somaiya Hospital resources 1b. Positive health experiences
2. Stigmatising	2. No corresponding strength
3. Discrimination in the community	3. Non-discrimination in Somaiya Hospital
4. Discrimination in the family	4. Positive experiences within the family
5. Fear of discrimination	5. No corresponding strength
6. Fear of courtesy stigma	6. No corresponding strength
7. Lack of support	7. Support from Somaiya doctors and team
8. Lack of awareness	8. Awareness
9a. Disruption to family structures	9a. Changing roles brings growth 9b. Support from within the family
10. Absence of family in the future	10. No corresponding strength
11. Strain on the family	11. Duty of care

In Box 5, I have listed the threats and strengths to social ecology. There may not be counteracting strengths in this area which the women can draw on to ameliorate the threats. This exposes gaps requiring further intervention in order to build women's resilience.

Threat 1a: Lack of healthcare

There are unfortunate families who are unable to access any services. For example, Vijaya related an extreme case of a hospital's refusal to treat her husband:

“When my husband was jobless after he fell sick, I took him to our native place (Satara). The rural area being backward, the hospital in the village refused to admit my husband as a patient there, so I kept him at home.”

Strength 1a: Access to Somaiya Hospital resources

The women in the study are fortunate to be able to access the Somaiya Hospital, which charges a small fee for services. For Neela, (the mother who lived under the bed) it is a lifeline. The Somaiya Hospital provided medical treatment, food and clothing, during the floods. Shamlam received medication, treatment, and participated in a savings scheme, and felt better and healthy.

Threat 1b: Negative experiences in health care

Kamla and Vijaya had experienced discrimination in healthcare. Shuja had recently been in hospital. Shuja is a woman of 28, who was told she was HIV- positive at the delivery of her baby. She said had they told her right from the start, she would have aborted the baby. She mentioned that:

“The nurses at a hospital pointed at us and teased us a lot. That hurt. I heard it all quietly. Since that experience, we haven’t told anyone (but) my aunt came to know.”

Vijaya said that when her husband was critically ill, she took him to Sion Hospital:

“But they took him in only once. The second time they said that even if they did take him in, they would not touch him, so it was useless keeping him there, and that made me get him back to Somaiya Hospital. My husband was one of the first patients at the HIV cell at Somaiya Hospital. Had he received treatment on time, he would have survived, or lived a few more days.”

Kamla was strong enough to speak up against the doctors at Somaiya, who told her to get a plastic kit to wrap her sister’s body, after her death:

“I refused because I knew there was no need for anything like this. I asked the doctors if they had all the information about the infection or they would not have asked for the kit. They said it was just a precautionary move. I told them that if they didn’t want to wrap her body I could do it and I did do it. I signed all the necessary documents and my sister and I wrapped her body. The lady staff didn’t help either.”

Strength 1b: Positive healthcare experiences

Fatima had experienced help and support outside the Somaiya Hospital when she had taken her daughter to Sion Hospital where she was diagnosed and then to Wadia

Hospital where they told her how to take care of her family, about food and nutrition and other precautions.

“People don’t know much about it, but pretend to know a lot.”

9.2 Stigma and discrimination

Threat 2: Stigmatising

Transferral of blame onto the woman is not uncommon, and is supported in the literature. Vijaya describes her experience:

“Everyone in my family knew about it. They thought I was lying. My mother-in-law used to say her son was a good man and I was the one who was bad and characterless. She used to trouble me a lot. She used to say that I was the one who infected her son. No-one believed me or what I said.”

Sarita’s vulnerability as a widow without a male protector was highlighted by her comments:

“Everyone in the community knew about my husband being infected. Now some men come to me with bad intentions but I ignore them”.

Threat 3: Discrimination in the community

Once the husband had died of AIDS, the widow could still remain stigmatised. This kind of stigma is termed courtesy or affiliate stigma, as explained in Chapter 3. In the case of Aisha,

“Other people did discriminate and it continues till today. Some of my customers do not come to me as they think I am infected. In this slum, there is one toilet shared among five houses. No-one used to use our toilet.”

This could be seen as a non-intended benefit, but is only felt as a slight by Aisha.

Fatima noted that :

“When my husband is not well, no-one even comes to visit him. People may be knowing but as they are scared, they don’t talk much about it.” She attributed everything to ignorance: “Those who don’t know anything about HIV/AIDS are the ones who discriminate. It can happen to anyone. Awareness is the only cure to it.”

In one of the worst cases, Arwa relates :

“The people around us were terrible. They don’t allow my children to come out, and make them feel like animals. They even wash their doorsteps if they see us walking over it.”

Mina mentions:

“We had to vacate our previous residence because the people there came to know about my husband’s illness.”

Charu recalled the story of her sister-in-law, she felt:

“Everyone discriminated against my sister-in-law. My sister-in-law used to fall sick very often. She used to get fever and cold. We admitted her to Sajivani Hospital and got her checked. It was there we came to know she was infected with HIV/AIDS. Everyone told me not to take care of her. I called her parents but they refused to take her responsibility, so I couldn’t leave her in that condition. I took her in. She used to be alright for a week, then suddenly she would be sick. She would be so sick that I would get scared. She was like my little sister. I did everything for her. While she was on her deathbed, she told me that nothing wrong or bad would happen to me.....She was worried about her daughter. She left food and water (did not eat or drink). She was only worried about her daughter. After I did away with that worry, (i.e. her daughter) she was carefree. She wanted to die in her village, but she suffered a lot there. She didn’t get good food and everyone discriminated against her. So I sent her daughter to meet her. She didn’t eat and drink for 15 days. She died peacefully.”

In the case of Pushpa, the doctors told her to keep away from her mother who was HIV positive. Their advice may have been well-meaning, but was judgemental, because the mother had been married three times – very unusual in the Indian sense.

She takes up the story:

“According to me, she must have got it from her first husband. I am the daughter of her second husband. So I felt angry but at the end of the day she is still my mother. My husband didn’t like my mother. He behaved well with her and he let me visit her but I couldn’t leave my daughter alone so I stopped visiting her. Doing the household chores and visiting my mother took a toll of my health. My husband then told me not to visit her. He allowed me to visit her once in a while but never allowed me to stay there. Doctors told me to stay

away from my mother. I couldn't do that as she was my mother. I took care of her. There was no-one else to help. My father and brother used to go to work, so there was no-one left.... I coped with it because she was my mother. I wouldn't have done it for anyone else.”

Shamla related how her brother was the first HIV positive case in their community:

“In our area, there was absolutely no awareness about this disease. My brother was a very simple man. No-one could even think he could get infected. People thought he might have contracted the disease by wrong means. It is a possibility but I don't think so. His friends used to come over almost every day to have fun. All that stopped slowly. Except my brother's friends, everyone helped us. When my brother died, no-one came to pay their respects. I used to think that people should come forward and help us. I think they were too scared to come.”

After initial reactions, the women made decisions about keeping the news to themselves. Seema said:

“Slowly we became normal again. We don't want our children to bear the brunt of this.”

Strength 3: Non-discriminatory practices at the KJ Somaiya Hospital

The HIV/AIDS sensitisation and awareness programmes which the KJ Somaiya Hospital have implemented appear to be effective. All staff are trained and no instances were reported of discrimination within the hospital setting, apart from Kamla's experiences which were in the early years before training had taken place.

20 women (44%) reported the lack of discrimination from the Somaiya doctors – (Rita, Mina, Pooja, Kalavati, Charu, Sheela, Sita, Seema, Veena, Nirmala and Leela). Gita said:

“There was nothing wrong in the doctors' behaviour.”

Munira and Shuja were able to talk to the doctors. The doctors told Shobha how to take care of her family and keep them healthy. Jwala said:

“The doctors were very helpful and took good care of my husband.”

Nirmala said:

“Doctors do not discriminate. They are God for us. We trust them completely. They will always do good to us.”

Suruchi felt that the

“Doctors behaved very well with my husband and treated him with lots of care.”

Tara said that the doctors

“Behave very well with me. They answer all my queries and don’t discriminate.”

Shamla said:

“The medical staff at this hospital was very helpful.”

Usha said:

“Doctors helped a lot. They told me how to take care of my son.”

The effect of being well treated in these circumstances can have far-reaching effects. It may be the first experience for these women, and can give them confidence for the new roles they have to face.

Threat 4: Discrimination within the family

Instances of discrimination within a family were reported:

“My mother-in-law used to tell me not to go too close to him and maintain a distance, but I didn’t listen to her and did all I could to make him feel comfortable. I knew he was HIV positive for almost 3-4 years” (Priya).

This is despite the fact that her husband did not tell her of his infection. She happened to see his reports. Jwala says her mother-in-law and others

“Told me to stay away, but I couldn’t. He was still my husband, and I couldn’t leave him alone to suffer”.

Reema said:

“My sister-in-law tells me to keep a distance from him. I even keep my children away from him”.

Vijaya related:

“We told our family about my husband’s infection when he was healthy. As a result, no-one believed us. And at the end, when he was critically sick, they asked me why I didn’t inform them earlier as they would have done something.

So they were talking on both sides. My in-laws know that I am not infected so they behave well. Had I been infected they would have abused me.”

In-laws can be a source of discrimination, as in Munira’s case:

“My in-laws did not behave well with me.”

Kalavati described her daughter’s experience.

“Her in-laws used to discriminate and not treat her very well. They used to treat her like an untouchable – not giving her enough food, water, keeping her away from others and so on. I couldn’t (bear to) see all of that so I brought her home and took care of her. I took care of everything right from food to medicines to hygiene, I did everything.”

There can be a lack of awareness of what discrimination is. Nirmala says there is no discrimination in the household, and yet her son’s children go to a private school whereas her widowed daughter-in-law can only send her children to a municipality school. She continues:

“The children are small and don’t understand this. They see other children and ask for things their mother can’t provide. My heart breaks for them. None of my neighbours know about this. There is no need for anyone outside the family to know about this.”

A 25 year old widow, Sheela, spoke of her mother’s treatment towards her:

“My mother discriminates a lot. She doesn’t let me sit with everyone while having lunch or dinner. My plate and glass are kept separately. My clothes and soap are used only by me.”

However she understood her mother and was grateful.

“My mother is scared for my son so she acts like this. She is only taking precautions. Everyone at the hospital made her understand that these precautions were unnecessary but she refused to budge, so I let her be. My mother looks after my son well. That’s all I want...Had I stayed in the village, I would have died. I thank my mother for bringing me back to the city and taking care of my son”.

In one of the worst cases mentioned beforehand, Neela was living under a bed with her two children, in an outer room whilst the rest of the family lived inside. The whole family lives in these small dwellings often of one room. To be excluded in this

way is particularly harsh. She was working on dupattas whenever she felt well enough. Neela said:

“There is no money and no proper food to be cooked also. I get a lot of loose motions. They let me use the kitchen and the bathroom, but they have made me stay under the bed for the last seven years. I think this kind of discrimination is wrong.”

Strength 4: Positive experiences in the family

There were families where there was no discrimination – only help from mothers and sisters (Anju, Leela, Rita, Abha and Smitha).

Kavita said:

“All our relations in the family are intact”.

This is quite an achievement given the circumstances.

In Gita’s family, there was a lot of love and care:

“When her elder brother-in-law and wife were diagnosed with HIV/AIDS and TB, her mother-in-law would bring them their medicines if they did not have the time. She used to take care of their food and other requirements. Since we had all information about HIV/AIDS, we knew it would not spread through touch or talking to them; so we did not distance them from us. We felt sad they had to go through all this when their children are small. It is after all a disease. We did not keep it a secret. We knew the fact that it is incurable, so we decided to make the persons infected by it feel loved and wanted. That would make them live longer.... No sort of discrimination happened in our community”.

This family did not expect any help as:

“They were capable of helping them. As long as she was able to work, we let her. As long as she could feed her children, we let her do that also. When she was not in a condition to do anything, we took over. I took care of her children whilst her mother attended to her.”

Pooja also said that :

“Everyone behaves well with him (her husband). There is no kind of discrimination.”

Rekha said regarding her husband:

“No-one discriminates against him. Everyone behaves well”.

Kamla’s family experienced sudden transitions. She described the situation:

“I was doing all the work at home as well as working and taking care of my brother. My mother had done a lot for him. I started collecting information right away. By the time we came to know everything about HIV/AIDS he had a few days left. After all, we were all very scared as this was all very unexpected. He was fit and healthy for some time, then suddenly he got sick. We think it was a very bad bout of malaria. Leaving my sister who was also infected; she was very delicate and tender-hearted. So she used to go to my brother’s room quickly, and she couldn’t see his suffering. There is a lot more love in my family. I remember him a lot and miss him. After his death, responsibility is a lot more, and to add to it, his child is blind. We didn’t understand the gravity of the disease, so we told everyone.

Everyone was very attached to my brother. After my brother, there have been three more cases in my family. Every day I used to talk to them, do counselling, and help them so that no-one thought of it as a big and horrible disease anymore. When my sister got infected she was healthy, but she got reduced to skin and bone, and a month’s time was all she lived after that. This happened because she took a lot of tension and refused the medicine and food I gave her. Her husband expired before her. I got her children tested, and they were thankfully negative, so she died peacefully.”

Threat 5: Fear of discrimination

When people have observed discrimination, they become fearful of it happening in their family. Asha mentions :

“All of us know how the world treats HIV/AIDS patients. I think that the reason people do this is because of the causes that lead to this infection.”

Lina said:

“I think there will be some amount of discrimination against us because I have seen it happening, and don’t think my case is any different. No-one will even talk to us. We will have to vacate our room. No-one will help us”.

Ritu said:

“The people here (in the community where she has lived for 30 years) wouldn’t let us live if they came to know and Rukhsana said: “I don’t want anyone to speak ill about him. I don’t want the discrimination in my house.” And Seema who had not told even her family, said: “We did not tell because we have small children. There is a lot of discrimination done because of this disease. We don’t want that.”

Bidya said:

“We have not told anyone because we come from a very conservative community. People won’t talk to us and will discriminate.....my family will break all ties with us. My sisters-in-law will gossip and bad-mouth us.”

Kavita said:

“No-one knows. I didn’t tell anyone because I am scared that people will talk bad about us.”

The fear of discrimination extended to the family. Suruchi told her family about her husband being positive but not about herself because she is scared for her children. When a young woman is diagnosed, the family fears discrimination.

Priya commented:

“If people come to know, they won’t let her play with their children and talk bad about the family. We feel that no-one will play with her and talk to her.”

And Suruchi said:

“Only my two brothers know about it. No-one else knows. I did not want to tell them because I am scared for my children.”

Vijaya said:

“I didn’t let anyone know of my husband’s sickness because it is understood that people would bad-mouth about him. It is up to us to understand this. We have to think of our reaction to something like this and then about others. Knowing the stereotype mentality, I decided not to tell them anything. My husband was an alcoholic, and a dominating man. He used to trouble me a lot, but in spite of all this, I never let anyone know”.

Having had the previous experience of being ousted from their dwelling, Mina explains

“I have not told anyone, because I fear discrimination.”

There may be some misconception about the meaning of discrimination. Veena said she has not told anyone because:

“People here will fill my husband’s ears against me. So I don’t want to tell anyone. That’s it – no other reason.”

Shamla feels that there is a difference between sons and daughters and is fearful of her sons’ response if they know she has HIV/AIDS:

“Madam came to my home and asked me to do some tests which I refused to do because I was feeling well. I don’t know exactly what they (her sons) would feel. But they are after all boys. ... What will I say? They will in turn ask me or abuse me verbally. They will get worried and scared for me. Instead of this happening, it’s better to keep things quiet....There may be a change in their behaviour. I cannot tell. They are my sons. Some years down the line they will get married and their wives will stay with me. They will also discriminate by keeping my utensils separate, asking me to sit in a corner or just throw me out of my house. Right now I can guarantee my sons’ behaviour, later on, I cannot.”

Threat 6: Fear of courtesy stigma

Veena was caring for her widowed sister who was HIV positive. She was prepared to go to a remote village with her sister and live, however her husband supports her in the care of her sister. Veena was more worried about her husband who earns money and has a good name in the family and community:

“I don’t want people talking and raising questions on his character.”

9.3 Support Structures

Threat 7: Lack of support

Secrecy – a double edged sword

People can avoid discrimination by secrecy, but it prevents them from receiving help if they do not reveal the situation to healthcare deliverers or the community. They made a decision to not receive help rather than face discrimination. Shobha and Pooja had not told anyone outside the family and therefore:

“No-one has helped us”.

It was the same for Rukhsana :

“Only my sons know about it. No-one else knows about it. It was a joint decision to do so. We haven’t told anyone so we don’t get any help.”

Sita managed to hide the nature of her son’s illness:

“Everyone knew my son was sick, but I don’t think they knew what the disease was. I kept all his things separately, I kept everything clean. I did everything for him. My daughter was the only person apart from my husband and me who knew about it. No-one discriminated against him. I opened the shop for him. He used to sit there all day long”. .”

Nirmala said:

“I don’t talk about this to anyone and we didn’t tell anyone in the family”

Ritu managed to keep the information to the family who

“Didn’t discriminate. He lived only for three months.”

Traditionally, the community would respond in times of family crisis. There were instances where the family was left to fend for itself.

“None of my neighbours or relatives helped. I did everything myself.”

Saras’ husband was very ill and “took pills in order to commit suicide.”

Telling everyone does not necessarily mobilise community support. Jwala said her only support has been her mother-in-law. Neela has had no emotional help from either her family or the community:

“I have no-one to talk to. There is no way anyone can help me. No-one shares our troubles. Stigma and discrimination are preventing women in the community from joining together. I observed that there were other groups of women meeting regularly (i.e. because of domestic violence, or their husband’s alcoholism). These appeared to be acceptable groups in the community.

Lack of support from nurses

The majority of nurses in the hospital are women, yet they were rarely mentioned as a source of information or reassurance. That prompted me to interview a group of

nurses in the hospital. The nurses were somewhat reticent, perhaps because they lacked proficiency in English, but understood the concepts of stigma and discrimination, and were able to cite instances they had observed. Doctors have such a position of power that perhaps nurses do not rate, or they face discrimination as women, or nursing is a low status profession.

Women who feared discrimination did not reveal their relatives' sero-positive status. This meant there was no chance of help. This was the case for Bidya and Kamla, who also did not receive any aid. The second family was fortunate that they could afford to buy medicine. In some cases, there was no spare money once the breadwinner has died and these women were destitute. Fatima, Munira, Pooja and Rekha received no help at all.

When asked about supports, Aisha said:

“He (her husband) was the only support we had. I still remember him. Now my world revolves around my children.”

Kavita said:

“My family is my emotional support,”

However, she added :

“As long as our family supports us, we have no worries.”

Strength 7: Support from KJ Somaiya Hospital services

The reputation of the KJ Somaiya Hospital attracted Shuja, who had been treated badly in another hospital. Irfa said:

“We got help from Somaiya Hospital. I think an HIV patient should get all the support and love from family members; otherwise the patient loses will to live.”

As the women in this study had been identified by the SAHAS team, many of them had received some kind of support from the KJ Somaiya Hospital. Mina received medical treatment, and Ritu was counselled, whilst Keya was helped by a social worker, and Shuja appreciated the emotional support provided. Anju had been diagnosed through a survey carried out by the hospital and received counselling which helped her to understand how to live her life and get over her fears. She had

also received medical and nutritional help from the hospital, as had Keya, Shamla, Neela, Sheela, Ritu, Kavita and Sarita. Mumbai was affected by severe flooding in July 2006, and the community slums around the hospital were washed out. The SAHAS team distributed mats, clothing and food to those left destitute. When I was there in November, they were still handing out mats and bags of rice.

SAHAS counselling and support

The beneficiaries of the SAHAS programme are fortunate to have a psychologist as Co-ordinator. Counselling in India is usually taken to mean pre- and post-test counselling, but there are real benefits in psychological and supportive counselling, which helps women to come to terms with their emotions. Shuja and Suruchi acknowledged the value of that help. Anju's husband had died of HIV/AIDS. She said that

“The counsellor at the hospital made me understand how I could live my life healthily.”

In two cases, the counsellor was the only person that the woman had told, and therefore she assumed a very important role in supporting their wellbeing.

Support from the team was appreciated by Rupa. Shuja said:

“We were very scared. The counselling at Somaiya Hospital helped us.”

She had to overcome being told she was HIV positive during the delivery of her baby. Smitha did not talk to anyone else about her situation “except the counsellor.”

Support from other hospitals

Support was also experienced by one woman who was advised by a nurse in a hospital to go to the Salvation Army at Byculla, where “the people there counselled me a lot, and they also sponsored my rations for six months.” Some families seem to have taken their family members to several hospitals, like Suruchi, who took her husband to a hospital in Ghatkopar, then to Ruby Hospital in Pune.

Threat 8: Lack of awareness of the community

Lack of awareness of HIV/AIDS has been noted in Chapter 7. There was an overall lack of knowledge about HIV/AIDS, the nature of the illness, and how to prevent it. Women learned of the disease when they or a member of the family were diagnosed.

I observed posters in the hospital but not in the community, and these were written in Hindi, which the women could not always read, partly because of their lack of education and partly if they were migrants to Mumbai, and therefore spoke another language.

Strength 8: Awareness

KJ Somaiya Hospital has a programme of awareness both with all the staff and also for the surrounding community. They have organised street plays, and surveys, and I was present for World AIDS Day. The hospital used this opportunity to hold a ceremony with dignitaries, with pledge taking, and a play by children. The SAHAS staff reported an upsurge of people reporting for testing following surveys or awareness programmes.

There is no doubt that community health workers (CHWs) have a pivotal and vital role to play in education and awareness. Information is more effective when delivered from peers, because there is understanding of the local conditions, and the information is delivered in a suitable and relevant manner. The respondents hold doctors in such high esteem that any information given by them carries a lot of authority. Doctors have a different role from the one in Australian society, where increasingly, the patient is taught to take responsibility for his/her own health, and to ask questions. Perhaps the doctors need to be more aware of the power of positive and negative suggestion, and use their authority to impart correct information.

Threat 9a: Disruption of family structure

Jwala is a young widow who summed up the devastation of families:

“This is a killer disease. It ruins the entire family.”

Latabai is 67 years old, and has lost 3 sons. The household has only women left. The elderly mother cared for her daughter in law who had HIV/AIDS and 2 grandchildren. and Charu, who is caring for her orphaned niece. These changes alter the normal structures of families. Young women have to assume breadwinner roles, and may be ill themselves. Priya was caring for her seven year old sister who has contracted HIV/AIDS.

If finances became too strained, children were sent back to the village. Suruchi was widowed with two children. She kept her 11 year old son who is infected with her, and sent her daughter back to her mother in the village. Sarita's household consists of herself, her brother and her brother's brother-in-law. In Fatima's household, seven people in her family are suffering from HIV/AIDS. Irfa's father was staying at home to look after the smallest child. Irfa was disturbed about her mother's untimely death and the fact that her little sister could not remember her mother.

Strength 9a: Changing roles brings growth

Shamla was a young woman, who has had to assume the breadwinner role.

“I am the one who has to look after everything. Had my husband been alive, he would have done so. But in his absence I'm supposed to do the needful.”

Kamla had been able to transform her roles from “doing all the work at home as well as working and taking care of my brother” to learning about HIV/AIDS, and she had been able to spread awareness, and better herself by studying and supporting her family.

Strength 9b: Support from within the family

In 17 cases, families were the major source of support. Suruchi said:

“My family supported me a lot.”

In this culture of family support, certainly the immediate family would give help, as in Anju's situation, where her mother and sister helped her to take care of her sons without any discrimination.

What was not expected were the sources from which help came, as in the case of the sister-in-law, Charu, who promised to care for her niece to relieve her sister-in-law's worries, and give her a peaceful death. Sarita got :

“Emotional help from her brother.”

Suruchi was able to :

“Talk and share my troubles with my brother.”

Her brothers also supported her financially.

For Rita, her husband and her brother are very supportive. Veena cared for her widowed sister, but was afraid to tell anyone because

“People will fill my husband’s ears against me. They will tell him not to support my sister, and I have only his support.”

Jwala’s mother-in-law

“Supported her a lot. She took care of my children when I was taking care of my husband”.

For Shobha’s household, where she and her husband and their four year old child are all infected, so the in-law’s support is vital, as it is the only way they can survive.

“They help us by sending extra money, food and sometimes they visit us.”

Nirmala had defended her daughter-in-law against her own son and other daughter-in-law:

“My other daughter-in-law almost kicked her out twice, but I always intervened, because she is also mine. As long as I am alive, I will not let that injustice happen to my daughter-in-law and her family (i.e. 11 year old daughter who is HIV positive). I want to get her a place of her own so that her family can live peacefully in whatever they have.”

Seema and her husband are infected with HIV. She said her husband is her only support:

“My husband is a very nice man. It’s been 13 years to our marriage and we have not fought or had any disagreements worth a mention. He takes good care of me. He is very even-tempered, and never yells or scolds.”

For Bidya, her brother acts as interpreter, and takes her to the doctor :

“Because he understands Hindi well and then he explains everything to me later on.”

Arwa had the help of her sister-in-law :

“One year back, my husband had fallen sick so I admitted him to Kalya Hospital with the help of my sister-in-law.”

She encouraged Arwa to get herself tested, so she “went to a private hospital in Kalya to get herself and the children tested.”

Threat 10: Absence of family in the future

Sometimes, children provided the only focus for the future. Mothers worried what would become of their children, once they had died, like their husbands. When

couples had come from rural areas, there were no immediate supports to take on the load. There is estimated to be 100,000 street children in Mumbai exposed to all manners of abuse (Manohar, 2006). Survivors in these families are not well represented in research. It is as if the people are of interest when they are alive, but what happens to families afterwards. What will happen to the four year old in Shobha's family, if her parents die early?

Although Mina felt :

“My children are solely my responsibility now. My son takes a lot of care of me.”

It was her children who supported her emotionally.

The death of a mother in Irfa's family had altered the whole family. The father had to stay at home to look after the youngest child, and Irfa, who was 18, said that had her mother lived, her two brothers would be at school, and not in the workforce, and she would not have lost a year in college. She also said:

“If her mother were alive, her father would be happy and not so tired”.

Nirmala, a 50 years old woman says about her widowed daughter-in-law.

“I always think that she should live and see her children excel in life. Who will look after them if she dies? She is their only support.”

Sita's son died after being ill with HIV for five years, and she spoke of him with longing:

“My son was a very nice person. He was very talented. Of all my children, he was the one who was ready to take our responsibility. I wanted my son to live longer”.

Threat 11: Strain on family

In addition to the reduced finances in a household, it is obvious that women are expected to shoulder extra emotional burdens. These arose from taking on extra members of a family, and worries about the future. Sita said:

“Now we are all tensed about all the work around us. First, he did all the work and now all has fallen on our shoulders. We have to run our shop all alone. I hope someone helps old people like us.”

In some households, children were orphaned. Gita has been left with her sister's two children, one of whom is mentally retarded. She related:

“He is 22 years old and doesn't understand anything. He only knows to eat, sleep and drink. I took the younger son under my wing thinking he would go to school and settle down in life. But he also has disappointed me a lot. He lies a lot and doesn't go to school. I cannot trust him anymore. He doesn't do anything. I asked him to work if he doesn't want to study. He is 17 years old. He stays up all night and sleeps during the day. He loiters around in the evening. If I let him do like this, it is going to affect me in the future. He doesn't back-answer me when I scold but he does what he wants...He doesn't say much but does what he wants. As he is a bad influence on small children, I cannot send him to a hostel. I only hope he gets better for his future.”

Suruchi's husband

“Started feeling sick very often, so did I and my son. There was no money in the house. He had to resign from work for the only reason he was weak and the mill needed a stronger person.”

Kamla said that after her brother's death:

“Responsibility is a lot more and to add to it, his child is blind.”

Strength 11: Duty of care

Responsibility and social attitudes were strong forces which resulted in women developing skills of caring for terminally ill husbands and other members of the family. This was a singular strength in these women. Jwala, a 26 year old widow, overcame feelings of anger and disappointment and betrayal, to nurse her husband.

“Had I not taken care of him, people would have laughed at me.”

In the case of Sarita, where her husband had not had marital relations with her for the duration of their 10 year marriage, having contracted HIV from another woman, she said:

“I would have supported my husband even if he would have told me about his infection early.”

Gita's sister-in-law took care of her husband, until the very end. Gita said:

“My sister-in-law wanted to go to the place in Panvel which the social workers here had told her about. But we refused to send her there. She is a mother and she should see her children before she breathes last. She is one of us and we want her to be with us till the very end. Her mother and children went to see her. The children are negative, and even if they were positive, it would have been our duty to look after them. I don't think they are a burden.”

Pushpa had to persuade her husband to let her care for her mother in the last stages. Thus, I had a glimpse into some of the difficulties of caste, and the consequences of stepping outside the expected norms,

9.4 Summary of the chapter

The dimensions of stigma and discrimination were examined in this chapter. The participants described graphically their experiences in their families, community and healthcare. The factors which threatened the participants' ability to cope were these experiences, or the fear of discrimination. Stigma and discrimination led to disruption of their families, resulting in extra strains and burdens. The counteracting positive experiences were provided in the main by the KJ Somaiya Hospital which had trained staff in non-discriminatory services. These services were valued by the women. There was a diversity of views expressed in most of the dimensions. The information expressed confirms existing research into Indian stigma and discrimination (Aggleton, 2000; Arunkumar et al., 2002; Bharat, Aggleton and Tyrer, 2004; Parker and Aggleton, 2003).

CHAPTER 10

HUMAN CAPACITY

“Everyone seems to care, and is very sorry about what has happened, but no-one comes within touching distance, and no-one is willing to touch me or be touched. Your whole world disintegrates within one day (of disclosing).”
(Arjuna Hewapathkrane (Sri Lanka), cited in Health & Development Networks, 2007, p.31).

10.0 Introduction to the chapter

This chapter continues the analysis of the data from the interviews of the women, regarding their response to HIV/AIDS. I wanted the study to reflect the voices of the women – not one voice, and not my voice, but their voices (Warren, 1996). In addition, some women asked for my assistance, which I was not able to give at the time of interviewing. Recording, and giving voice to their story, is my way of helping. This section describes the feelings and experiences of the women in their own words, and therefore is the most important part of the study. Through their histories, and descriptions of these difficult and distressing situations, we are able to grasp some of the enormity of the problems presented to them as young women, isolated from their community, with very little supports in place.

10.1 Human Capacity

Human Capacity is defined in the Psychosocial Framework as health, both mental and physical, knowledge and skills of the individual (The Psychosocial Working Group, 2003). Strategies which improve or enhance these dimensions act favourably on a person’s ability to cope in difficult circumstances.

Box 7: Human Capacity

Threats	Strengths
1.a. Lack of knowledge and information 2.a. Secrecy b. Social isolation 3. Caregiving – a burden 4. Emotional reactions 5. Unresolved grief, loneliness 6. Worries about children	1.a. Information b. Awareness of HIV/AIDS c. Confidentiality d. Knowledge of HIV/AIDS e. Knowledge of transmission 2. Sharing our stories 3.a. Caregiving as a source of pride b. Special cases of caring 4.a. Passivity/acceptance b. Adjustment, tolerance, resilience 5. Active coping 6. Positive future focus

10.2 Knowledge and information

Threat 1: Lack of knowledge and information

There were only two women in the group who had some knowledge of HIV/AIDS before diagnosis. Even though the women had been to school, they were not literate in the sense that they could understand and absorb information from the written word. This has been described in Chapter 7. Therefore, the community health workers and the psychologist in the home-based programme at Somaiya Hospital have become vital links and sources of information, regarding testing, treatment and home care for these affected and infected women.

Education and ensuing gainful employment can provide the opportunity to move out of slum communities. It strengthens human capacity, if it provides women with the confidence to make decisions regarding their health. Education is also the most significant factor in women's health (Ojanuga and Gilbert, 2002). There is no doubt that education and awareness regarding HIV/AIDS would improve the situation for women. In this group of functionally illiterate women, the method of dissemination of information needs to be more sensitive to be effective. Shamla would not have

been diagnosed unless the community health workers had encouraged her to be tested. She said:

“The ladies from the HIV Cell (SAHAS) came to my place and asked me what was wrong. They asked me if I had any children. They told me to come here and get myself checked.”

Tara was another woman visited by the SAHAS team, who provided a link between the women and the hospital. She said:

“The ladies from the HIV Cell come to my house and check on my health. They keep encouraging me to come here and start medicines. They also tell me not to take any tension.”

Suruchi did not know anything about HIV/AIDS before:

“My husband’s reports came. My husband was admitted here (Somaiya Hospital) when the reports came positive. The doctors asked me to do the test. Even my test came out positive. We then got our children checked of whom only my youngest son (11 years) is infected.”

Tara said:

“The women from the hospital come over to my house to check on my health and to invite me for the programmes in the hospital.”

The interviews conducted in this research were another opportunity for the community health workers (CHWs) to talk about programmes at the hospital, and elsewhere. I observed at one interview that the CHWs invited the daughters of one woman to join the newly set up sewing group at the KJ Somaiya hospital. The women interviewed regarded the doctors as divine beings, who could do no wrong, even when one of them told a woman to wash her children in Dettol (Bidya). Arwa’s husband had HIV/AIDS, and then transmitted it to her. She lost 28 kgs in weight, and was obviously depressed and suffered discrimination. The doctors told her to “live life happily!” Seema, who was infected with HIV/AIDS by her husband, said: “The doctor made us understand that this was not the end of the world.”

Bidya, Kavita and Suruchi were all advised by the doctors to observe safe sex practices after their husbands were already diagnosed as positive and doctors advised women to be tested after their husbands tested positive (Suruchi, Kavita). Pushpa

was a young woman who ignored the doctors, who told her to stay away from her infected mother. She nursed her mother in the last stages, and did all she could to ease her passing. Kalavati brought her daughter home as her in-laws were not caring for her. In another case, good advice was given by the doctors, but fear overcame the mother of a young woman, and as a result she was unable to provide care for her daughter. In other cases, it was the doctors who provided good advice about the right food to increase strength and immune responses (Usha, Suruchi, Shamla), medicine (Neela), care (Shobha, Priya), and cleanliness (Bidya):

“They (i.e. doctors) used to call us and explain to us the time he was supposed to have a particular medicine. The doctors also gave me a list of food items he could eat in order to keep his strength.”

As discussed in Chapter 7, the right to education for girls is a law, by virtue of Article 16 in the Indian Constitution. However, in these slums, it did not count for much. The women had been to school, but had been withdrawn at times of family crisis. Irfa had lost a year of college when her mother became ill and died. Some women had come from other parts of India, and were not able to speak Hindi; and so had not learned to read and write. Bidya was illiterate, and did not understand the seriousness of her situation, even though the doctors told her “it is a dangerous disease.” Consequently, she conceived a second child.

Where AIDS is concerned, education and information can help to prevent transmission. Reema said:

“I had always had safe sex, so I did not get infected, but now I will avoid even that (i.e. sex)”.

Sometimes the information was not right, or had been misinterpreted. Reema said:

“I even keep my children away from him.”

Arwa said the doctors told her

“It’s a small illness which has been hyped about a lot.”

Pushpa was one of the few women who knew about the disease beforehand:

“I knew it spreads from unprotected sex, unsterilised needles, etc.”

In her case, it was her mother who was infected. In some cases, information was not enough, or it may have come too late. For example, Seema knew about HIV/AIDS from TV and newspapers but it did not prevent her from being infected by her husband. Veena related the story of her sister:

“All I knew was there is a disease and that there is no cure for it, but I didn’t think in my wildest dreams that my sister would get infected.”

Lina was only 26 years old, married and childless. She was reeling with shock, knowing she would be widowed, and that she and her husband had HIV/AIDS. She expressed surprise:

“I had heard about cases of HIV/AIDS happening around me, but I had not expected it to happen in my house.”

Even when the risks were emphasised, I had the impression that mothers and wives would still care for their husbands, sons and brothers. Usha said she knew HIV/AIDS was a “dangerous” disease, but cared for her son, as she was the only one who was free to do so. Sometimes it was important to ignore advice. Vijaya was warned by her mother-in-law not to go too close to her husband, but said:

“I didn’t listen, and did all I could to make him comfortable....I stayed with him and supported him till the very end”.

In Rukhsana’s situation, there was a sense of powerless for this woman, caring for her HIV positive husband. She said that she had heard about HIV/AIDS only two months ago, via her son who told her that her husband was infected:

“I don’t know much and I don’t want to talk much about it. I don’t know my status”.

Strength 1a: Information about HIV/AIDS

Bidya said:

“At first I did not know anything about HIV/AIDS. I did not know much about it when I first came to Mumbai as I could not speak Hindi. This was roughly the same time I was pregnant with my elder daughter. I came to know about this during my second pregnancy.”

Sarita’s situation was unusual, as her husband had had no sexual relationship with her for 10 years. She only became aware of HIV/AIDS when her husband was

diagnosed. She only made sense of her marriage, when her husband became HIV positive. Her story was very sad.

“I am not positive. I fought with all the doctors saying my husband was HIV positive. I could not come to terms with the fact I would lose him. My husband never had any physical relationship with me. In our marriage of ten years, we didn’t have sex even once. My husband had an affair with a lady in the neighbourhood who was HIV positive. That is how he got infected. My husband used to make me understand that we will adopt one of my brother’s children and look after them. Now I know why he never touched me and avoided relations of all types.”

Overall, the women only acquired information at the time of diagnosis of their husband, or a family member, as in Irfa’s case where she learned about HIV/AIDS from her father; and Usha, who

“Hadn’t heard of HIV/AIDS infection before my son was infected by it. I don’t know much about it. I only know it is a dangerous disease”

Tara only learned of HIV/AIDS when her husband was diagnosed. She continued:

“The doctor asked if my husband had any bad habits. I said he was an alcoholic. Then the doctor asked me (about bad habits). I said I didn’t use anything like cigarettes or charas (opium) then my husband told me he was infected with HIV/AIDS and said there were chances of me being infected. He also told me to start medication.”

However, it was too late, as she was already infected.

Strength 1b: Awareness of HIV/AIDS

I asked how the women came to know that either they or a family member were positive. In some cases, it was the doctor who told them (Priya, Sarita, Kalavati, Veena). In the case of Rita, it was the counsellor in the SAHAS team who

“Gave her basic information and revealed her status”.

Sheela was a 25 year old widow, and she said:

“The counsellor told me that I was infected and so that my baby wouldn’t get it I had to be on medications.”

For Abha, it was the sister-in-charge who informed her. Sometimes, it was medical reports which alerted the women, like Aisha, whose entire family is infected by HIV/AIDS. Leela learned about HIV/AIDS only when her daughter was ill, and then diagnosed at the hospital. Similarly, Nirmala learned the diagnosis of her daughter-in-law when she took her to various hospitals. Reema had been persuaded by her sister-in-law to have her blood checked. Although she was scared, she got herself checked, and found she was negative; but her husband learned he was HIV positive after many tests.

For some women like Sita, the information given was confusing. The doctors at one hospital informed her that her son did not have HIV/AIDS, and at Somaiya Hospital, the doctors said he was HIV positive. Sita said:

“The doctors at Sion (Hospital) told me my son didn’t have AIDS, and the doctors at Somaiya (Hospital) said he was HIV positive. I don’t know who to believe.”

In Nirmala’s case, the family took their daughter-in-law to J J Hospital, Sion Hospital and many others.

“The doctors at Somaiya told us about it.”

After her husband was tested, the children were tested as well.

These stories indicate that people from community slums are not receiving proper medical attention; and that women learn of their HIV positive status only after other members of the family are diagnosed. Tara acted on the information that her husband was HIV positive, and separated from him on the day she learned of his diagnosis, but it was too late, as she had already contracted the disease. Nine women learned they were HIV positive when they were pregnant. This brought up the unbearable decision of either termination, or else living with the prospect of the baby being born with HIV/AIDS. This naturally upset the women greatly. When Smitha was informed that she was HIV positive during pregnancy, she said:

“I almost died when I heard I would have to abort my baby. I still can’t get over it.”

Equally difficult was learning about HIV/AIDS at delivery like Shuja; or in the advanced stages of pregnancy like Shobha, who said:

“So unfortunately we could not take precautionary measures to save my baby from being positive.”

Kamla believed that information about the disease

“Can help you stay sane through it....This disease can happen to anyone. We should not get scared and must try to collect as much information as possible. The more the awareness about this disease, the happier I will be.”

Usha spoke of her son being diagnosed.

“Only the family knew about it. I did not doubt my son at all. Even his wife is infected.”

It was often unrelated symptoms which forced women to present at the hospital. There was a lack of knowledge of the symptoms, although this is understandable when there are concomitant conditions such as respiratory infections, TB, and a number of diseases given the living conditions. Shamla said she

“Didn’t know anything about HIV/AIDS, but my skin used to itch a lot, and I used to scratch it. I used not to eat food. I used to only lie down as my limbs used to ache. After coming here (Somaiya Hospital), the doctors examined me and tested my blood.”

Strength 1c: Confidentiality

Confidentiality has a different meaning in India. Overcrowding, both at home and work, and the lack of human rights for women in particular, contribute to a lack of confidentiality. Due to the crowded living conditions, it is almost impossible to have a private conversation within the home. This situation was repeated in the office at the hospital. Often the room was crowded with up to 12 people as the Co-ordinator talked to clients and organised staff. Confidentiality in India has a more fluid meaning, and clients did not seem to be concerned if their conversations were overheard by members of the team. It may also mean that the clients lacked assertiveness to insist on privacy. Usha, Bidya, Sheela, Rita, Arwa, Suruchi and Lina said that they were told about their diagnosis “in total confidentiality.”

Women did not say whether they wanted family members with them or not. Rupa was told by the doctors with her mother-in-law present. This may not be a good idea, in a Western context, given the reported instances of discrimination from in-laws. Mina said that the doctor

“Told my son and he explained it to me”.

Pushpa was told by her brother who had been informed by the doctor. Gita related how

“We got my elder brother-in-law checked. They told us he was positive, or at least his mother came back and told us.”

The whole family then took responsibility for the care of this man.

Strength 1d: Knowledge about HIV/AIDS

There was a range of knowledge expressed. Some women knew nothing at all, some understood how HIV/AIDS was transmitted, and others had accurate knowledge. Rita said:

“I don’t know much about HIV/AIDS. As far as I know, it is caused because of wrong doings. Characterless people having more than one partner get it.”

Sarita was 38 years old, and lived with her brother, and her brother’s brother-in-law. She has no children, and faces life as a widow. She mentioned that men approached her with bad intentions. She said:

“I think this happens to people who have affairs and sleep around a lot.”

Neela said:

“It is a very bad disease. It has taken my husband’s life. Even my condition is deteriorating. My daughter’s life is spoilt and she is not at fault for it.”

Vijaya was only 24 years old, and had learned about HIV/AIDS, and tried to educate her community. When her husband died, she said:

“No-one came to pay their last respects. I try and make those people in my village understand but they are illiterate and backward, so they cannot understand. I tried explaining to everyone but to no avail. They said that after death all germs fall out of the person’s mouth. I said that even if that happened, the germs wouldn’t survive in the open air.”

Strength 1e: Knowledge of transmission

I wanted to ask the question whether the women knew how they had contracted the disease, but it was considered too sensitive by the Co-ordinator of SAHAS, on whom I was dependent for the interviews. However, some women did reveal this of their own accord. Arwa's sister-in-law told her about her husband, and told her she should get herself and her children checked. Rupa says her husband told her:

“He was infected, and I should get myself tested. He was a lab technician in a hospital. That's how he got infected. I took care of him. Now he is no more.”
Mina said: “My husband used to donate a lot of blood, so I think he must have got infected in that way.”

Charu cared for her sister-in-law and asked her how she came to be infected.

“She told me she was not characterless. She told me that she used to take care of a lady who was very sick. Her family members would not even touch her. I think that lady must have had AIDS. My sister-in-law took care of that lady for two years. Now that lady is no more.”

For two women, there was doubt, and resulting confusion. In the case of Rita, she has been diagnosed HIV positive, and not her husband (who has been drinking “ever since he came to know of my infection”). She claimed she had no idea how she had been infected. It was a mystery to Shamla how she became infected, reflecting her lack of knowledge regarding HIV.

“When they told me I was infected with HIV/AIDS I told them I shouldn't get this disease. I had a husband and when he was alive, I wasn't infected. Then how is it I got infected now? I am not a characterless woman. I have children.... The doctors made me understand that anyone can get this disease. I needn't get afraid.”

Sheela said:

“I know I got infected from him (her husband). I used to feed him, bathe him – everything I used to do. I didn't know my husband was infected”.

Fatima knew that her husband infected her with HIV/AIDS after he had worked overseas. In another case, Neela said:

“My husband got infected by it and I through him.”

Tara's husband told her himself, however she was already infected.

“The day he told me we separated. We stayed in the same house and ate together but slept separately.”

10.3 The effect of secrecy and social isolation

Threat 2a: Secrecy

Fear of stigma and discrimination resulted in secrets. Sometimes, the women did not even tell other members of the family, as in Seema’s case. Latabai was one mother who did not know her son was infected with HIV/AIDS, until he was on his deathbed. In the case of Jwala, the family knew her husband was infected, but did not tell her, because:

“They thought I would leave my children and go, so I went to the doctor personally and asked him exactly what was wrong with my husband.”

Rupa said:

“At first only my eldest daughter knew about my infection. No-one in our neighbourhood knows my infection.”

She was worried about her daughter who

“Got married. She is very innocent, and told her husband about my illness, but he is a very nice man. He comes to see me and cares for me.”

Pushpa’s mother

“Never spoke about her illness. She used to talk, but not about HIV/AIDS. She may have spoken about it to her husband. She was very shocked and sad from the time she heard about it. She used to pray to God to take her”.

“No-one knows I am infected with HIV/AIDS. Madam (the Co-ordinator) told me not to tell anyone I am infected. They told me not to tell my children about it. I didn’t tell my children because I thought they would be scared. You can tell all your troubles to your daughter as she can understand, how do you tell this to your son?”

Many women were afraid to talk outside their family because of fear of stigma and discrimination. Kavita said:

“I didn’t tell anyone because I am scared people will talk bad about us”.

“The people here wouldn’t let us live if they came to know”

Keya commented:

“I haven’t told anyone because I think people will think wrong of me. No-one will help me. I don’t talk about my illness to anyone”.

Mina added:

“I have not told anyone because I fear discrimination.”

Lina also feared discrimination because

“I have seen it happening and don’t think my case is any different.”

She said:

“Only my brothers have come to know about his (her husband’s) reports. My in-laws also know.”

The women were concerned about their children. Priya expressed her fears thus:

“If people come to know, they won’t let her play with their children, and talk bad about the family. We feel that no-one will play with her and talk with her.”

Shobha said:

“We have not told anyone outside our family because then people will not respect us and will discriminate. My daughter goes to school. We want her to study and be independent.”

There was sometimes pride, which affected privacy issues, according to Rupa and Reema. Usha said:

“I did not feel like telling anyone” – it had nothing to do with discrimination”

Suruchi said:

“Even if people know (about her husband) they will not ask me, and I, on my part, will not tell them because it is none of their business.”

Secrecy blocks help and services. As Rukshana said:

“We haven’t told anyone so we don’t get help.”

Her family battled on. Or there may be a fear that no-one will help, as in Keya’s case. Experiences within the family led to lack of trust to tell others; Vijaya said:

“My mother-in-law used to say that her son was a good man and I was the one who was bad and characterless.....No-one believed me or what I said.”

Threat 2b: Social isolation

Secrecy also resulted in social isolation. When women lack confidantes, and are unable to share their thoughts and feelings, they suffer greatly. Women need to talk. There is something about the lack of a voice, which is troubling. In *The Secret River*, Australian author Kate Grenville understands this lack of female company, and describes this situation for women who had come from busy cities in England to the wilds of the Hawkesbury River in New South Wales.

“Thornhill saw for the first time how much she missed having people around her. It was a little death, not being able to make a tale out of the small moments of life, and share them with someone for whom they were new.....She had never spoken of her loneliness. And he had not thought to ask” (Grenville, 2005).

Grenville has captured this important facet of women’s lives. It is vital for women to be able to share the minutiae of everyday life with other women. This sharing becomes even more important in times of stress when women usually seek out female company (Taylor, 2000). In this study, women are blocked from such sharing by the stigma and discrimination which accompanies HIV/AIDS. Saras, a young widow with children, said

“I don’t tell anyone about my problems”

Keya is depressed, has not told anyone because of fear, and

“Plans to end her life when she is too ill.”

Vijaya received such blame from her mother-in-law, and the family who did not believe that her husband had contracted HIV/AIDS, that it is unlikely that she would reveal the circumstances to the wider community.

Tara, another young widow reveals:

“No-one in our neighbourhood knew he was infected. I am all alone now.”

Her husband left her for another woman for some years then returned and infected her.

“No-one knows I am infected.”

Neela said:

“No-one will help me. They will only taunt me.”

Strength 2: Sharing our stories

I know from my counselling work with women and my own life experience that for a woman, contact with and support from other women is essential to female psychosocial wellbeing. This is a heightened need in times of stress. Kamla said:

“I have not kept anything back. I get my strength from this.”

Sometimes, women were able to talk to male relatives. Suruchi said:

“I share my troubles with my brothers,” but in other cases, women did not feel comfortable talking to their sons.

Shamla said:

“You can tell all your troubles to your daughter as she can understand, but how do you tell this to your son?”

and later:

“If I had a daughter, the story would have been different. I could have answered (questions) comfortably if my daughter asked me. You can talk openly to your daughter or a woman, but not to your son. Some years down the line, they will get married and their wives will stay with me. They will also discriminate by keeping my utensils separate, asking me to sit in a corner, or just throw me out of the house. Right now I can guarantee my sons’ behaviour; later on, I cannot.”

Munira said she talked to everyone about her husband’s infection, and feels she is brave, and is supported by her mother-in-law. Jwala is only 26, and widowed. She said:

“I feel very bad because I am still very young and I need support and help, but I have no-one to turn to help for me.” Rupa said her daughters “are my best emotional support’.

Tara said:

“I have not spoken to anyone but the counsellor about my infection. I talk to the counsellor about my life and HIV/AIDS in particular. They treat me well.”

Threat 3: Caregiving: a burden?

The caregiving was usually undertaken by the women of the household. This has been noted in other studies such as D’Cruz (2004). Care was sometimes taken on unexpectedly by in-laws. The response in this study was more mixed than was expected. Mothers, mothers-in-law, sisters-in-law and sisters helped each other with caregiving. As the numbers in a family dwindle with households experiencing multiple deaths, caregiving can be repeated over and over, with more members of the family dying, resulting in retraumatisation. With each experience, however, women gain more experience in caregiving, resulting in better qualified carers.

In Rukhsana’s situation, she described the pull of duty, versus the caring for a difficult spouse:

“I look after my husband. I feel bad looking at my husband. He has always been the backbone of my family. It pains me to see him like this. He is very stubborn. He doesn’t listen to anyone and yells all the time.”

Strength 3a: Caregiving: As a source of pride

For some women, the caring was transformed from a duty into a source of pride. Young women took on this role long before they would normally have expected to, and older women were called on to replace other members of the family who had died. Saras was a young widow who said:

“I am brave and was able to do everything” (for her husband).

An older widow, Sita said:

“Everyone knows I kept my son alive for six years.”

Looking after her son became a focus for her – “I looked after him to the very end.”

Vijaya who had emotional problems before the disease struck her household, said with pride:

“I didn’t fall apart even once.”

Even though Jwala is only 26 years old, she managed to take care of her husband and do everything for him. Usha looked after her son because she was the only person who was free.

“Everyone says that in the last stage patients suffer a lot, but my son went away peacefully. He had stopped eating. I used to coax him to eat but no response from him.”

The whole experience of caring for members of her family has been the impetus for Kamla to study about HIV/AIDS, and to obtain a good job at the hospital, as a social worker, where she continues to spread awareness in her community.

Kalavati said :

“I wanted her (daughter) to die in peace. She died in very bad conditions, but I did all I could for her.”

The level of caring was substantial. Vijaya is a 24 year old widow who said:

“I did everything to care for him, right from giving him a bath to giving him his medicines. I did all I could. I even brought him here.....I kept him home ...I did all I could to make him comfortable. I knew he was HIV positive for almost 3-4 years. Even then I stayed with him and supported him till the very end.”

Strength 3b: Special cases of caring

It is difficult enough for a woman to assume the role of caregiver under any circumstances, but I had extra admiration for women who had emotional problems beforehand, and then overcame them and adopted a positive outlook. One such woman is Arwa, who by her own admission “*lost her mental balance*”, but overcame it to keep a positive outlook for her children’s sake.

Aisha said the first thing that came into her mind was that her husband was sick, and could die at any time. So:

“I have been mentally unstable from the age of 16. I have suffered a lot in life” and yet she was able to care for her husband. I wanted to spend as much time as possible with him and make him feel loved and wanted.

Vijaya was another young woman who had managed to overcome her own fears, in order to look after her husband.

Priya was a young woman, who took on the care of her sister, aged 7 years. They had not told the young girl of her diagnosis, because of her age, and because she was so weak. She did not even have the strength to take medicines. The family were all “shocked and scared”. Despite that, they were willing to care for the child. They did not know how this child was infected.

10.4 Emotional aspects

Threat 4: Emotional reactions

AIDS is a serious, life-threatening disease, worse even than cancer because it is contagious, and has sexual links. Reactions, such as shock and fear, denial, anger, depression and feelings of being out of control, follow diagnosis either of oneself, or a family member. These emotions were noted by Kubler-Ross in her seminal work on grief (Kubler-Ross, 1969). Chandra et al. (1998) found that anxiety and depression levels were higher in India, than in Western countries. They attributed this to the high levels of stigma, lack of understanding about the infection, and people regarding themselves as desperately ill, in the early stages. With regard to the initial shock reactions, these women were normal, and were able to express these feelings openly. Very few did not express any feelings at all.

The first stage of shock and fear which Tara, Mina and Lina expressed, were common. Understanding the serious nature of the condition followed.

“There were many thoughts in my mind when I first got the news. I was very scared because of the lack of cure”

said Suruchi. A newly diagnosed woman of just 20 years, she said:

“I am in a state of shock. I haven’t eaten at all. I keep thinking my life is over” and Lina, who said:

“Whenever I think about it I feel I am only 26 and will have to live alone the rest of my life and youth (sic) because he is my only support.”

Aisha read about her husband’s positive status:

“I read the reports and understood. I was so shocked that I returned without waiting for the doctor to tell me anything.”

Fear was notable in the participants' reactions – firstly, fear of infection for themselves. Kavita, Keya, Saras, Rita and Priya also expressed the fear they felt. Veena's reaction was to get her husband and herself tested, after her sister was diagnosed HIV positive.

“I was scared because it's been more than a year that we have stayed together.”

And Anju, who said:

“I was very scared and wanted to die. My husband died of HIV/AIDS.”

Secondly, Priya also had concerns for the rest of the family:

“We are all very scared because I also have children. My husband is worried about them because HIV/AIDS spreads through blood and if my sister (aged 7 years) falls or hurts herself, we have to keep her away from my children so they don't come into contact with her blood.”

Seema said:

“We were so tense before we got our children's reports that we couldn't do anything properly. My husband told me about his infection almost a month later. He was so shocked that he wouldn't tell me anything. I had to literally force him to tell me the truth. He was only thinking of our future and about our children.”

Fear of the future without the breadwinner becomes reality, as widows have to take out loans, or rely on family members for support. Sarita said:

“It is difficult to stay alone. People look at me with bad intentions. I also miss my husband.”

She came from Bengal, but said she was

“Going to stay in Mumbai. My husband died here so I will also die here. I don't want to be a burden on anyone.”

She sounded resigned and old, before her time.

I asked the women if the fear had remained after the initial shock of diagnosis. Pooja said she “gets scared every time my husband falls sick.” For some women, the initial shock was devastating. Tara graphically described her feelings. When she was diagnosed, she

“Was shattered. Something was gnawing in my mind.”

Arwa said she was so

“tense” when she heard the news. I couldn’t think straight for two months. I lost my mental balance and came down from 50 kgs to 22 kgs. Now I feel it’s just another disease. It’s not as terrible as we make it sound.”

Aisha suffered severe reactions:

“What happened was that when I came to know that my husband was infected, I could not handle the news. I fell into severe depression. I had to undergo shock treatment twice.”

For many women the initial shock was ameliorated by time, as they adjusted into caring for themselves or a family member. Many spoke of the extra burdens of work, without money coming in. Aisha says she wanted her husband to feel loved and wanted, despite the fact that she suffers from “*chronic tension*.” This was probably what we would term severe depression, as she had electro-convulsive therapy twice.

“I felt bad for awhile, but now I guess I have moved on. I live for my children now. There is no point in crying as it is not going to help in any way.”

Tara said that:

“After medication and treatment, I now feel I am infected by just another disease. I feel better and healthy. My opinion about myself has not undergone any change whatsoever after I came to know that I was infected with HIV/AIDS.”

Bidya regretted having chosen to have her baby, despite the diagnosis of HIV/AIDS during her pregnancy, and a widow spoke of the loss of her three sons – “they were good people.” Sadness was expressed by Pushpa, who said:

“I didn’t like what I heard about HIV/AIDS because I hadn’t heard it before. I felt sad.”

Seema also “felt very sad and tensed when the doctor told me about this.”

Veena said

“My sister is very sad and shocked with this news. She still cannot come to terms with it (only a few days since diagnosis) but I know she will cope with this very soon.”

Powerlessness was expressed by Saras:

“I didn’t leave any stone unturned, but my efforts didn’t yield fruits. He left us.”

Personally, I was surprised at the lack of anger expressed, given that these women had been infected by their husbands. This may be cultural, as the relationship between wives and husbands requires the woman to regard her husband as her god. Tara has been left widowed, and had HIV herself. She said:

“I feel very sad when I think of my husband. He got infected by the other woman he left me for.”

Gita related the story of her brother and sister-in-law:

“My brother-in-law got infected as a result of unprotected sex. He shouldn’t have done so as it infected his wife also. This has left his children orphaned. She used to get angry about her husband because she thought that if he hadn’t kept a physical relationship with her, she would be here to take care of his children. She blamed him.”

Strength 4a: Passivity or acceptance?

What might be seen as a passive way of dealing with these difficult situations may be a strength, in that acceptance leads to a more positive way of coping. The 57 year old mother, Nirmala had a lot of hope that her son would survive, but he died.

“You cannot predict the future. I am talking with you now but God knows what might happen to me in the next few days. You have to face whatever is there in your fate.”

There is a finality and acceptance in that statement. Religion helped in some cases:

“Beyond the medicines, we have left the rest to God”.

Sometimes the tragedy of the diagnosis was transformed by the women’s love for a husband, child, or other family member. There was acceptance, and lack of self pity in most respondents. Leela said that the family were coping, despite the fact that they were all infected.

Sheela said:

“To be honest, I didn’t feel anything. I accepted the fact I had HIV/AIDS.”

Fatima normalised her experience thus:

“Everyone in the world has some problem. No-one is problem-free.”

Jwala said:

“I felt bad for a while, but now I guess I have moved on. I live for my children now. There is no point in crying as it is not going to help in any way.”

Strength 4b: Adjustment, tolerance and resilience

In India, there is the concept of adjustment, tolerance or resilience. It is very obvious in all facets of everyday life – travel, working long hours, enduring poverty.

One woman, Rekha said:

“Everyone from my mother’s side is dead, so I tell my children and husband to adjust a little and help me take care of him.”

Shamla said that:

“After medication and treatment, I now feel I am infected by just another disease. I feel better and healthy. My opinion about myself has not undergone any change whatsoever after I came to know that I was infected with HIV/AIDS”

Tara said:

“Now I feel a little better. I feel hungry and eat healthy food. There has been no change in my opinion about myself.”

A young woman, Priya, who was confronted with caring for her seven year old sister diagnosed with HIV/AIDS, said:

“You have to do it, irrespective of being scared.”

There is a selflessness and altruism about such behaviour.

Threat 5: Unresolved grief and loneliness, denial

One woman spoke of the awful decision she had to make when she learned she was HIV-positive during her pregnancy. This woman was 30 years old, and her husband had died, so she had little chance of having another child. She had told no-one. She said she wanted to die when she first heard, and that she almost died, when she heard she would have to abort the baby, and she still cannot get over it. I wondered what

would have happened if she had been given more options, and therefore more choices. Smitha's loneliness is expressed in the last sentence:

"I have nothing and no-one to live for."

Latabai had lost three sons, and felt all alone sometimes, despite living with her daughter-in-law and granddaughters, and much more depressed at the thought of her son who had died. Jwala found the absence of her husband "terribly unsettling". Sheela was another young widow, whose husband died in the village when she came to Mumbai for her delivery. "He was sick for a long time. I took care of him" Regret is expressed by Bidya, who did not realise the seriousness of HIV/AIDS, and conceived another child.

Usha had lost her son and her daughter-in-law, and her children have gone to the village.

"I feel there is nothing to live for in this life after the death of a son. It is good if God takes me also."

She had a good relationship with her daughter-in-law

"She is a lovely lady, and comes for vacations. She calls up regularly. The grandchildren are 9 and 7 years old."

Abha said she was scared, and refused to accept the diagnosis. She told everyone she had TB. Seema said:

"We want to think about the future but something stops us from doing so. Whenever we want to try and think or plan ahead we get scared."

Strength 6: Active coping

Despite the problems and the initial shock and stress reactions, most women were able to overcome these feelings to provide a high degree of care and support. For example, Charu, who took over the care of her sister-in-law, who had suffered discrimination from her parents. Charu called her sister-in-law's parents, but they refused to care for her so Charu took her in. She became so ill that Charu would get scared, but she knew that the dying mother was worried about her daughter being left, so Charu promised that she would care for her daughter and then the woman

"Was free of cares, and died peacefully after I sent her daughter to stay with her."

The transition in Kamla can be traced. She started off feeling all of it was

“horrible and now as time has passed I don’t feel anything about the infection. I collected a lot of information, I spoke to counsellors. I read books on this subject.”

She has been able to translate her experience of coping for four members of her family into her work as a SAHAS outreach worker, and to educate her community.

Aisha said:

“I was very sad and tensed when the doctor told me about this. Slowly, we became normal again. We don’t want our children to bear the brunt of this. Life has changed a lot.”

For a young widow, Suruchi, her children were the focal point.

“It is not easy to cope. I know I have to live for my children. I cannot lose hope. They have only me.”

The 35 year old rag picker, Keya, who earned Rs 10 (27 - 56 cents) a day, was quite pragmatic:

“I will live as long as I can. Once I fall ill, critically ill, I will end my life. I don’t want to be a burden to anyone. This is a bad disease. People die because of it. Someone should find a solution to it quickly.”

Priya is caring for her little sister:

“You have to do it, irrespective of being scared.”

There were regrets for Bidya in having her second child, who became HIV-positive. She said that she still feels sad, and cries sometimes.

Threat 6: Worries about children

Despair and hopelessness was experienced by some of the women, who derive their only sense of living from their children. Anju commented:

“I don’t think about the future.

Then she went on to say:

“I want to live for my sons and see them excel in life. I want to live happily and healthily.”

Vijaya said:

“I have no interest in living. I live only for my daughters.”

Shuja said:

“We are living for them only – we will take one day at a time and live our lives as healthily as possible. We want to live a healthy life for our children though we do not know about their status.”

Similarly, Arwa said:

“I have kept a positive outlook as I want to live for my children.”

Jwala responded:

“I am only living for my children.”

Seema said:

“We want to think about the future but something stops us from doing. Whenever we want to try and think or plan ahead, we get scared.”

Tara said:

“I get tense when I think about my future. I wonder if things will work out well. I have no-one to live for. My parents are dead and so is my husband. My siblings are no more. I don't believe in thinking about the future.”

Shamla said:

“I have no wish to live. I live only for my sons.”

The future of their children was both a source of hope and concern. Bidya said:

“I am always scared if both of us die, who will look after my children?”

Arwa said:

“I am worried about the children's future. I want them to study and make a name of their own. As for me I want to die peacefully.”

Lina said:

“I get very tense about the future. My in-laws don't like my husband, so they don't look after us.”

She was fortunate to have her parents and siblings to support her.

Strength 6: Future focus

A future focus is important in gauging depression. It is a matter of concern, and a sign of depression, when women lack hope, and cannot see a future for themselves.

In these women's circumstances, I would have expected the women to lack hope, and be fearful. Instead they expressed hope, and positive feelings. For example, Leela said: "We are thinking positively.....All of us live happily and don't take tension." Pooja added: "I have a gut feeling that something good will happen to us." Sheela had a small son who was infected, and yet she could "see a bright future for my son and myself."

Sometimes, their hopes were unrealistic. Fatima thought "about a good future with her children well settled" and Pooja thought her husband would become better. "Taking one day at a time" was more realistic for Kavita:

"We are happy and healthy the way we are – as long as our family supports us, we have no worries".

And Suruchi who said:

"People infected with HIV/AIDS can live for 20 years also."

Sometimes, all they could do was to take one day at a time, like Suruchi and Kavita, and ignore the future, in the case of Shobha. She is 26 years old, her husband and herself and her four year old child are all positive. Shuja said:

"We will take one day at a time and live our lives as healthy as possible."

Ritu said:

"Now everything is alright. Work is fine."

One participant, Tara, progressed from doubt to acceptance, with the help of her religion:

"I get tensed when I think about my future. I wonder if things will work out well. I have no-one to live for. I don't believe in thinking about the future. I am taking one day at a time. I just believe in God."

Children were an important focus, and mothers wanted to live long enough to see their children grow up, to study like Kalavati, and to become independent. They dreamed of their children becoming happily settled and happy (Shobha, Gita, Leela and Seema, Priya, Shobha and Saras).

Suruchi said:

"I want to support my children and see them happy,"

and Anju said:

“I don’t think about the future. I want to live for my sons and see them excel in life.”

Fatima wants to see her daughter studying.

“If she can cope well, I want her to go to college also.”

Rupa

“Want to get my daughters’ financial security.”

The saddest wish from Rita, a young woman, who was found to be positive:

“I want a baby now. It is the only thing I can live for. I have no other aim in life.”

Wishing or wanting a better future was frequently expressed. Shamla said:

“I want to keep a positive outlook. If I am happy, my children are happy. In a happy atmosphere, life is beautiful and I forget about my infection. I feel content looking at my children. However, doubt crept in - “But how can I guarantee my future?”

Some expressed their wishes for the future as Anju,

“Wanting to live happily and healthily”

whilst Tara told us of her hopes:

“I will tell you something. I had TB some years back. I took medicines for nearly 6 months and got myself cured.”

This analysis from the interviews highlights many of the problems which have been elicited from the literature review. These include a lack of knowledge and information, secrecy and social isolation, added caregiving, and emotional reactions such as unresolved grief and loneliness and worries about their children. At the same time, the women demonstrated their ability to overcome the substantial difficulties, and to transform caring duties into a source of pride.

10.5 Summary of the chapter

The interviews revealed the personal reactions of the participants to the difficulties associated with HIV/AIDS. Despite the fact that most of the women had been to school, only two women had much knowledge of the disease; and this occurred only

because of testing after the diagnosis of a family member. Awareness strategies have not been successful in this group; and attempts to be diagnosed involved persistence. Secrecy and social isolation are factors which contribute to the plethora of emotional reactions. In general, the participants showed normal reactions to the difficulties they encountered. Time proved to be a healer with some reactions, and the women had high resilience, which has probably developed over time and their life experiences. The cultural concepts of adjustment and resilience help the women to cope. Strategies to support and strengthen resilience are discussed in Chapter 14.

CHAPTER 11

ANALYSIS OF DOCUMENTARY DATA

“The media does want to sensationalize issues and ...this becomes even more dangerous when media personnel are not that knowledgeable on the issues to start with, nor do they make any attempt to seriously learn and empathise. HIV stigma in my opinion, does stem mainly from misinformation and/or lack of information.” (Aster Birke (Ethiopia), cited in Health & Development Networks, 2007, p.43).

11.0 Introduction to the chapter

In all cultures, we absorb many of our ideas through various media. The images or words presented are often what we remember most about an event, and are the most easily accessed elements of our minds (Nairn, 2007). We form our opinions, and make sense, by gathering together resources of words and images in what Fiske (cited in Nairn, 2007, p.139) terms “a cultural bank.” For example, the media have a significant influence on how HIV/AIDS is perceived in India (de Souza, 2007). Airhihenbuwa and Obregon (cited in De Souza, 2007, p.257) state that our concepts of HIV/AIDS have been largely determined by what we read in the media. The manner in which a health issue is reported will affect public opinion. Negative reports may further marginalise or stigmatise a person with HIV/AIDS, and however unintentional, may perpetuate stigma (Corrigan et al., 2005). People portrayed in the media may only reinforce the stereotypes that HIV is “a woman’s disease, a gay plague, a junkie’s disease or a punishment for deviant behaviour” according to Aggleton, Wood and Malcolm (2005, p.8). Karnik (cited in de Souza, 2007, p. 258) researched Indian newspaper reports from the 1980s, and found that medical and political actors used Western definitions and risk factors of HIV/AIDS, such as CSWs, truck drivers and other “lower-class” victims, whilst denying the particular conditions which led to such behaviours.

The first purpose in collecting the documentary data was to demonstrate that stigma and discrimination still exists in India. This forms another source of confirmation of the data, in addition to the interviews and demographic data. The second purpose was to explore media perceptions of HIV/AIDS, and thirdly, to examine the media responses to gender issues affecting Indian women. Frame analysis was used to study the Indian newspaper reports which were relevant to this study. Firstly, the issues which were relevant to the study were separated. The broad themes were then categorised into the style in which they were reported; for example, if the report was sensational, informative, mere reporting or advocating in its approach. The data consisted of newspaper reports in Indian and other newspapers and Indian government reports.

Frame analysis refers to the theoretical approach used in communication studies, news reporting, politics and social movements. This approach examines the use of frames in the media as guides to perceiving and representing reality (de Souza, 2007). Media frames refer to the interpretive contexts, which help us to make sense of a message (Bateson, cited in De Souza, 2007, p.257). Framing occurs as journalists select material, and use it with varying motives, thus defining a problem, or exploring a cause, or making a moral evaluation, or suggesting a resolution to a problem (De Souza, 2007). Goffman (1963), who initiated research on stigma, is also attributed with the origin of frame analysis.

11.1 Methodology

Over the period of my 10 week stay in Mumbai, I collected 135 articles from English-speaking newspapers every day. The security guards in the front lobby of the student hostel were diligent in their collection, and delivery of the papers to me. After my use, the papers were returned for recycling. The Indian newspapers collected were: *The Times of India*, *The Statesman*, *The Indian Express*, *The Sunday Times*, *Mumbai Mirror*, *Hindustani Times*, *Chembur-Ghatkopar Plus*, *The Economic Times* and *the Bombay Times*. Five of these newspapers are nationally circulated. For example, *The Times of India* is the fourth largest circulated daily newspaper in India (Press in India, cited in De Souza, 2007, p. 259). The *Mumbai Mirror* and *Bombay Times* are Mumbai papers, and the *Chembur-Ghatkopar Plus* is a local

suburban paper. Data regarding HIV/AIDS was also collected from reports of organisations such as AIDS Action, AIDS Alliance for Children, Youth and Families, AIDS Educational Global Educational System, AIDS Education and Training Centers, International AIDS Society, National AIDS Policy, Embassy of India Policy Statements, YOUANDAIDS and Government of India. The material from these reports and conferences appear embedded in Chapter 1, 2 and 3.

Data on HIV/AIDS was collected from international conferences such as those held in Barcelona 2002, Melbourne 2001, the 4th International Conference on Home and Community Care for PLWHA. India's electronic media articles were gained from Mahiti and Saathii. Positive Peoples Networks, and AIDS India E groups, and information was sought from other electronic sources such as *Global Information Network*, *New York Times*, *Nam aidsmap news*.

11.2 Frame Analysis of Indian newspapers

Frame analysis was used to identify themes and issues of concern in the newspaper articles. From the 135 articles collected, a total of 73 were included in the analysis. The remaining 62 articles collected included articles regarding Mumbai's social conditions, cultural concerns and broad social issues. These have been excluded, because their content was too general. The following themes were identified and named: 1) HIV/AIDS, 2) HIV/AIDS research, 3) stigma and discrimination of people living with HIV/AIDS, and 4) gender issues. Those themes were then examined for the manner in which the news was reported. The next step was to use a constant comparison technique (de Souza, 2007), which compared and contrasted the themes and concepts from the articles in the same category. This was to examine the content, and how these concepts were presented to the public. The manner and language of media articles affects the way that information is processed by the general public. For example, India's print media has a history of sensationalising HIV/AIDS information, according to de Souza (2007). Frames were therefore developed to explore whether news articles differed in the manner in which HIV/AIDS was reported. These frames were: 1) Sensational, 2) Informative, 3) Descriptive, 4) Reporting and 5) Advocating change.

The following table shows the categories and manner of reporting:

	Stigma and Discrimination	HIV/AIDS	HIV/AIDS Research	Gender Issues
Sensational	3	3	1	4
Informative	8	7	1	8
Advocacy	2	1	0	0
Reports	2	19	2	12
Total	15	30	4	24
Total articles	73 articles			

Table 3: Number and categories of newspaper articles

11.2.1 Stigma and discrimination

11.2.1.1 Sensational articles

Fifteen articles reported stigma and discrimination concerning HIV/AIDS. Three articles used **sensational** reporting: A man had been wrongly diagnosed because the doctor wanted to keep on prescribing ART at a high rate rather than telling him he did not have AIDS ('Clinic, lab pulled up for wrong HIV tag on patient', in *Times News Network*, February 2006, p.10). A pregnant woman told to "swallow this (medication) or who knows if your baby will suffer from HIV" (Sridhar, 2002), and a person who "slit his throat with a blade soon after his blood reports confirmed he had the virus" ('Man with HIV kills himself', in *The Statesman*, 21 December 2005).

11.2.1.2 Informative articles

There were seven articles which were **informative**. These included the need to educate local peoples' representatives, and employers (Ali, 2006b). The role of migration and mobility of betel vine workers in spreading HIV was discussed ('A look at HIV' in *The Statesman*, 1 December 2005). In addition, the effect on children was highlighted in an article about the difficulty of placing babies who were

once HIV positive but are now clear (Ali, 2005). Secrecy, stigma and denial were discussed in one article (Morris, 2005), and a successful programme where widows meet and share (Nagaraj, 2005). Another success story was a special project which targets truckers, helpers and sex workers in Kalamboli. Three awareness camps had been set up at the truck terminal, and 150 truckers tested. Interestingly, given this is a high-risk group, none were reported to be HIV-positive ‘HIV/AIDS health camp’ in Chembur-Ghatkopar Plus – January 2006.

11.2.1.3 Advocating articles

A new law banning stigma and discrimination was highlighted at this time by (Rashid, 2005). The Lawyers Collective, who have played a key role in changing India’s laws, advocated further amendments in the area of mandatory disclosure by husbands of sero-positive status (Tanna, 2005).

11.2.1.4 Reports

Two articles reported strategies which could be used in coping with stigma and discrimination. Firstly, information aimed at youth with a lot of prescriptive advice, (Nag, 2005). The Bollywood film ‘*Phir Milenge*’ which discusses HIV/AIDS had just been released in Mumbai, however I had no means to view the DVD. Intervention by the High Court had resulted in a bar on employing HIV positive policemen being lifted (Srivastava, 2005).

11.2.2 HIV/AIDS

11.2.2.1 Sensational articles

There were 30 articles on HIV/AIDS during this three month period. Four articles were **sensationalising** in their approach. The first one was a picture of a child who was HIV positive photographed with Richard Gere, the American actor (*The Times of India*, 9 December 2005). This violated privacy of the child, and was potentially dangerous, knowing the stigma attracted by HIV. The second report was of a girl stabbed by a syringe, filled with HIV positive blood, whilst she was at the cinema. The language was fear-producing (Focus on fight against AIDS, *The Statesman*, 18 November 2005). The third article was how well-educated people were being treated with electro-convulsive-therapy because they were so depressed from the fear of

contracting HIV (Ali, 2006). This treatment would only be used in extreme cases of depression in Australia. The fourth article was written in a flippant style, describing spouses “dragging” their partner to the courts, in response to India’s law, which makes it mandatory for a HIV positive person to inform their partner (not specified whether married or unmarried) (Tanna, 2005).

11.2.2.2 Informative articles

There were eight **informative** articles, well-written and accurate on topics such as the high cost of the proposed female condom, (*Sunday Times*, 1 January 2006, p30; the installation of condom machines (Sinha, 2005); and the reaction from conservative, religious groups in ‘Condom vending machines invite ire: Muslim organisations in Chennai say condoms are “anti-Islamic” in *The Indian Express* (14 December 2005), and in ‘Move to install condom machines opposed’ in *The Statesman*, 5 January 2006, p.5, on the grounds that such machines would lead to “dissipation and profligacy”. Blood safety was another topic well covered, exposing the difficulties in ensuring a safe, effective and clean service (Iyer, 2005).

Sex education was well covered. I felt there was an anomaly of readers agreeing that sex education is a good thing when the reality is that this type of education is opposed by religious and conservative groups. It was also noted that awareness of HIV/AIDS is not the only answer, and that fear needs to be addressed as well (Nagaraj, 2005). With regard to sex education, there was a sex information column which gave out some strange advice coupled with intimate details which ran counter to the taboo on the discussion of sexual matters. The *Bombay Times* asked its readers whether sex education should begin before the age of 15 years and 92% replied in the affirmative. In fact many Mumbaiites felt that it should start as early as age 7. (*Bombay Times*, 16 November 2005, p.11).

11.2.2.3 Advocating articles

One article **advocated** a better approach than targeting only the high-risk groups when it reported on the march against the Traffic Amendment Bill (Lawyers Collective, 2006). World AIDS Day is in November, and it would have been a good opportunity for the announcement of new initiatives. At the KJ Somaiya Hospital, all the medical and nursing staff joined together to make a pledge and renew their

promise to do their best to eradicate HIV/AIDS. This was organised by SAHAS. In the newspapers, some attempts were made to highlight the problem.

11.2.2.4 Reporting

There were 19 reports. Three reports used celebrities to promote AIDS awareness included the visit to India of Richard Gere to launch a campaign; Ravi Shankar to perform at an international concert (Singh, 2005); and other arrangements to mark World AIDS Day in Sikkim by the use of street plays (*The Statesman*, 2 December 2005, p 4). A report from Paralakhemundi reported hundreds of cases go undetected, and that the figures for HIV/AIDS had risen despite awareness in *The Statesman*, 5 December 2005. In four articles reporting lack of awareness, two surveys on youth exposed misconceptions and beliefs in the *Chembur-Ghatkopar Plus*, 4 January 2006 and Nag (2005); whilst Nair (2005) reported general lack of awareness, and more particularly in Sikkim, where women were surveyed for the first time as to their awareness and revealed only 54% had any ideas of HIV/AIDS.

Another article reported Kenneth Cole, designer and humanitarian, saying that India is seen as a low risk country, with the infection contained in high-risk groups which was erroneous and not corrected (Preeti, 2006). Child marriages were suggested as one of the contributing causes of the spread of HIV/AIDS in two articles: (Rashid, 2005a); and 'Government bid to ensure girls wed after 18' in *Indian Express*, 22 November 2005. The only reports of initiatives were firstly, the opening of a new ten bed unit in Kolkata as a dedicated HIV centre (Sarkar, 2005). Whether this would further stigmatise people was not discussed.

There was a promise of the government to give free ART to the poor in 'Government may gift free drugs to the poor in the New Year (Kumar, 2005). Also there were plans of 2% percent less finance to fund health subsidy schemes for cancer drugs and AIDS centres' in *Mumbai Mirror* (30 December 2005, p.22). Whether this was translated into action, I am not sure, but there was no reaction at the SAHAS programme. Another article reported that more men were aware of HIV/AIDS, but not deterred from sex, they were just asking for condoms or HIV-clear sex workers (Sharma, 2005). The figures for the incidence of HIV/AIDS for the state of Maharashtra were reported as 129,011 between 1986 and 2004 (Nagaraj 2005),

whereas in Gujarat, the number of cases had increased, but the prevalence had decreased which was attributed to awareness in sex workers (Sulaimani, 2005).

11.2.3 HIV/AIDS research

There were only four articles on HIV/AIDS research in the three month period. There was one article on research into yoghurt as a preventive device. ('Yoghurt could help stop spread of AIDS', *Press Trust of Indian*, 18 January 2006). This news was taken up by a lightweight article on how Indian housewives could contribute by using yoghurt in their cooking (Karkaria, 2006). There were **reports** on a vaccine in Phase 1 (Rashid, 2005) and a very complex and detailed article on the mechanisms of infection, with doubtful value to the general public (Srinivasan, 2005).

11.2.4 Gender issues

11.2.4.1 Sensational articles

Gender issues were often in the news. Of the 24 articles, the overriding number of articles were informative, and mostly stories in which women overcame the barriers. However, there was a degree of **sensationalising** these issues. For example, there was a case of *honour* killing in Uttar Pradesh which was chilling – “Man beheads sister for ‘honour’ in UP’ after attacking her earlier with a knife” in *Times of India*, (20 December 2005, p.6); and a woman who received 100 lashes for an extra-marital affair. In this case, the reporting was justifiably angry in its reaction in the “travesty of justice” in *The Statesman* (30 January 2006, p 12.). In *The Statesman* (21 January 2006), a woman was ostracised by the village for travelling to Rajasthan with her brother. This had relevance for me travelling as a single woman. In *The Times of India* (5 March 2006) the text which outlined the exploitation of women in so-called ‘safe houses’ was offset by the drawing of a distressed woman.

11.2.4.2 Informative articles

In the area of **informative** articles, there were enlightening examples of Muslim women standing up for their rights. In the first case, the women had objected to a model law and issues a parallel model (Mishra, 2006b), and secondly, a report on the changing face of work for Muslim girls in call centres in Hyderabad; ‘Voice behind the veil. The poor-girl, rich Arab image is giving way to call-centre burqas in

Hyderabad’ in *Sunday Times*, 22 January 2006. Excellent examples of the power of self-help groups for women were given in *The Times of India*, 17 December 2006. Family planning can be affected by war and loss of men, so young parents were ignoring family planning in Kashmir - ‘Three’s company’ in *Indian Express*, 19 November 2005. The story of a *dalit* woman in a rural area who had been given finance for income-generating activities was used to report on a credit scheme for women in ‘Buffalo story in the heart of Maharashtra’ *The Times of India*, 17 December 2005.

Issues of secrecy illustrated the difficulties for women. One article outlined reasons why women do not use telephone AIDS hotlines. In ‘Women need to break silence, speak out’ in *Hindustan Times*, 27 November 2006, women were blamed for not revealing domestic violence whilst Poonam was murdered for complaining about an illicit liquor outlet in her neighbourhood (Kowshik, 2006).

11.2.4.3 Reports

Ten **reports** addressed the inequality of women. ‘HIV infected woman dies’ uses the story of a widow with three children, who could not get any help from the district administrator or the Health Department to illustrate the lack of help in rural areas – *The Statesman*, 7 January 2006. Female foeticide figures are disturbing in a country where the male-female sex ratio is increasing. The report claims 500,000 unborn girls are aborted every year in ‘The confirmation: Female foeticide in India crossed 1 crore (1 million) in 20 years’ in *Indian Express*, 8 January 2006, and news of a website developed by the Datamation Foundation which registers illegal ultrasound clinics rife in India (Bhagat, 2006). Sexual assault figures continue to rise in New Delhi. For instance, increases of 36% in rape and 64% in “*modesty outraging*”, and 73% in overall atrocities on women compared to 2003 according to an article titled ‘1000 rapes, 5000 murders contradict Govt claims’ in *Hindustan Times*, (29 December 2005, p. 8). There were two eloquent pleas for gender equality, one of which was written by a schoolgirl, and another highlighting the difficulties for women from childhood: ‘How to ensure a better life for the Indian woman’ in (*Indian Express*, 31 December 2005).

Two articles brought out the underlying cultural difficulties. In the first, ‘Controversial dowry law under NCW scanner’ in *Indian Express*, 22 November, 2005, those accused under the dowry law were seen to also have rights; and a report that doing commercial sex work raised women’s status in this country was hard to believe. Another article made a plea to all Indians to look at the lives of women and recognise the inequities in ‘How to ensure a better life for the Indian woman’ in *Indian Express*, 31 December, 2005. There were two articles on child marriage, and the effects of being widowed at a young age through HIV/AIDS (Srivastava, 2005), and a pilot project in Madhya Pradesh and Rajasthan to try and ensure that girls do not marry before the age of 18, in order to lower the birth rate (Rashid, 2005a).

11.3 Discussion

I was able to collect articles from at least eight newspapers in the English language, however, there are many more produced in other state capitals such as New Delhi. In addition, there are newspapers written in Hindi, Gujarati, etc. English speaking newspapers cater to the middle and upper classes of Society. More research is required to compare news items on the same subjects from different language media and also TV and films. There were instances of headlines written in a sensational way, no different from our own. Sometimes, they were written in a kind of “shorthand” described by Develotte and Rechniewski (2007) where cultural knowledge is necessary. For example in the header: ‘Behind every memsahib is a *bai*’.

I found many of the articles ‘sensational’ both in their content, and in the way they were written. I have classified an article sensational, if it were written in a frame which continued a stereotype, or victimised the person. There were few news items reported from overseas in the Indian newspapers, in the area of HIV/AIDS, despite the English language medium. Cross-pollination of ideas is important in any field, and this would have added to the debate of relevant interventions in the Indian context.

Freedom of the press was difficult to gauge for an outsider. Journalism may be affected by corruption, as in many areas of Indian bureaucracy, and so some articles

may be suppressed, although there was no dearth of articles relating to stigma and discrimination, HIV/AIDS or gender issues. Nussbaum (2007) claims that the Indian press is freer than that of the United States, as the leading papers are privately and diversely owned, and therefore less vulnerable to economic pressures. The statistics were certainly reported in the press, the stories were real, and yet I felt that the audience was probably desensitised from years of such information.

The articles that I collected provide a snapshot of news in one facet of the media. There may have been more items in the months I collected. World AIDS Day is on December 1, and there was a flurry of items in that month. AIDS and the resulting stigma and discrimination took up far less space in the papers than news about celebrities and events in Bollywood. However, this trend is noted in Australian newspapers. Sporting events and sports heroes particularly in cricket were well reported as in our own papers.

Overall, I felt there were some attempts to educate the general public about HIV/AIDS, and successful interventions. The use of particular people, for example Gudiya, whose illness and death were followed from day to day, and the child photographed were sad examples of the lack of confidentiality in India. I observed certain differences between the newspapers. The *Mumbai Mirror* tended to be more sensational, but it constantly brought the social conditions in Mumbai to the notice of the public. *The Times of India* had more thoughtful and reflective articles on a whole range of subjects. Given that this sample of papers is aimed at the middle classes, who have ample awareness of poverty, low status of women, disease and corruption, there is a need for advocacy by the media rather than mere reporting or sensationalising cases. The struggle between modern and traditional values, the need for openness about HIV/AIDS and sexual taboos, celebrities and reality is played out daily in the newspapers.

The newspapers played an important part in my life. I was seeking information about my field of interest, but at the same time, it was a major source of information about daily life. I searched for cultural events without success. It was also a continual source of reading material which I lacked on the whole and I read the

newspapers avidly from cover to cover even though some of the information was difficult for an outsider to follow.

The newspaper articles confirmed the presence of stigma and discrimination in the community, and thus provided another source of triangulation of the data in this study. Newspapers in India play an important role in shaping individual and community perceptions of HIV/AIDS (de Souza, 2007).

11.4 Summary of the chapter

In this chapter, I have analysed the documentary data gained from newspaper articles collected over the period I was engaged in field research in Mumbai. The newspapers were a valuable source of media perceptions of HIV/AIDS, stigma and discrimination and gender issues. I reflected that these newspapers were unlikely to be read by the women I interviewed as they could not read or speak English, and so ways of reaching such women lies not in the written word we find so important but in language-specific oral transmission or media such as television.

CHAPTER 12

THEMES FROM THE GROUP AND KEY INFORMANT INTERVIEWS

“We behave with them as before, but there is some distance that we now maintain. This is natural, isn’t it – I mean it’s caused by our anxiety.”

(Male sweeper in a Mumbai private hospital, focus group discussion, cited in Bharat 2001, p. 35).

12.0 Introduction to the chapter

Focus group discussions are well established as a mainstream method in social science. The group dynamics mean that people within the group are influenced by each other, which gives more depth than a single interview. This chapter examines the contribution of the group and key informant interviews, to the data of stigma and discrimination accumulated in the interviews, and the documentary data collection. The accumulation of data from different sources forms triangulation which strengthens the overall results. Groups are used extensively in qualitative research in order to provide methodological and data collection triangulation (Dushku, 2000). This form of collecting data is particularly valuable where the participants may be “reluctant to be interviewed on their own or feel they have nothing to say” in their own right, but would be encouraged to discuss issues in a group and therefore provide a considered opinion (Kitzinger 1995). The group interview followed a general guideline, which was adaptable enough to allow the group to explore different lines of enquiry.

I decided to include the nurses at the KJ Somaiya Hospital in a group discussion because I felt that their role was not fully explained in the interviews. Obviously, the nurses are in the front line of care at the hospital, but the women interviewed did not make mention of them. This may have been the fault of the interview questions, or it

may be because the nurses' essentially female role is not valued as much as the medical staff. In Chapter 5 it was noted that the early history of nurses followed the structural norms of society, in that it was considered that only lower castes could provide hands-on care such as that required in nursing. As a former nurse, I was interested in the role that nurses play today, and what they thought about the issues of stigma and discrimination.

12.3 List of key informants

In addition to the nurses' group, the key informant interviews were arranged with great difficulty, because of the time that was necessary to spend on the interviews and the distance from the city itself. The ten key informants consisted of the following people.

- Key informant 1 (KI 1): Researcher into HIV/AIDS and stigma and discrimination from a key institution in Mumbai
- Key informant 2 (KI 2): Honorary Secretary General AIDS Prevention and Control Organisation, Mumbai, PhD thesis on HIV/AIDS, Reader at a research institution.
- Key informant 3 (KI 3): Psychologist, and Co-ordinator of SAHAS, K J Somaiya Hospital
- Key informant 4 (KI 4): Principal of a College of Social Work, Mumbai
- Key informant 5 (KI 5): Accountant, SAHAS
- Key informant 6, 7, 8 (KI 6, 7, 8): 3 Community Health Workers from SAHAS
- Key informant 9, 10 (KI 9, 10): 2 Programme Assistants and Outreach Workers from SAHAS
- Key informant 11 (KI 11): Outreach worker from the Ra Foundation

12.1 Focus group discussion - Nurses

The Matron at the KJ Somaiya Hospital willingly provided me with access to the nurses at short notice, and about 50 nurses gathered in the lecture theatre. This number was much larger than I expected, however, Denzin and Lincoln, (cited in Dushku, 2000, p. 765) asserts that this is "another level of data gathering". The nurses were reticent at first. This may have occurred because I assumed that their English would be good enough not to have the interpreter with me. Additionally, I

felt that they were unwilling to speak about the hospital to a stranger. Gradually they relaxed, and using a spokesperson who could speak good English, they responded to my questions. The aims in this discussion were to explore stigma and discrimination in the community and the hospital, health beliefs and women's issues.

The nurses expressed their understanding of stigma and discrimination as being “a state when someone has a disease, and people react to it by ignoring them or treating them differently.” They did not think there was any discrimination at the KJ Somaiya Hospital, and that people with HIV/AIDS are treated differently, but not with discrimination. They attributed this to good training of all the medical personnel. (The Somaiya Hospital has aimed to provide stigma and discrimination education to all employees of the hospital from the doctors to the cleaners). They added that they lacked practical experience in certain areas. They were taught to wear gloves and masks and to wash their hands – i.e. nursing duties, but there was no special training in how to treat patients who had HIV/AIDS, or how to counsel them. I asked if their training was different from the doctors, but they could not answer that, because they were “only nurses.” There seemed a big distinction between the professions. They felt that the World AIDS Day was a good opportunity to spread awareness amongst the staff at the hospital.

The nurses were adamant that treatment was equal for men and women within the hospital, and that was borne out in the interviews, where many women commented on the lack of discrimination in the hospital. They felt that differences in access to services for women were not within their area of expertise. The reason for people attending the hospital was not for voluntary testing on the whole. People came because of opportunistic infections such as coughs or TB. They were then sent for HIV testing. They were aware of discrimination in the community, and had a fatalistic acceptance “discrimination will still go on despite the laws.” New laws banning the practice of discrimination were being processed at that time.

Denial was used by patients who explained the mode of transmission of the disease by saying that it happened through a blood transfusion rather than sexual intercourse. The nurses did not try and break down that defence mechanism, saying:

“We do not ask more about it. We just know the truth.”

I asked what they thought would help people with HIV/AIDS. They were aware of financial problems, and lack of support in these slum communities and the effects on families. They stressed the need for counselling and social work intervention.

Finally they expressed the difficulties which women faced which were different from men because of the discrimination that they attracted.

“Women often get the blame and end up with no support, and yet women need more support so they can bring up the children.”

12.2 Key informant interviews

From my experience with community health workers, I have learned that these women have a distinct and special role not only in providing home-based care, but also informal counselling and support, and health information. I have also witnessed the same process that these community health workers describe of empowerment in their own lives through being able to work in their communities. In Australia, I trained women who had had little formal education in the care of people with dementia (O'Connor & Kingsley 1991). These women gained confidence in their own abilities and became very skilled in their work. I have therefore included the perceptions and experiences of the SAHAS team because of their knowledge and observations of their community. They are also important examples of transformation described more fully in the narrative section. The key themes distilled and analysed from my discussions with the ten key informants were: -

- Stigma and discrimination,
- Lack of awareness of HIV/AIDS,
- Mode of transmission, discrimination in health care,
- The unequal status of women and suggestions for effective care in the community

12.3 Stigma and discrimination and lack of awareness

The difficulties with stigma and discrimination have not disappeared despite awareness campaigns (KI 1). To some extent, this is because the campaigns are not tailored to the needs of women in community slums, and their isolation (KI 2), but also because awareness is seen as a government responsibility. This means the initiatives are left to the government, but they are not doing enough (KI 3). KI 5 said it was difficult to educate doctors and some areas have been over-accentuated like premarital sex. The lack of awareness is considered to be widespread (KI 3, KI 5). The lack of treatment of HIV/AIDS was attributed to sexual taboos (KI 5, KI 3), in that people could not discuss these matters, and therefore remained ignorant; community perceptions that HIV/AIDS was a punishment for immoral behaviour (KI 3); and because it is a fatal disease, with no cure (KI 3). These statements replicate the literature on stigma and discrimination in Chapter 3. KI 4 noted that women may know about how HIV/AIDS is transmitted, but lack privacy in the home to fit a condom. I have described households where there are remaining members of a family affected by HIV/AIDS living together who would normally be in separate households. There were households with up to five members ranging in age from children to adult.

There was frustration expressed that, despite the efforts of the SAHAS programme, discrimination was everywhere (KI 5, KI 6), despite the new anti-discrimination law. KI 4 said that the law would help in employment situations, and with medical personnel who had refused to treat people with HIV/AIDS in the past. KI 5 was also confident that legal approaches would have a positive effect; whereas others felt that it would have a negative impact, and could actually be used against people, like the dowry law (KI 3). Community health workers such as KI 6 noted a lot of *courtesy* or *affiliate discrimination* towards affected family members in the community; i.e. discrimination was extended to widows who were not infected, but their husbands had died of AIDS. The CHWs could relate this kind of stigma to their own experience, as they described their families' reluctance to them working in the programme (KI 5, KI 10). It is to their credit that they have persevered, and continue to work in the area.

12.3.1 Mode of transmission

KI 4 described the confusion for women who are infected through their husbands. The wives did not always understand the mode of transmission, and they are left wondering about how this could happen and “gnawing doubts.” Migrants from other regions take the disease home to their wives. She considered that denial is strong, as did the nurses. Women think their husbands will not betray them, and so the women put on a brave front when it happens because of a strong cultural image that women should trust their husbands. There is a reluctance to blame the husbands. For example KI 3 said it is natural for men to go to CSWs, but the men need to be tested, and prostitution needs to be legalised to prevent HIV. KI 1 saw blaming men as unhelpful, and KI 4 suggested eliminating the demonisation of PLWHA, and to emphasise acceptance of the disease and the sufferers.

12.3.2 Discrimination in healthcare

Discrimination was noted by KI 4 in particular from her experience of working with PLWHA. She described as “strange”, the behaviour in Mumbai hospitals where in order to qualify for ART, people have to undergo three interviews one week apart. After one interview, they are asked questions about HIV/AIDS and they may fail. If they fail a second time, they do not receive ART. The consequence is that families may not believe they have HIV/AIDS if they are not receiving ART. Hospitals had stopped outreach to peoples’ homes because it was considered too difficult to provide services. By using trained CHWs, this community service had had a 90% success rate in stigma and discrimination programmes over a six month period. This evidence supports my perception of the value of these community health workers.

12.3.3 Empowerment of women

The process of transformation in the community health workers was described individually by these women. KI 6 described how when they started their work, they were disturbed by the plight of women in the community, unsure of the programme’s worth, and did not know whether it would work. The CHWs were also not confident of their ability, as “just normal housewives” to effect any change (KI 8). With time, they had noted the many changes in their communities – such as the growing awareness of women of family planning, education and having money (KI 6, KI 7, KI 8, KI 10, KI 9).

The three directional benefit of home respite I have described (O'Connor and Kingsley, 1991) was repeated in this home-based service. Firstly, the benefit that home-based care provides to the person suffering from HIV/AIDS which has been discussed in Chapters 8, 9 and 10. The second benefit is to the affected family members, mostly women, who are in the caregiver role. I have described the pivotal role that a service like this can have in delivering care and support; and the benefit to the workers in the SAHAS programme themselves. The workers described how proud they felt of themselves and their work, and the changes they had wrought. They were enthusiastic and they could see the results of their endeavours despite the challenges and opposition (KI 6, KI 7, KI 8, KI 9, and KI 10). KI 7 felt she had the power to change the lives of people who need her assistance and help.

This empowering process raises these CHWs from their earlier perception of themselves as just housewives (KI 9) to women of value, and this is transmitted to their clients. KI 9 summed up their perceptions when she said that she had always known what kind of a job she wanted to do, and felt very satisfied because she could do something for society. She was proud of herself and her job. In this situation, there is also a fourth benefit to the community generally, because the service fills a gap in government provided community services which would be expected in other countries such as Australia. The CHWs such as KI 6 noted that the community is becoming a better place gradually.

12.3.4 Discrimination of women

This was noted by the nurses and the community health workers and KI 4. She described the allocation of food to the male in the family first, and how their community-based service focuses on women whom they see as socially isolated, and needing support. She said that the community notices everything including people falling sick and then the community socially isolate the women resulting in secrecy. The result is that women only disclose their illness when they are at a desperate stage. KI 2 felt that HIV/AIDS had put the status of women in the slums back many years.

12.3.5 Effective strategies

KI 4 was the most able respondent in this area, because of the depth of her experience in community care. The community-based service focuses on women and consider the three essentials are nutrition, medicine and work. They have two work centres where they are training women to make bags and petticoats to be sold, and they are seeking travel concessions so that women can attend.

Likewise, the CHWs encourage women in the community to join the Somaiya Hospital's income-generating sewing programme (KI 3). The CHWs note health and nutrition of their clients, and are able to access food which is distributed to clients for one year. In addition, KI 11 informed me of the initiatives that a hospitality company had put into place to provide women with low interest loans and health work training for women. They had set up self-help groups for women in a microcredit scheme where the women were learning to save.

Education has been shown to be effective when it is delivered by community health workers, peer educators and street plays (KI 4). The nurses and CHWs felt that awareness was gained by their training, but KI 5 felt that doctors were difficult to educate. KI 4 said that education needed to focus on care as well as prevention and precautions (such as condom use) although these areas were still important. In order to cope with the social isolation I have described in Chapter 9, the community service provides a protected environment where women can meet without fear of stigmatisation. They endeavour to make ART readily available to women.

12.4 Summary of the Chapter

Some of the key themes revealed by the nurses and key informants were stigma, discrimination and lack of awareness of HIV/AIDS in the population served by the K J Somaiya Hospital. It was acknowledged by the nurses and the key informants that stigma and discrimination existed in healthcare settings other than the hospital. The nurses felt that they had received good training in this area, but it could be improved in the area of counselling and specific care. The participants interviewed also praised the KJ Somaiya Hospital for the lack of discrimination. The nurses and key

informants said that stigma and discrimination existed in the community and opinion was divided as to whether the new laws would help stamp it out.

There was a lack of awareness in the community about HIV/AIDS according to both the nurses and key informants. This existed particularly in the area of transmission, and was attributed to lack of effective campaigns or beliefs or taboos regarding discussions of sexual matters. Discrimination towards women generally and in the area of HIV/AIDS, was discussed and generally acknowledged by most informants. The other area discussed was the effect of home-based care and the positive benefits for the clients, carers and workers. These results confirm research literature discussed in Chapter 2, and the interviews analysed in Chapters 8, 9, and 10. In Chapter 13, a new voice is added – that of the researcher in the form of a reflective diary, and narratives derived from observations during my time in the field.

CHAPTER 13

THE POWER OF VOICE 1: Reflections on the research

“A man is always a teller of stories. He lives surrounded by his own stories and those of other people. He sees everything that happens to him in terms of those stories.” (Jean-Paul Sartre, cited in Bruner, 2008, p.1).

13.0 Introduction to the Chapter

Social sciences are focused on humans and their relationships with themselves, their community and their environment (Clandinin and Connelly, 1994). It is essential to include the participants’ voices as well as a study of the text, field observations and an account of the research. As a researcher, one is not only observing the participants, but in a reflexive way, also observing the interaction between these actors, and one’s own reactions. In this chapter, my voice as a researcher and narratives of the women give them a voice.

As the research progressed, I was aware that I was adjusting, whilst observing the ever-changing scene around me. Through personal reflections, the transformative process (Earnest, 2003) becomes a part of the research process. There was a definite benefit in writing a diary, daily log and reflections for myself as the researcher. Writing a reflexive journal helped me to come to terms with my environment, often shocking to an outsider. It was the part of research which gave me a sense of autonomy.

The other imperative which drove me to write was to place these women against the backdrop of their environment, which has such an impact on their lives. If the reader does not understand the background, then the voices have little meaning. I could not always take photographs, but I could place the memory in my mind to be recalled

later in my diary. There is an increasing trend in social research to use the personal story as a mechanism for assessing human experience. However, the struggle for the research voice is difficult as Connelly and Clandinin (1990) note. The researcher has to constantly decide what to add of his/her own personal story, ever mindful of self-indulgence and irrelevance. For researchers, schooled in other disciplines, it is a daunting experience. However, the social sciences are shifting from more traditional quantitative, pre-set approaches of information gathering to allowing categories and concepts to develop within the act of collecting data itself (Polkinghorne, 1990).

Narratives have a unique ability to provide an unprecedented insight into local and personal experience, and are therefore a valuable method in qualitative research. The narrative allows the research participant to define the categories of analysis through the *process* of telling their story, and creates a shift to enable the participant to be the author of their own story (Besemeres, 2007). This gives a power to the voice. Narratives are a phenomenon in themselves, in addition to being a method of data collection, placing human experience in time and space, and allowing the reflective process of others to be examined (Connelly and Clandinin, 1990; Polkinghorne, 1990; Riessman, 1993, 2005).

It has to be acknowledged that in any context there are barriers in interpretation, limiting the capacity to truly conceptualise local realities (Benatar, 2002). If these remain hidden and unacknowledged, the barrier is considerable. Researchers have to trust their experience, maturity and ethical training, to offset barriers like the lack of language, social position, or a different culture. The reflective diary reveals the researcher in a new light – struggling with the complexities of field research, and my own inadequacies, but completing the tasks which were set.

Narrative research has an especially critical role in studies of illness and disability, because there is a phenomenological desire to understand the lives of others in their particular circumstances (Riessman and Mattingly, 2005). The focus on objectivity has meant that the fact that all communication is metaphorical has been forgotten. None of us can really experience the pain or suffering except through our observations of their subjective experience (Angel, 2006).

Through narratives, the storyteller is given the opportunity to not only engage in reciting the events of their lives, but also entering into a process of organizing the experience (Rosenwald and Ochberg, 1992). This is very evident in counselling when clients relate their story in order to help the psychologist understand. As they do that, the information that they hear themselves say has a powerful effect in reorganizing and transforming the data in their minds into a more manageable state. Rosenwald and Ochberg (1992, p.11) suggest this is a critical stage of healing: “If our development is to be socially meaningful and consequential, we must be heard.” Riessman (1993) further argues that individuals at the household and community level are constantly redesigning and reconstructing their environment, based on their own resources and experience. Therefore analysing their narratives can provide powerful insights into the organizational principles of human action (Reissman, 1993). There are limitations in narrative research arising from the necessity for interpretation, hence the use of the researcher’s voice. As Reissman (1993, p. 8) states:

“We cannot give voice, but we do hear voices that we record and interpret. Representational decisions cannot be avoided; they enter at numerous points in the research process...Transcribing discourse, like photographing reality, is an interpretative practice”.

Thus researchers have to constantly struggle with their own interpretation and filtered perceptions of the world (Riessman, 1993). There remains no more appropriate method to convey local experience than the voices of the people themselves, speaking and defining the framework of the narrative process.

This chapter is concerned with my critical awareness of my assumptions, beliefs and actions (or the researcher’s voice in the enquiry). Critical reflexivity acknowledges that the researcher is an integral part of the setting, and context that I, as the researcher, was trying to understand and represent. Most importantly, reflexivity in research allows more space for the voice of the people who are being studied. I wrote narratives that took into account social action that is “locally distinct and situationally contingent” and was designed to develop a clearer picture of the interplay of factors (Erickson, 1998).

Narratives are an excellent medium for the current experience of people in a particular locality to be analysed rather than historical interpretations of the past (Peel, 1995). Riessman (1993, p. 2) suggests that “Nature and the world do not tell stories, individuals do...studying narratives is...useful for what they reveal about social life - culture- ‘speaks itself’ through an individuals story.” Beyond the narrator’s own experience, the language and subtleties inherent in the story can be critically examined as representations of power structures and social dynamics (Besley, 2002). Thus narratives become a legitimate process to illustrate ‘meta’ levels of social organisations and a method to analyse the structures of power; gender inequities; the socio-political context and the impact these factors have upon local people’s lives.

13.1 Reflective diary and journal

This chapter is an account of my research journey. A reflective journal is a powerful way of representing experiences and it allows a merging of personal and professional elements (Darell, 2003). The emotions that we feel affect our research, and particularly in fieldwork, distressing and frustrating elements combine to sap one’s energy, and affect motivation and ability to persevere. As we encounter difficult scenes, we become vulnerable and exposed. Darell (2003) describes the value of a colleague who can aid the reflection. I was fortunate to have friends available who shared my frustrations, and allowed me to vent my feelings.

13.2 My arrival in the Mega city of Mumbai

I arrive in Mumbai in the late evening and breathe in the smell and flavour of India. The airport still has those strange yellow lights, but it feels good to be here again. Step one is accomplished – I have arrived, and I have been met by a driver. I feel physically fine, and an urgency and enthusiasm to begin. My accommodation is in the guest house on the sixth floor of a large college, and it looks reassuringly presentable from the outside. I sleep deeply and undisturbed, and in the light of day I can see that the guesthouse has been newly painted, and just needs a good clean and I can cope with that. Within walking distance there are plenty of fruit on barrows – pineapple, guava,

apples and mandarins and other fruit I don't recognise. I prefer to buy from the man with the barrow on campus as I know the proceeds go to the women's collective. Vegetables include English spinach, garlic, ginger, tomatoes, onions and eggplant.

I feel a resistance in me to go to the hospital in order to start my research journey. This involves driving by auto-rickshaw through the incredible traffic. Apart from fear of the traffic, this feels like fear of the unknown – What are the people in the programme going to be like, what I am going to encounter in the slum, and will I be able to cope physically and mentally with the smells and conditions?

13.3 The HIV Cell (SAHAS) team at the K J Somaiya Hospital, Sion, Mumbai

I meet the young Co-ordinator and the community health workers, the administration person and a young social worker. We discuss my project in between a steady stream of patients coming for assistance. The Co-ordinator appears to be helpful and welcoming, and willing to arrange interviews and translation which will take 5-7 days. A young Psychology student has been assigned to be my interpreter. When I meet her, I am impressed with her English and her manner. She chats easily, and has worked in a leper colony with her grandfather and can speak Marathi. I do not have a lot of choice as time is going on, but I think this will work with a little training.

I force myself to make a tour of the hospital with an outreach worker despite my resistance, which I now recognise is related to the fear of seeing things which might be distressing. The hospital is very basic with open windows and overhead fans and iron beds. Birds swooping in from outside are a bit daunting, and views of the slums below not very inspiring. It is not overcrowded, and I ask about the HIV/AIDS patients, and whether they are identified in any way. It seems that they put a red bucket under the beds of these patients and I wonder how confidential that is. I speak to some of the nurses and to a doctor who is newly arrived. She says there is no stigma and discrimination in this hospital.

Back at the office, I observe the Co-coordinator always sits behind her desk, but is otherwise very sociable, and these women come from very different social strata, although I cannot tell the difference in their dress. They all look beautifully groomed, and sometimes one of the community health workers wears a fresh flower tucked into her thick black hair. The Coordinator is Brahmin, and the health workers have been selected from the communities they serve.

13.4 Biting the bullet and undertaking interviews

The next day I decide to face the community with the person assigned to interpret for me. I feel relief that the community is not as bad as it could have been, but it is very hot, and I must look a sight with my dripping brow under my black umbrella as I determinedly walk the whole length of the area, which takes one and a half hours. Right at the end, a Hindu priest comes out of his shrine and blesses me – an auspicious start. I try out my Hindi and greet people, and they smile at my endeavours as they are Marathi-speaking. The dwellings are very small and cramped for sometimes 5 people or more. They are mostly constructed with bricks as walls, windowless, with corrugated iron roofs and wooden doors.

The interpreter and I conduct the first interview in the hospital with a team community health worker who has lost three of her family to HIV/AIDS. She is articulate and the interview goes well and we record it. The Co-ordinator listens to the audiotape and corrects some discrepancies. This is very important as I cannot understand Marathi and the interpreter has to be careful and accurate. Interviews are arranged for a community at Chunabhatti. This will test our interviewing in the community.

We cross over the rickety bridge into the community slum near the hospital. The public space is dreadful – piles of rubbish and a foetid stream/drain close by. Auto-rickshaws and motorcycles rattle along the narrow road between the dwellings between goats and chickens and leprous looking cats and quiet dogs. There are mosquitoes and flies everywhere. I am surprised at the number of little shops selling all manner of things from food and sweets to bangles. I am introduced to the community leader, who speaks of the need for sanitation and rubbish disposal, and difficulties for the 2500 inhabitants since

the floods last August. The Co-ordinator had told me that she was marooned and struggled home after 48 hours with water up to her neck in places. There was no water or electricity, and the rubbish twice as bad, as it was impossible to collect it.

I visit a room with a bed, underneath the bed is a small space where this widow lives with her two children as she has HIV/AIDS, and she is dependent on her mother-in-law's charity, and earns a few rupees knotting the ends of dupattas. After that, we cross many a drain to another tiny, airless room where another woman tells an equally harrowing story. This time I am sitting on a bed when there is a sudden movement at the door amongst the metal water pots and I look into the baleful eyes of a rat. I wonder - how do these people manage in all this pollution and disease?

In this community, there is electricity and most dwellings have fluorescent lights, fans and TVs. Women are grinding *masala* (cooking spices) or washing on the stones outside their dwellings, or chatting in the sun. The children playing in the street have no toys except marbles. I see two small boys holding empty cigarette packets up to their ears as pretend mobile phones.

Urban poverty is so drab and colourless, except for the women in their bright dress. Here the people face an endless struggle and it shows on their lined, unhappy faces. We are living in a part the tourist does not see. I start to think of the enormous gaps between the people in the suburb where we are living. The beautiful jewellery shops with security guards indicate the presence of wealthy families. It is quite common for a family to have their own goldsmith as jewellery is still very important. Why are there slums when there is so much wealth? I learn there are as many as 42.6 million slum dwellers in the country. More than half Mumbai's population and over 60% of the city's children live in the slums. Greater Mumbai's 6.5 million slum dwellers far outnumber the other cities. Given the unhygienic living conditions in the slums, their health is significantly at risk.

I spend the first day in the community interviewing in tiny, cramped dwellings – me on a plastic chair, and the others seated on the floor. The Indian women all look so calm and serene, even in synthetic saris whilst I am sweating all the time. Some of the dwellings we visit are in five storey old buildings, but more

substantial flats, unlike the makeshift community near the hospital. I am surprised to see electricity, in the form of fans, TV and fluorescent tubes. They also have running water and sometimes toilets, and sometimes more than one room. I often see the garlanded photo of the deceased husband (who died of AIDS) on the wall. The interpreter and the outreach worker remark on how the women open up in their own surroundings, which I find reassuring. The stories are similar – the women are too afraid to disclose their HIV+ status to the community. Fortunately they can access SAHAS for counselling and that is sometimes their only outlet. They had taken on responsibility for the children of other family members who had died. Mothers-in-law blamed them, even though they knew it was not their fault.

We are getting 2-3 interviews a day, then the interpreter takes time to translate, and then the Co-ordinator checks the tapes, so by the time I get the translation, it is some time after the interview. I am getting very tired with the research now.

I am distanced enough from the interviews as I cannot understand one word, thank goodness for the tapes. I will have to halt the process until the interpreter catches up. They say they have booked five interviews so I will wait until after then. After one month I have 13 interviews done but only one written up.

We visit another slum area near a huge fertiliser factory set in a beautiful garden. Across the road lives a widow with three children and few possessions and little security living in a room with three sides corrugated iron and one side made of blue swimming pool liner. I observe the outreach worker making her comfortable as she often does, and by the end of the interview, the woman escorts us through the community. I realize that not being able to talk to the interviewee has two advantages – I am shielded from the full horror of the story and also I am prevented from doing any counselling. However, I still find it very frustrating.

The community we visit today is even worse and we start off down narrow alleyways where the outlook is dirt and a metre high rubbish heap which goes on for miles. From here, we went to Antop Hill where there were pigs in the street and into more awful slums, and I felt claustrophobic and somehow

disturbed. In one tiny dwelling, a young woman who looks old reaches out her hand in greeting. It is like a piece of sandpaper. She clammers up a ladder into the loft to get a mat for everyone to sit on, and a white plastic chair is produced for me to sit on. Unfortunately I cannot sit cross-legged on the floor which isolates me from the proceedings. Is this a good or bad thing? I wonder. She sits under a hammock, which after awhile starts to move, and a tiny baby makes its presence known. She rocks the baby so vigorously I worry that s/he will fall out, however there is silence once more. Most children here seem to tolerate light and action and noise much better here than in Australia.

And from there to another place with an 18 year old girl whose mother died of HIV/AIDS and what sounded like a CVA (stroke). By the time we leave, all the interviewers have tears in their eyes at the story. The girl has had to leave school to care for her mother, and now her father stays at home to care for her little sister, and the boys have gone out to work instead of staying at school. The interviews at home are valuable as they open up more and seem more relaxed than in the hospital environment. We are interviewing in a window of time – these women's rest time and they may be ill as well, so I am very aware of the privilege, and do not want to upset anyone. It is very good for me to see the conditions, but it does affect me too. I get very tired and this is so unusual for me. I am known at home for my energy and work long hours.

We visit Chembur which is well known in India as the area for shoemaking. We plunge deep into old slums, sometimes three storeys high with narrow, twisting alleyways. Dickensian London has nothing on this. When I think of shoemaking, I imagine huge sweatshops, but this work is carried on in tiny, airless dwellings with piles of shoes in various stages. One family look out at me as they punch holes manually into the Aussie icon, i.e. thongs, and I grope my way along trying not to enter into the open drains full of the discards of leather and glue. I am so scared of falling into the quagmire, that I pick my way gingerly through it all in my old sandals which I shall happily leave behind in India. They have already been mended twice by the roadside cobbler, but they are like a wooden boat, very forgiving and tolerate me falling about without actually giving away altogether. I could touch the walls on either side and I put up my hands to steady me, but I never know what I am going to encounter on the walls. Women edge past in their saris without a qualm. I

want to take photos but it is very dark and restricted with constant movement. I am slow enough just to walk without blocking the alley. I feel I am vicarious enough in my entry into their houses without taking photos, but the pictures in my mind will haunt me forever.

Our interviewee is a thin gaunt woman in a beautiful green sari who continues to work cutting the glued linings of shoes with huge scissors. Her two adolescent daughters sit quietly by in saris of apricot in a room not much wider than a passage. They only earn Rs 100 (\$2.00) a day which makes it worse when one daughter returns for a cool drink for me alone. This area with its close walls and unhealthy, narrow dwellings and terrible drains full of glue and waste made me want to pluck them all out and take them to a better place.

Well, the strategy to allow the interpreter more time to translate did not work. . . I am aware that it takes a long time to listen and transcribe because I did that kind of work for 14 years. However, it is most frustrating. We have now completed 28 interviews, and I have eight fully done. It also alters the research in that by this time, I just want them completed without adding any other complications. If I had more time, it would be better, but as it is, I cannot afford to be anything else but patient.

Sometimes I sit, like today for one and a half hours waiting whilst arrangements for the interviews are discussed and lunch is eaten. Today, my patience is rewarded by being able to interview the team, which I have been planning for ages. This came about spontaneously, and resulted in frank stories of discrimination which they have all observed. These workers suffer from “courtesy” stigma. Their husbands and families do not want them to be working in this area (so they have to be strong to do it). Even the Co-ordinator’s father is reluctant to reveal where his psychologist daughter works. They ask me questions about me and my life, and cannot comprehend a city without slums. I cannot convey the cleanliness of Perth as I know they have never seen anything like it.

In the main, I have achieved my goal – the interviews are done, translated, verified and in my hand, like the team said they would be. I can actually touch these valuable pages, dirtied by the pollution of Mumbai; otherwise I would not believe it. I know now that patience and persistence have paid off and I can

leave, knowing that I have prepared for the next person as well as I can. At this point, I start to feel what Martin Seligman (a psychologist) says is 'authentic happiness'. He says that if you dig deep for your core strengths and use them in an altruistic way to meet a challenge, then you do feel happy and content. Content is the word.

On one of the last days when I have finished the interviews, the team asks me to go to the nearby slum community. When I arrive there I am told it is Haldi Kum Kum day when married women are honored. We wait patiently for two hours and then the women appear one by one, rather self-consciously in their beautiful orange and green saris and all their marriage jewellery. Unexpectedly, I am asked to sit behind a table and the community leader thanks me for coming in to their community. Then five women bless me with daubs of turmeric, red colouring. Then they present me with a clock as a present. I feel humbled.

On the eve of my departure I am thinking of the journeys I have made here. I feel I have done my best and survived, and there is some joy in that. The women in the team have relaxed, and tell me no-one has asked their opinion before. I have great respect for them, and the job that they do and I think their visits are vital for these isolated IWLWHA. I have hoped that they would feel this respect, but for it to be mutual, is an added bonus. Even the interpreter, so young and not given to waxing lyrical, says the research has shown her the true meaning and value of life. Wow, that is something, another journey for her.

13.5 Going to the Movies

Suddenly it is my last day at the hospital. I have arranged with my supervisor that I take all the team to the movies, partly because I know they will have the afternoon off in the process. My associate supervisor plus the Administration Head at the hospital, and another man who has always arranged transport for us, are invited to the movie too. We start off at the hospital with a "picnic" lunch that everyone (not the men of course) contributed to. The interpreter and I were delegated to buy sweets. Waiting around as usual meant we were running late, and there were no taxis, however we made it to the big Imax theatre with its extended screen.

It is my first Bollywood film, but an even more important journey for these women. We all sat in the same row which I liked, as everyone was equal from the Head of the hospital to the community health workers without whom I could not have done my research. The film “Rang de Basanti” was about a massacre by the British which sparked off the whole Indian Independence movement. I could only understand a little of it, but the themes were pretty clear, and the story told with a martyrdom theme, without rancour. Afterwards, the women ask to speak to me through the interpreter and say they will never forget me because this is the first time they have been in a cinema, or on an escalator! It is very humbling, and I am glad my gift has been well received.

13.6 Interview with a key informant

On my very last day in Mumbai I arrange to meet an academic from a Social Work Institution in Mumbai, India. She graciously gives me a long interview and confirms my opinions about the discrimination metered out to women. Then its home again from Victoria Terminus on the train, and I walk up the dusty road to the college for the last time. And I think about my journey here. It has been such a test of my physical strength. No-one stops to help you, and self-indulgence is not encouraged so I have just had to get on with climbing the mountains of stairs. I have had to negotiate drains and sleeping dogs and cows and traffic without a murmur. For all that, I have not had a minute's illness despite sleeping on a hard bed and not drinking enough water and eating all sorts of things.

13.6 Summary

For a brief moment in time, all the people I have met have joined me on my journey only to disperse again onto other journeys of their own. My journey home awaits me. I shall never complain again, I think, knowing that will not last. Despite all the frustrations, it has been worth every step however tentative and difficult.

CHAPTER 14

THE POWER OF VOICE II: Narratives Depicting the Socio-Cultural Milieu

“This (HIV/AIDS) is due to the sins committed by my family. My mother gave birth to five daughters, that itself is a sin.” (35 year old widowed sex worker cited in Tarakeshwar et al, 2006, p. 41).

14.0 Introduction to the chapter

In this chapter, I have used narratives to convey impressions of living which I observed during my stay in India. This narrative construction gives me a voice, and seeks to collaborate with the study’s researchers, journalists, key informants, workers in the field, and finally the women participants, in creating what Zagarell called the “narrative of community” (cited in Emihovich, 1995, p.45). Stories have a universal presence in every culture, often transcending the written word to convey meaning and sense out of experience. In seeking to understand the reality for myself, I have sought to create a bridge between the objectivity of social science research, and my own feelings, perceptions and observations.

The narratives in this chapter present the complexity of human action within interpersonal and environmental contexts. These representations of my experience are constructed from real, remembered observations, which were gathered as I moved around the city, hospital and the slum communities. The subject matter of the narratives allows the human experience to permeate the stark statistics of poverty in a community (Scholes, 1981; Nichols et al., 2001), and to represent a way of knowing and thinking (Casey, 1993) by using my images, understanding and interpretations.

Narratives are an important way of understanding and communicating the personal, and the particular. This form of research is increasingly used in “illness narrative literature” according to Riessman and Mattingly (2005, p.428). Narratives combine

the subjectivity of personal experience with the physical reality of the body and the surrounds, and can illuminate ethical and moral implications of research. Because of its resonance with human experience, narratives can be considered a more relevant form of communication, and particularly in understanding different cultures and communities. At the very centre, is an interest in presenting the complex actions and nuances of human behaviour (Nichols, Tippins, Bilbao, Barcenal, Castellano and Morano, 2001).

Four of the narratives presented below, are derived from the interviews with the participants of the study. The last narrative is taken from my observations during field research, and were chosen from the interviews in order to give a composite picture of four women participants. I chose these particular interviews because they illustrate some of the difficulties which have been described in the literature review, newspaper articles, and interviews. All four narratives reveal the stigma and discrimination prevalent in the community, and the women's reaction and their resilience. The first narrative is the story of Kamla, a young single woman whose family have been decimated by HIV/AIDS. She has risen above the situation to become the main breadwinner for her family, and has learned much about herself in the process.

The second narrative, related by Vandana, illustrates how a woman has overcome the obstacles of forced marriage, and mental illness, to care for her beloved husband, and to find, in widowhood, the strength to care for her children. Neela's story is one of extreme discrimination within her own family, and the lack of property rights. Yet she finds her own inner strength, hope and resilience, even though she is affected by HIV/AIDS. In the fourth narrative, Veena displays the willingness to sacrifice money and her own marriage if necessary in order to care for her sister, who is affected by HIV/AIDS.

Polkinghorne's (1995) method of interpreting and analysing the narratives has been used. This involved subjecting the narratives to a process of constant comparative analysis whereby the narratives were read and reread, and an interpretive commentary was provided at the end of each narrative.

The narratives do not represent all Indian women, not even all women in the study, as they expressed diverse opinions on most topics, but they do represent some of the facets of the participants' difficulties. The narratives were written early in the process, and then refined with my growing understanding of the women's lives. Fisher, (cited in Messinger 2001), says the two criteria for narratives are coherence and fidelity. Coherence relates to the story making sense and having form, whilst fidelity is concerned with being true with one's own experience.

14.1 Narrative 1: Kamla

The tragedy of Kamla's brother dying of AIDS has been the catalyst for this young woman's care of his children and to educating her community

Kamla is a 29 year old single woman who lives in Chembur, a very poor part of Mumbai. Her father and mother moved there from Gujarat in 1942. She is from a scheduled caste, and speaks Hindi, Marathi, and Gujarati. Kamla went to school, and completed 10th standard. She is a lovely looking woman with a ready smile, and gentle eyes, which belie her hard life. She has a calm manner, and people say she has a good sense of humour. Her brother contracted HIV/AIDS. Before that Kamla did not know anything about the disease. Kamla related:

“There was absolutely no awareness about HIV/AIDS. I think my brother was the first case in our area. My brother was a very simple man. No-one could even think that he could get infected. People thought that he might have contracted the disease by wrong means. It is a possibility, but I don't think so.”

He was much loved by his family and friends. Kamla cared for her brother, and had to do a lot of the work at home, as well as having a job. Her brother was fit and healthy for some time, then suddenly, he became ill with malaria. Kamla's sister also became infected with HIV/AIDS, also her husband, and another family member.

Kamla started learning about HIV/AIDS, and by the time her brother was dying, she knew a lot more. Her family was very scared, as it was all so unexpected. She was very proud, as her knowledge meant she could help

other members of her community, and they still come to her if they need medical aid. She felt she has created awareness too. Her confidence grew. When her sister died, the doctors at the hospital told her to get a plastic kit to wrap her sister's body. She refused, because she knew there was no need for this. She asked the doctors if they really knew about the infection, otherwise they would not ask her to do this. They said it was a precaution. She told them if they did not want to touch her sister's body, she would do it, and she did. Now, Kamla is the family breadwinner. She studied, and became an outreach worker, and is now a valuable member of the HIV/AIDS team at the hospital.

She has educated people in her community and also her own family. Her sister was so scared when her brother became infected, she refused to enter the house. Kamla helped her to understand, and watched her sister go from being healthy to skin and bone in a month's time. Kamla is the carer for her sisters and the orphaned children, one of whom is blind. She speaks of the discrimination attached to HIV/AIDS, not in her own house, but in the wider community, and she is determined to make people more aware. She said:

“I have seen in many families that if the husband is infected first, he creates a scene in such a way that it looks like the wife has infected him, and not vice-versa, which is actually the case. A male child will get more attention than a female child. A wife is mostly put to blame, no matter what.”

14.1.1 Interpretive Commentary

The area of Chembur is well known throughout India as a shoemaking area. The community who carry out this work has been lower caste for many generations. Working with leather is considered a despised occupation as it is derived from the cow, sacred to Hindus. Originally the caste structure was somewhat related to occupations such as warriors and rulers - *kshatriya*, merchants –*vaishya*, artisans and agricultural labourers – *shudra*, and those at the bottom of the scale – *harijan* who performed the most menial of tasks.

The conditions in which they live are incredibly awful. The slum housing has also existed for a long time and is full of narrow, dank alleyways with green mould up the

walls. Gutters run down the middle of the walkways, which are constantly wet, because the workers dump the waste materials, such as glue, into the drains. The houses are usually one room, and windowless, dark, and cramped. The workers - men, women and children, attend to all areas of shoe making – i.e. cutting the patterns of sandals from leather, sewing soles together, and punching holes in thongs. In these dwellings, they also eat and sleep.

Kamla lives in one of these dwellings with six members of her family, and yet she appears cleanly dressed in a sari, and pearl earrings, with a smile on her face. Even more amazing, has been her ability to use her experiences, and turn them into the basis for her job as a para-social worker – no mean feat for a woman from a scheduled caste. Despite her experiences, she is satisfied with contributing to society, and is proud of herself, and her job, and her ability to sustain what remains of her family. It is unlikely that she will be able to marry at her age, and in these circumstances. Kamla is an example of two generations of upward social mobility. It may have been that her father moved to Mumbai to escape the grinding poverty of village life, only to find himself in the urban squalor of Chembur. However, his daughter has managed to escape into a much more valued occupation, made possible by her education and natural intelligence, changing attitudes, and the opportunities that a large city offers.

14.2 Narrative 2: Vandana

A woman who triumphed over her own mental health problems to care for her husband with AIDS.

Vandana is 40 years old. She was born and bred in Mumbai, and went to school till 6th standard, and she can read and write. She has been living in the slum community since 1994. She is widowed, and has four children - three daughters, and one son. Vandana says that since the age of 16 years she has been mentally unstable, and that she has been affected by the fact that she was married “forcefully” against her wishes, and her husband was jobless, and her in-laws were not good to her. Her second husband was Muslim, and she is Hindu. Despite this difference, and disapproval from their families, they married, so no-one visited them much.

Her husband was diagnosed with HIV/AIDS in 1998, and remained fit and well for five years. He then became ill with malaria and jaundice, and was ill for one year. At first, Vandana was so shocked by the report she read that she left the hospital. She said:

“All of us know how the world treats HIV/AIDS patients. I think the reason people do this is because of the causes that lead to this infection. The first thing that came into my mind when I saw my husband’s report was that he was sick and could die at any time”.

She wanted to spend as much time with him as possible, and make him feel loved, and wanted. She nursed her husband, and took out a loan to pay for all the medical expenses. However the shock of his diagnosis meant she fell into a severe depression, and had to undergo shock treatment twice. She says her husband was the only support they had, and she still remembers him. When Vandana’s husband was alive, they had a shop, but she shut it up after his death, and now stitches blouses at home. She can earn up to Rs 4,000 (\$107) per month, but it depends on her being well mentally. With regard to discrimination, Vandana said:

“People did discriminate (against my husband) and it continues till today. Some of my customers don’t come to me as they think I am infected (although she has tested negative). In this slum, there is one toilet shared among five houses. No-one used to use our toilet. I cannot keep anything to myself and I cannot lie, so the whole community came to know. No-one helped us.....Now, my world revolves around my children and my work.”

14.2.1 Interpretative Commentary

Vandana says she was “mentally unstable” from an early age. It is unclear whether this was a result of being “forcefully” married, or depression, even before that. She was definitely unwilling to marry the man chosen by her parents, and was badly treated by her in-laws. These situations are reported daily in Mumbai, and make up the fabric of many women’s lives. She must have started with her second marriage with high hopes. Despite the religious differences, she was prepared to start a new life, and her husband was prepared to take on the three children from her previous

marriage. Unfortunately, HIV/AIDS interrupted that life. She expresses no rancour or bitterness towards her husband, or the difficulties that being a widow presents. I often saw garlanded photographs of husbands on the walls of widows' houses.

The stigma that Vandana describes is what is called *courtesy* or *affiliate* stigma which means she is not affected by HIV/AIDS, however she had an association with a sero-positive person –her husband. The layers of different stigma are present in her story: firstly, being married to a Muslim, then as the wife of a HIV positive person, and then as a widow. Long after her husband has died, her neighbours are discriminating against her and her children, who are free of HIV/AIDS. The consequences of being open in her community are clear – discrimination and lack of support.

I considered the fact that her neighbours would not use the shared toilet as a distinct advantage, but she only perceived this as a slight, and further discrimination. The conditions of the slum communities mean that many dwellings do not have their own toilets, and only limited washing space. Vandana was a special woman who had triumphed over her mental condition, in order to support her family, even though what she is earning is below the poverty line.

14.3 Narrative 3: Neela

Neela is widowed, without property and affected by discrimination in her family.

Neela was born in Uttar Pradesh and like many others, came to Mumbai after her marriage. She is a Brahmin (Mishra) by caste, and Hindu by religion. She now lives in a slum community near the hospital. She went to primary school, and can read, but not write. Ten years ago, Neela's husband became infected with HIV/AIDS, and he died 3 years later. Neela also found out she was infected, when she became ill eight years ago. The doctors told her she could live longer by taking medicines and proper nutrition.

She was dependent on her in-laws for shelter, and they have made her live under a bed with her three children, for seven years. The remaining seven members of this family (her parents-in-law, brother-in-law and wife, and two children, and another brother-in-law) live inside the house, which is really only one room. She is allowed to use the bathroom and kitchen, but she gets tired

very easily, and has lots of loose motions. She still has to get her children to and from school, care for them and cook meals. She earns money by knotting the ends of dupattas when she is well enough. Neela comments:

“I think this kind of discrimination which results in me living under the bed is wrong. I have seen cases where families have thrown away people infected with HIV/AIDS. So, in comparison to them, I think I am in a better condition.”

She concludes with:

“I have no-one to talk to. There is no way anyone can help me. No-one shares our troubles. No-one will help me. They will only taunt me. My daughter’s life is spoilt and she is not at fault for it”.

Asked about her belief in God, she says:

“I think that my trust in God will not go in vain and my condition will improve”.

14.3.1 Interpretative Commentary

This interview was carried out in the appalling living conditions which Neela is forced to accept. This consisted of a narrow passage way, where we sat, and space for a bed. A male relation lay sleeping on the bed, underneath which she lives with her children. The interview was whispered, so as not to disturb the man who slept throughout. Like many other women, Neela has no rights to property, and depends on the goodwill of her in-laws. She is far from her land of her birth, and has no family, or community support, in Mumbai. She is infected with HIV/AIDS, which makes her ill, and not always able to earn any money. To be treated like this through no fault of her own, is such an insult, but at the same time, there were seven other members of the family living in one room. In her eyes, even though she knows this discrimination is wrong, she says she is fortunate, because she has witnessed the treatment of other widows who can be thrown out on the street. This constant threat is another stressor in her life. Her children also suffer the same stigma and discrimination, which women in this position felt keenly.

The only people she can confide in are the community health workers from the KJ Somaiya team, who provided food and clothing when this area was flooded in July 2005. Despite overwhelming odds, Neela displays strength, hope, and resilience. She still has hope and trust in her God. One can only wonder what will become of her children if she dies. If she can remain healthy until they are old enough, she may see better conditions.

14.4 Narrative 4: Veena

A woman who has determined to take on the care of her HIV Positive sister

Veena is 39 years old, married with one daughter. She lives with her husband, her child and mother-in-law. She is Hindu by religion, Maratha by caste, and from Mumbai. She has limited schooling to the 2nd standard. Her husband has a temporary job as a driver, earning Rs3000 (\$80) a month (Rs4000 (\$107) is considered the poverty line). Out of this money, they send money home to her husband's family in the village.

Her experience of HIV/AIDS is very new, as her sister was diagnosed at the Somaiya Hospital, only a few days before the interview. She knew that there is no cure for HIV/AIDS. Even though her sister's husband had died 3 years ago, they did not suspect the infection. They felt that she would get ill, and then recover.

At first Veena was very scared that she and her husband may be infected, because her sister had been staying with them for a year. Caring for her sister had resulted in financial hardship, and she had to pay for her medicines by pawning her jewellery. Veena is very committed to her sister's care. She thought that, if she was also infected, she would take her sister to a remote village to live out their lives, like the lepers of old. Beyond that, she was very concerned about her husband's reputation, as he has a good name in their community, and she did not want people raising questions about his character. Fortunately, her husband decided to continue caring for Veena's sister. If he had not agreed, she would not have had any choice in the matter. The fear of discrimination is strong, and she says that she had not told anyone:

“She does not want people to fill my husband’s ears against me. They will tell him not to support my sister. And I only have his support. So I don’t want to tell anyone”

They have not found any discrimination from the doctors at the hospital, and they are receiving some financial help arranged by the social worker. It is early days since the diagnosis of her sister, and, although her sister has been very shocked and sad about this news, Veena knows she will cope with this very soon. There is a sense of relief about it all, as Veena had taken on the responsibility of her sister, whatever the outcome.

“It is very simple really. She is family and we don’t leave our family just like that.”

14.4.1 Interpretive Commentary

Veena’s story highlights the significant level of care in families. As a loving sister, Veena was prepared that if her husband disapproved, that she would take her sister into isolation to live out her life. Already Veena had pawned her valuable jewellery, which is kept as a symbolic mark of a married woman, in order to pay for medicines for her sister. It is not easy to find the money for extra expenses in poor families. Her desire to preserve her husband’s reputation is strong, and yet she also fears the community reaction, and how they would act against her, and persuade her husband not to care for her sister. This fear may prevent her from accessing services for her sister. Certainly she has turned to the hospital, rather than her community, in extremis. It has to be remembered there is no social security system for people to call on in times of illness, so they are very dependent on their families. Veena’s sister is indeed fortunate to be able to depend on a relative for aid, as this is not guaranteed in situations where there is HIV/AIDS.

After many days of observations, I wrote composite stories of real-life situations during the data collection phase, which had affected me personally both as a researcher, and a human being. I wanted to portray the conditions and endeavour to bring the situations to life by describing them. These narratives are designed to portray the complicated interplay of settings of life in the slums of Mumbai. I have

presented these narratives as described by Guba and Lincoln (1989, p.181), who suggest that the analysis is

“Characterised by a description that not only clarifies context, but also makes it possible for the reader to experience it”.

14.5 Narrative 5: The children of Mumbai

The children of this city continue to haunt me. You could never doubt the love of children in the indulgent looks of parents, as they carry their children across the busy roads. And they do get carried, because you could never hope to guide a pram through the traffic, or the uneven footpaths. Mothers set off so bravely, and with such aplomb, carrying children, and holding hands with little ones, weaving through the auto-rickshaws. Sometimes it is little children who join hands, and take their chances in crossing busy streets. Schoolgirls with their hair looped up in plaits and checked uniforms, and old-fashioned English shoes, make their way through the chaotic, hooting traffic. You see children in taxicabs and auto-rickshaws, sometimes ten crammed into one taxi, careering around, with not a safety belt in sight, unless the driver has one on.

As I careered along myself, I would see children who look unsupervised, playing near the roads with no fences. I wondered if they have a better sense of danger, that they can be trusted like this. These are the most independent of children on the fringes of danger all the time. Of course, there are many pedestrian deaths, but I did not see one accident, hurtling around the city as I have done. There are other dangers too; that I think about – not only the wild dogs that came alive at night, but human predators too. There was a police raid on businesses which use child labour, and the children were “nabbed” at the railway station as their employers were hurriedly packing them back to Rajasthan where they had been recruited.

Many slums are right on the road, and you have glimpses into the intimate details of the families. One night at dusk, I saw a child of about four years crouched on a second-storey window ledge cleaning his teeth, and further on, two children in their one-roomed shack, sitting on the floor doing their homework. Boys, (never girls), fly kites or play cricket with the most primitive bats in dusty spaces.

The suburb where I stayed was a very poor area where you could see mothers and children curled up on the pavement in all weathers. The street children tug at your heart and look so miserable and sad. Then you turn around, and they are laughing and teasing each other. Who to give to? - that is the question. Is it to the old grandmother stooped and walking with a stick, and a huge sore on her ankle, carrying a pile of plastic on her head who is not begging. Or is to the little girl at the traffic lights who carries a wrapped-up baby? I have seen her unwrap the bundle, and it is not a baby at all. Or is it to the little boy with a dirty Santa cap, or the young boy who wafts incense into the auto-rickshaw, or the thin little children at the railway station. The list goes on. One day, when we were driving into the city, I was startled by a sound at the window, and a baby's arm was thrust in at me, burnt and all caked in blood and dirt. The baby looked drugged and was quiet. Who would do such a thing? Later, I read in a newspaper report that this sort of begging had been reported.

Then there were the little children in the slum communities, who had HIV/AIDS, or their father or mother has died from it. They are even thinner and smaller than usual, and their hair is different – not the beautiful, luxurious hair of other Indian children. They lack energy, and are listless, and their future is bleak. Without the major breadwinner, the income of the house is compromised. Some families were living on as little as Rs5000 (about \$133) a month. No-one wants to predict their life expectancy or future in this city with their parents gone. They are thrown on the mercy of extended family, who may have difficulty in making ends meet themselves. I never saw a toy or a game, but I did see two children pretending they had mobile phones with two empty cigarette packets, and I saw children's enthusiasm and pride, as they crouched over their writing on the tiny slum community schoolroom floor, wearing their uniforms and singing their national anthem with verve and energy.

14.5.2 Interpretive commentary

The above narrative is derived from my observations as I traveled from where I lived to the hospital. Private lives of people are exposed in the cacophony of movement, action and sound which are the streets and highways of Mumbai. Dwellings about the

heavy traffic, and sometimes I felt I was intruding into their very lives, thus reminding me of the dilemma of vicarious observations.

The children seemed so vulnerable. There was the risk of disease from unsanitary conditions, pollution, and proximity to the constant traffic. Their dwellings were unsafe and crowded, Yet, as children everywhere, they laughed and played amongst the rubble of newly demolished houses, and made their way across busy streets to school, and sold their wares on busy intersections. What a contrast to our pampered and protected children.

14.6 Narrative 6: A Day in the Life of a Housewife in Mumbai

She lives in Chunabhatti, a suburb on the outskirts of the mega city of Mumbai. The surrounding area is flat, with open fields leading up to the hospital of KJ Somaiya, a medium sized, grey building in the distance. The expressway, which leads to the city, is beyond the fields where young men are playing cricket. The highway is always full of traffic, but the noise is muffled from this distance. It is difficult to see that far anyway, as a constant, polluting haze is in the air.

By now she has been awake for six hours, even though it is only 9 am. She had to rise at 3 am, because the water is only pumped to the community for half an hour. She filled her big metal containers with water, sufficient for the family's needs for the day. She then started cooking for the day. The dhal, chapattis, soft bread, rice and vegetables, must be cooked daily as there is no way to preserve them; and in just the right quantities, so there is no waste. At this hour of night, it was cold outside as she coaxed her small fire into life in order to get just the right heat for cooking. She did her puja (prayers) and had to walk to the public toilet. She can wash at home and do her hair. Combing her hair and dressing in a fresh sari gives her pleasure as she planned her day. Her husband suffers from HIV/AIDS and now she has the responsibility of his two children from a previous marriage. Their mother died in childbirth. Unfortunately she too is infected with HIV/AIDS and battles with her own health. At least she has a place to stay, although these are illegal dwellings in the government's perception, and there is always the chance that the area will be gazetted for levelling, and they will be sent elsewhere.

Now she washes the clothes on the front step, whilst she supervises the children doing their homework. She can only watch them as she only had schooling up till the third grade, when she was called home to care for her mother. By 7.45 am she is ready to walk the children to a school outside the community for extra classes, before they start their lessons at 11.am. She makes sure this is done because she understands the importance of education for her children.

She returns to the community by means of a makeshift bridge over a murky, grey viscous drain, bordered by rubbish piled high, and down a narrow alley between dwellings to the street combined with walkway. She greets her neighbours - men returned from work playing cards in groups, women always working – pounding spices for the daily meals on stones, washing clothes on their doorsteps, laying out chillies in piles to dry, drying their hair in the sunshine, watching their children play, looking after their babies. She speaks in Marathi, the language of this community. There are many shops selling everything from general groceries to sweets. She stops by a cart to buy small carrots and onions. She also stops briefly by the tiny Hindu temple, and the holy man blesses her. It has taken her half an hour in the hot sun, and she is glad to reach her dwelling.

The one room of her dwelling is occupied by her husband, herself and the children. The bed just fits between the two walls. At least there is electricity so there is fluorescent light, and a fan to make up for the lack of windows. She has a bench on which to wash her pots and pans and plates. She does this carefully as she knows that a woman is judged by the size and condition of her '*steel kitchen*'. The small area where the family wash is cleaned and the whole area swept free of crumbs which would only encourage rats and cockroaches.

Her husband returns for lunch and expects a hot meal as he has to keep up his strength. It worries her how long he will be able to work as he is frequently ill with chest infections. He drives an auto-rickshaw, and is tired from the continual traffic noise and pollution. Usually after cleaning up she would rest. However, she has been offered the opportunity of doing a sewing class at the hospital. Who knows how long her husband can continue to work, and then

all the responsibility for the children will be hers. In any case, she really looks forward to these afternoons. She has not been able to tell anyone in the community about the disaster of HIV/AIDS, which has befallen her and her family; but at the hospital she usually can talk to other women and share her life, and get advice, but she knows this is special. She has seen other families being teased and avoided, and she does not want the children to be at risk of being hounded out of school, so she tells people she is well.

At the hospital she can talk to the other women who also are battling with this awful infection. If she is particularly upset, she can go to the counsellor at the HIV/AIDS office and she will help her not to take tension from her situation. At 4 pm she sets off again from the hospital and picks up the children between 5-6 pm. She then cooks dinner for the family, eats last, cleans up and is in bed by 10.30 pm. She always feels tired these days, but counts herself fortunate that she has a husband. She does not look very far into the future, but feels God will protect her and let her live long enough to bring up the children.

14.6.2 Interpretive commentary

The sixth narrative is derived from an interview of a housewife living in the community, as well as my own observations of the life and conditions. It was important to obtain some sense of the working day of these women and to relate it to the pollution, overcrowding and generally unhealthy conditions of these slum communities. In doing so, I inevitably contrasted this life with my own experiences both in Africa and Australia. I have to say that I have never been able to get my pots as clean as those shining examples in the steel kitchens in the slums of Mumbai.

14.7 Summary of the Chapter

These narratives represent the harshness of life in slum communities. The conditions make everyday housework more difficult and are felt more keenly by women. The threats which arise from the social, economic and environmental dimensions have been described in previous chapters, and are further demonstrated by the scenes I confronted in each day as I navigated the communities. The strengths I observed lie in the resilience and sacrifice of the women living in such difficult conditions.

The narratives navigate these women's lives and display the nuances of stigma, discrimination and prejudice. They reveal threats but also special strengths, and epitomise the unique ability of human capacity to adapt to difficult environments, making use of the available physical and economic resources. The next and final chapter concludes this study with an overview of the thesis, conclusions and recommendations.

CHAPTER 15

CONCLUSIONS, SIGNIFICANCE AND RECOMMENDATIONS

“Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it is the only thing that ever has.” (Margaret Mead, cited in Bent, 2003, p.215).

15.0 Introduction to the chapter

In this chapter, I provide an overview of the overall research, and discuss the threats which affect women’s coping ability. The factors which can lead to strengthening the agency of women are also defined. I have made recommendations based on the findings from this study, and previous research. The significance and limitations of the study are discussed, and finally, a concluding statement is included.

15.1 Overview of the research design

A qualitative approach was used in this research study as I wished to explore the themes more fully than a quantitative design would have allowed. This resulted in valuable, rich data. In-depth interviews, documentary data collection, a reflective diary, narratives, photos, interviews with key informants, and a group discussion fulfilled the criteria of triangulation. The interview schedule was semi-structured, and open-ended, except for the demographic information, which was represented by graphs and commentary. The interview included the participants’ background, and demographics such as language spoken, age, religion and caste. These dimensions have effects on knowledge and awareness, living conditions and socio-economic status. Education levels were asked, in order to inquire about the knowledge, and awareness of HIV/AIDS. Financial information placed the women on a socio-economic level. In addition, the number and composition of households showed the financial position of the participants. Stigma and discrimination was explored by

questions about confidentiality, and how the participants were informed of their diagnosis. Their perceptions and experiences, adaption to the progress of the disease, secrecy, and the impact of HIV/AIDS were elicited through interviews. Family and community reactions were sought as well as the participants' experiences of healthcare. Questions were asked about their physical and emotional needs, whether these needs were met, and what helped them to cope.

Information from government reports, and internet sources was collated and analysed, and news articles from India and elsewhere, were subjected to frame analysis. Key informants were interviewed, and a focus group discussion held in order to discuss the key questions of the study. Data from all of these sources confirmed the presence and fear of stigma and discrimination, and allowed examination of the effects of the social, cultural, economic, physical and environmental forces.

15.2 Overview of the research process

The psychosocial framework was a useful tool to examine the effects of HIV/AIDS on individuals, families, communities, society, and the resulting stigma and discrimination. The structural processes of society and culture can be seen to either weaken or strengthen resilience. In this study the focus is on women. Despite the threats to their human capacity, and the daily difficulties they face, they are extremely resilient, and remain sources of strength for their families and the communities in which they live. The framework was modified in the context of this study to examine threats and strengths more closely.

Any interventions which promote and support resilience can build on the existing strengths and knowledge of women, which have been developed partly through social expectations and complex cultural structures. By supporting women, the entire family is supported, and their own health and wellbeing improves. Collaboration of both women who are affected by HIV/AIDS, and therefore have minimal physical strength, and active people in the community, is needed. There is also room to establish new social systems and transform cultural mores. This is not impossible.

India has experienced many changes in its history, and is capable of great success such as family planning, and allaying famine. Culture is not immutable, and can change and respond. Any one intervention, however, is not sufficient to effect the desired outcomes. It is only by understanding the interweaving of culture and society with behaviour, that transformation can take place.

15.3 Stigma and discrimination

The key question whether HIV/AIDS stigma and discrimination exist today in the slum areas of Mumbai, despite information and awareness campaigns, has to be answered in the affirmative. The participants in this study described instances of stigma and discrimination in their own homes and families, in their communities, and in the healthcare system. These women have been exposed to discrimination throughout their lives because of caste, gender, socio-economic circumstances, and where they live. However, they reacted to the latest discrimination accompanying HIV/AIDS with feelings of unfairness. As Neela, the lady who lived under the bed said: “This discrimination is wrong.”

This finding is supported, and validated by the documentary data, in the form of media reports in India, which I collected over ten weeks in India. Despite the fact that the data collected in India was often sensationalised, there were news articles which reported instances of stigma and discrimination. Key informants also corroborated the evidence that they had observed stigma and discrimination within their experience. Any change has to start with awareness. Research has demonstrated the presence of stigma and discrimination of women and its effects.

There is still a long way to go with educating health care personnel in the basic treatment of IWLWHAs. Fear and ignorance lead to the attitudes experienced by these women. Particularly harsh and avoidable was the advice given to pregnant women which caused great suffering. Prejudice is rife, and healthcare rules are not carried out (Solomon, Chakraborty and Yephthomi, 2004). Although women have greater vulnerability to HIV/AIDS, they have equal survival rates, if treatment given to them is equal to males (UNAIDS, 2004). When women have a positive experience

in the healthcare setting, it has a flow-on effect of showing that discrimination is not mandatory in their lives.

Women, in this study, experienced stigma and discrimination within their families. This finding replicates research by D’Cruz (2003) and Bharat and Aggleton (1999). The very place (i.e. home), where a woman should expect to find safety, solace and care, is uncertain. Even when the situation is stable at the present time, these women fear the future, and what may happen. Women themselves can internalise and enforce the attitudes of the dominant patriarchy resulting in mothers-in-law neglect of their sons’ wives, thus colluding in the inhumane treatment of these women (Pradhan and Sundar, 2006). The plight of widows can be compounded by their youth, and lack of experience.

Addressing stigma and discrimination through individual behaviour change has proved inadequate. HIV/AIDS has to be recognised as a family and social disease, with far-reaching effects on the community. Fear will overcome logic and knowledge in most people. As in the case of the sister recounting the illness of her brother,

“I used to think that people should come forward to help us. I think they were too scared to come.”

The participants had observed instances of discrimination in the community, and so they felt that the same would happen to them, or their family, as they perceived themselves as equally stigmatised. Especially when children were involved, the families feared that they would be hurt by the reaction of discrimination. This fear was justified by a recent newspaper report that children had been ousted from a school in Kerala, and then reinstated, but the other parents had forced the school to reconsider and keep the ban (*The West Australian*, 19 June 2007, p.30).

Fear leads to withdrawal, and reluctance to reveal sero-positive status. This is an important issue both from the point of view that the IWLWHA and/or her family will be prevented from receiving services, and also women will be isolated in their families or communities. Isolation is one of the most severe punishments for anyone,

and is used in torture and gaols. There is evidence that it leads to physical and emotional illness (Simbayi et al., 2007).

The study documented the nine points below in relation to stigma and discrimination faced by IWLWHA

15.3.1 Women's vulnerability to HIV/AIDS

Although there are certain biological considerations and health conditions which make women more vulnerable to HIV/AIDS than men, women have the capacity to thrive physically and improve their status, if they are given equal access to adequate nutrition and health care. The significant areas of vulnerability which need intervention – domestic violence, commercial sex workers, child marriage, trafficking of women are socially driven by male power, rather than biological determinants. Cultural beliefs and mores make women into colluders of the status quo resulting in women discriminating against women.

In this study, different age groups experienced specific problems brought on by stress. The younger women had lost their means of livelihood through their husband's illness, or had been expected to take on other members of the family affected by HIV/AIDS. The youth of the women widowed through AIDS is a particular problem. They experienced the increased stigma created by widowhood, exacerbated by HIV-positive status, and it is important to consider this group (Pradhan and Sundar, 2006). In addition, there are the older women who are expected to take on orphans and daughters abandoned by their in-laws. They may not have the knowledge of AIDS that they need (Pradhan and Sundar, 2006), and not be exposed to awareness programmes, or have access to medical care. Their own health and fitness may be compromised.

Although HIV/AIDS is now globalised, it does not feature in international relationships or in political economy. Globalisation can mean sexuality is increasingly commoditised, and widely lauded sexual mores may conflict with older, traditional customs, with a concomitant breakdown in family values. The spread of the HIV virus can be partly attributed to globalisation, because the breakdown of geographical barriers and urbanisation rapidly dispersed the disease. The growing

internationalisation of trade in sex and drugs has played a major role in the spread of AIDS, and it is both a product and cause of globalisation. The breaking down of barriers has played a role in increasing demand for younger CSWs, often from rural areas, or girls from neighbouring countries – for example, young Nepali girls. The additional vulnerability associated with social dislocation, poverty and the absence of health services increases the rapidity of the spread of HIV (Altman 1999).

“Possibly, the skills and knowledge women acquire in the formal education system are not sufficient to enable them to take control over other parts of their lives...It may come too late to prevent them from being the victim of unwanted or transactional sex as adolescents” (UNAIDS/UNFPA/UNIFEM 2004).

Children are deeply affected by HIV/AIDS in India. There are girls who become caregivers and orphans created by the epidemic and there is little provision for them as their mothers become ill and die (Ekstrand et al., 2003). In 2005, more than 60,000 children died of AIDS in India (HIV/AIDS Forum, 2007). The women worried about the future of their children without protection of parents. Planning for their care after parents’ deaths would alleviate some of the mothers’ suffering.

15.3.2 Strengthening women

As discussed in previous chapters, there are many obvious areas in which women are undervalued. This situation demands an acknowledgement of women as informal healthcare providers. When we observe the level of work within the home as caregivers, providers of physical and emotional services, women are very valuable. They absorb the shocks and stresses of the family (Sen and Ostlin, 2007). Until there is recognition of their value and their work, denigration will continue. Gender inequality damages physical and emotional health of women, even though it gives men benefits through power and resources. It is very difficult to examine the structural, social and cultural influences separately. Each, and every one of these factors, impact on women unfairly, and when they are combined, the effect is formidable. There are agents who can positively affect the status of IWLWHAs by their actions such as men, other women, families, community, doctors and healthcare

professionals, religious leaders, policy makers, government and non-government agencies.

There is no doubt that education is a protective factor for women in the fight against HIV/AIDS, as well as benefiting the community. In the group of women interviewed, peer educators such as the community health workers are the preferred way of educating women (Pallikadavath, Sreedharan and Stones, 2006). There is a two-way benefit which I have noted in community health care when it is provided by women. Both the clients and the providers benefit from the service. The CHWs told me of their growing pride in their work as they overcame their feelings and began to make a difference. In time, these women can train others. It is extremely important that home-based care is provided by women, who not only understand the difficulties in the community slums, but also speak the same language. These are women from the community slums, who have received training, and are now proud of their occupations. This service is using the capacity and expertise of women from the community. There is a need for positive experience in healthcare, and community services. It is possible for allopathic and non-allopathic healthcare providers and healthcare workers, CHWs, community leaders and families to model non-discriminatory attitudes, which give women confidence and understanding. There were instances in this study where women modelled positive attitudes, which are now recorded. Additionally, the community health workers were excellent role models who could enable other groups to adopt better attitudes.

The women's lives were difficult enough with daily problems to solve, apart from this new area of HIV/AIDS. As I have discussed, everything is made harder by the loss of the breadwinner, and/or caring for members of the family, and by their own illness. For women usually dependent on family, some participants showed flexibility, and active coping skills, in adjusting to the circumstances. However, women need other women to help and support them. Sick women can barely manage their own lives and their families. The provision of a safe place for women to meet has proven very successful in India, as well as Australia. Key informant (KI 4) outlined how services of a community service can be a model of good practice. The concept of a "safe house" is a basic tenet of Australian women's health centres. Any

programme has to have built-in measures to compensate for the time taken away from household tasks, and child-care is essential if women are to participate.

The power of self-help groups to provide support, information and networks cannot be underestimated. AIDS-positive volunteers have been used successfully in programmes in South Africa and Uganda. The Positive People's Network is doing well in India, and collectives amongst CSWs have highlighted the need for, and the power of peer educators (Halli et al., 2006); and the power of HIV positive peoples' personal stories.

The concept of counselling is not always well understood in India (UNDP/UNFA/WHO/World Bank, 2003). Although pre- and post-test counselling may be employed, longer term counselling to address ongoing issues in physical and mental health is still regarded as a luxury commodity. However, if women are to be strengthened, it is by understanding what they deserve. In this study, they have expressed their opinions and perceptions of HIV/AIDS in their lives. Ongoing psychosocial support is essential (UNDP/UNFA/WHO/World Bank Special Program of Research & Development and Research Training in Human Reproduction, 2003). Counselling does not always have to be directly provided by a qualified psychologist although it is obviously beneficial. I have worked in situations where it has been more suitable to support staff to provide informal counselling. In the SAHAS programme, the Psychologist Co-ordinator was able to provide support to the community health workers.

15.3.3 Indian women's status

The issues of caste, class, poverty, patriarchy and gender are inseparable, and continue to affect the experience of HIV/AIDS for women in lower socio-economic positions. Male dominance in the home is reflective of the institutionalisation of privilege along gender lines in a patriarchal society. The documentary data provided many instances of the unequal status of women and gender issues. These were presented in an informative manner. The key informants and nurses also noted the discrimination towards women, which led to unfairness in healthcare provision.

Religion is used as the unquestionable enforcer of these structures, and to justify violent behaviour towards women. With strong leadership such as that shown by Gandhi, or Dr Ambedkhar, religion has the capacity to provide the breakthrough into these areas. There are signs of change. Targeting the leaders of religious sects could lead to changes in attitudes particularly in men. Some religious groups are models of care such as Catholic Relief Services. A new initiative which uses the sacred texts of Hinduism, Christianity, Islam, Jainism, Ba'hai and Zoroastrianism to urge people to take a pledge of fidelity to their partners was reported in 'Fighting AIDS, the Gandhian way', *The Indian Express* (7 October 2007, p. N/A).

No single intervention will provide the answer. History shows the power of social and cultural determinants on the status of Indian women. The stark reality is that women at this level of society are defined in terms of their use to men and family. The impetus for change may come from women who learn enough about other cultures through the media, or middle class women, able to look beyond their comfortable existence, or men who change enough to allow women freedom.

Multi-level interventions are necessary in order to change. Laws and knowledge of human rights have not been enough to ensure equality for women, although they are important. Education and awareness have not halted the transmission of HIV/AIDS to monogamous married women. Globalisation has not brought about desired changes for Indian women. Poverty renders women more vulnerable to HIV/AIDS which results in even more poverty

Advocacy for women by women is a source of strength that is yet to be explored. This can be achieved by supporting women-friendly programmes, organisations and people who are working at the coalface to improve women's position (key informant 4, community health workers). Respected female qualitative researchers such as Bharat, Solomon and D'Cruz have made valuable contributions. It is important to place women in large scale, quantitative and country-wide reports, discussing their needs and to encourage health systems to be more accountable. Interdisciplinary research brings together new understanding and explores possibilities beyond individual responses.

The media have an increasing role to play in the lives of women. The ubiquity of television provides a powerful and accessible medium for information as long as it is accurate and does not anchor the stereotype of subservience. To counteract this, women have a role in networking and informing the media.

15.3.4 Better healthcare for Indian women

Poverty is a major factor, but not the only one in determining the possibility of education, employment and awareness. Gender inequity in health is socially governed and therefore can be changed, and this provides hope for change. In order for women to be better served in healthcare, they need to be empowered. This can be achieved by firstly educating women as to their rights to adequate and equal services, supporting them whilst they develop confidence by counselling, and providing adequate funding and resources for women's specific needs (Kozub and Kozub, 2004).

Better healthcare for women in Australia has been achieved with difficulty by dedicated centres which focus on women. Medical and psychological help is provided by women who have been specially trained in women's issues. These centres have resulted in many women becoming empowered, and able to take charge of their own wellbeing. Mainstreaming or the provision of generic medicine, has not always been effective for women. It is not sufficient to provide services where biases against women exist. I noticed the presence of many young female medical students at the KJ Somaiya Hospital, and this may herald changes in the way women are treated in Indian hospitals. It is important to recognise women's contribution to the health system by informal family care, and use of community health workers. This could be enhanced within the Indian cultural framework by acknowledging the strengths of wives and mothers.

The KJ Somaiya Hospital is succeeding with its nutrition, social work, medicine, home-based programme, and its sewing group and collaborative micro-credit scheme. Although it could be seen as a drop in the ocean, it is an important drop, and should be supported financially in order to expand. There is a limit, however, in its expansion. Home-based care programmes are of necessity, time and labour

intensive. The scope is small; however the support that is given is extremely important for those fortunate beneficiaries.

The status of doctors appeared higher in India compared to Australia; therefore whatever they said carried weight and authority. Only one woman had the strength to question them. Because of their pivotal position in the healthcare system, they need to be provided with training in stigma and discrimination. This is not always reflected in the present system. The role of non-allopathic health care providers is important as they are often consulted first, and could be a link in referring women to other services. It is evident that allocation of funds for ART has been made in India but the actual rollout does not occur. This is a tragedy for people who could live longer and better. If the KJ Somaiya Hospital is not going to provide ART, then an alternative is to subsidise access at nearby hospitals. ART provision and availability for the poor is imperative, and a justice and equity issue. The provision needs to be streamlined and monitored.

Safer obstetric care is one way of giving women more choices during pregnancy and childbirth so that dire decisions can be avoided. For example, caesarean section is considered less risk for transmission to the baby than vaginal delivery (UNDP/UNFA/WHO/World Bank, 2003). Women may avoid voluntary testing from fear of their partner's reaction (Kippax, 2006). Knowledge and awareness will not empower women, unless the culture of patriarchy does not change. Many researchers place the onus onto women to negotiate safe sex in circumstances where women have little power, or knowledge of equity. For example, current researchers, Pradhan and Sundar (2006) argue that:

“Access to female controlled prevention options and improving women's skills in using such options and negotiating safe sex behaviours with their partners will go a long way in their attaining control over their body and protecting themselves from HIV and other infections.”

This is a naïve position in a culture where violence towards women is still condoned and practised. Considerable support has to be implemented for women to undertake

an assertive position safely. Additionally, the cost and availability of female condoms and microbicides may place these items out of reach for women in lower socio-economic conditions.

15.3.5 Family cohesion in supporting women

The interviews provided data on families with some women receiving adequate support, and others experiencing discrimination. HIV/AIDS challenges the traditional definitions of family, and concepts of normative family functioning. Roles change, girls are removed from school, young widows are returned to their maternal homes, and children are left orphaned. To date, the burden of such change appears to be falling on the shoulders of women. This burden is not supported by services, or extra consideration by family, or community. If these women are well, it would not be so hard, but when they are ill, it is intolerable. If they are supported, the whole household is supported.

15.3.6 Community understanding of women's issues

The slum community has leaders who understand issues such as sanitation and rubbish clearance. They advocate on behalf of the community to the government (often without avail); nevertheless they do have lines of communication, which can be used. *Panchayats* have been used throughout India with great success even the female crime *panchayat* in the slums of Mumbai, which have exceeded expectations by reducing crime by 25-40% in a 18 month period (Nair, 2006). One of the successful mental health approaches used affected people to work alongside active members of a community to solve a common problem.

Any intervention has to be community driven with a “bottom-up” approach, and culturally sensitive (Vincent, 2005). The women interviewed were aware that discrimination is harmful, and how it could affect their families, however they were not so sure about how change could happen or what sort of change was possible. It is tempting to suggest self-help groups for IWLWHA but there are obstacles. It may be dangerous to further stigmatise these women by an identifiable group in the community. If the meetings were at the hospital, the women may not have time or energy to attend. Therefore, the CHWs are still the best option at present. They are from the community, know the women, and can impart information in the most

sensitive way. They can carry information from other women. These workers already have training, and are doing their jobs enthusiastically. They need to be acknowledged, and strongly supported in a potentially stressful occupation; as they are already stigmatised by their work. Efforts to set up groups should be explored at every opportunity. I observed groups of women meeting in the community to discuss issues such as domestic violence and husbands' behaviour through alcoholism.

Interventions have to be concerted and persistent, if they are to be successful. They have to be multi-level, i.e. involving IWLWHAs as well as community leaders and representatives, government and private healthcare providers, allopathic and non-allopathic providers, and on up to government and political leaders, and beyond to national and international organisations. Collaboration with other sectors of the wider community who are more privileged, or from outside India is recommended.

15.3.7 Men's important role in change

Men have a pivotal role in transforming the status of women. Men have the benefits of power and resources, at the expense of the physical and emotional health of women. For example, the issue of transmission needs to be addressed by men taking responsibility for their actions and the consequences. The interviews showed that 76% had little knowledge of HIV/AIDS. There is evidence of a lack of disclosure of status to prospective partners and wives even after diagnosis (Pradhan and Sundar, 2006). Bharat (personal communication, November 25, 2005) said that "blaming men does not help", but women and children's lives are at stake. Even more disturbing is that women's status is not improving. Women may be the fighting ground for men's feelings of inadequacy and subjugation according to Nussbaum (2007).

Health beliefs and attitudes which support patriarchy have to be addressed, if change is to take place. These beliefs can be approached by understanding the culture, and using culturally appropriate modifications. There are programmes being developed in India which seek to change male norms which are harmful to women, high risk behaviour, and damaging lifestyles and these can be supported. If Indian men are to be true protectors of the family's health, then they must take up the responsibility. The socialisation of males into positions of power from birth makes change more

difficult. These have been fundamental and familiar attitudes for many centuries. Globalisation may impede women's progress, not only from a feminisation of poverty but also the fear of losing one's culture, leads to adherence to more conservative and traditional mores.

15.3.8 Policy makers to address women's issues

India is a working democracy and espouses anti-discriminatory ideals. It is also signatory to international agreements, which advocate women's rights and equal status. The problem is how to enforce laws and implement ideals which will help women. This depends on the general awareness and changing responses within society to the ideas of equity, and equality of women. It is important that resources continue to be allocated towards the implementation of equality in health care, education, and rights for women, and not eroded, and minimised. Effective policies and programmes that support women in their family role, and which also address their own needs and desires, are essential. These programmes can be evaluated and recognised. Women need to be present in figures of poverty, gender imbalance and other data. Supporting self-help groups is an efficient way of addressing women's needs.

In order not to support the status quo, women, particularly in lower socio-economic groups have to be included in the planning process. Until now, their voice has not been heard. Researchers have noted the difficulty in obtaining true opinions from participants owing to the sensitivity of the subject (Indian NGOs, 2005). I believe, in this study, the diversity of responses attested to honest opinions being expressed by the participants, and the rapport of the interpreter and CHWs. Interventions will not work unless the recipients are participants in the planning and implementation of strategies. For women to be able to do this, they have to be supported and encouraged over time to develop confidence in their abilities and strengths. This requires collaboration from more active women, who understand, and can support, until the participants gain enough strength themselves. The women may start as victims of the system but empower themselves in the process.

Finance is a constant problem in India, with a huge percentage of the population below the poverty line. A gradual expansion is indicated. Funding sources need to

be constantly and vigilantly explored. According to Bollinger (2005), collaboration and partnerships with foreign aid may be paradoxically easier to achieve, as there is a lack of trust between government and non-government organisations in India. Sometimes, there needs to be an outside point of view to cut into the apathy. Certainly, uneducated and illiterate women may be only now learning what life could be like through the medium of TV.

15.3.9 Human rights for PLWHA

Numerous authors suggest that a legal framework and human rights approach will solve the problems. It is true that laws are a necessary aid to changing human behaviour. However, the promise of human rights in India has not translated into reality. At this time there is no national legislation to protect PLWHA in India, despite the Lawyers Collective continuing to advocate on behalf of HIV affected and infected people. There is an assumption that people will know about any anti-discrimination laws. PLWHA do not know their rights, nor health care workers, and other holders of information. People may also not have faith in the law being carried out. Women have learned not to expect much when the legal system is fraught with corruption, and there are huge backlogs and slow processing of cases (Ekstrand et al., 2003).

Even the best legal protection of privacy may be limited in its capacity to influence the behaviour of people who perceive a social risk. This means that people will always value certainty over uncertainty. They may not have recourse to the law, or seek it out, because they see it as flawed, and already not in their favour. We need to know more about peoples' knowledge, attitudes and beliefs about legal protection and the system.

15.4 Recommendations from the study

15.4.1 Girls education and awareness of HIV/AIDS

Education for girls in India has to be understood as a social and economic benefit to the community, as well as a protection against HIV/AIDS. Taboos against sex education are still strong, and have still to be addressed. Healthy lifestyles can be taught to both girls and boys, where appropriate skills, attitudes and behaviours are

emphasised. This requires teachers to be well informed about HIV/AIDS, and to be supported, as they meet this challenge. There is an existing national curricula which addresses health, hygiene and nutrition. This could be extended to include appropriate information about HIV/AIDS.

Understanding and awareness of HIV/AIDS for women is extremely important. In this group of illiterate women, the health information needs to be delivered in a culturally sensitive and appropriate form. The medium of TV has been shown to be the most effective with radio and print having low effectiveness (Pallikadavath et al., 2006). In the United States, more HIV testing resulted from airing HIV/AIDS issues in the daytime 'soapie' *The Bold and the Beautiful*, despite a smaller audience than the news (Giles, 2007). Even the poorest dwelling that I saw had a television set. Street plays have proved successful in other programmes. The KJ Somaiya Hospital has commenced street plays, and these are yet to be evaluated. Peer education is demonstrated to be effective, but this requires ongoing and comprehensive training of the community health workers. Consultation with the community is important, if programmes are to be effective.

Schools have been used effectively in Brazil when HIV prevalence in girls shot up 75% from 1991-2000. However, these programmes can only be effective if children attend school and globally 115 million children do not attend school, and 57% of those are girls. In South Asia, only one in four girls has completed fifth grade (UNFPA/UNAIDS/ UNIFEM, 2004c). Sir George Alleyne, the Secretary-General's Special Envoy for HIV/AIDS in the Caribbean, points out that education alone is insufficient to enable girls to take control of some areas of their lives:

An example of consulting the community for their needs was used by the KJ Somaiya Hospital. Through surveys, they uncovered the needs of women, and the home-based care programme is the response. Support for IWLWHAs in the form of groups is recommended, provided they are safe, and do not add to discrimination. Support can be given to women to broaden their education, by providing funding for conferences and meetings and further research. There is a cautionary message about knowledge and awareness. Kippax (2006) points out that it is true that negative responses may exist because of a lack of knowledge, but knowing about HIV/AIDS

does not guarantee prevention, as there are cultural and social factors to be taken into consideration - such as the lack of empowerment and confidence to effect change (Tarakeshwar et al., 2006).

15.4.2 Changing attitudes and beliefs towards HIV/AIDS

Changing attitudes and beliefs is the precursor to behavioural change and is more complex than delivering knowledge and awareness programmes. Interdisciplinary research brings cross-pollination of ideas. For example, mental health educators have been struggling with these problems for many years before HIV/AIDS, and have found that active participation in projects where HIV positive and healthy people work together on a common project can change peoples' prejudices. Cultural research, which reveals the motives behind certain risk behaviour, is a valuable approach to be explored.

Additionally, governments are not absolved of their responsibilities because of the presence of overseas aid. Besides behaviour change, universal access to treatment of opportunistic infections has to be ensured, and working out how to integrate AIDS alleviation strategies into low socio-economic communities needs more research (Ainsworth & Teokul 2000). In order to cope with HIV/AIDS, some countries have focused on patterns of sexual behaviour, others on mobility and migration such as the 'Jaipur' paradigm which "seeks to explain susceptibility and vulnerability to AIDS by reference to the wealth and the social cohesion of any country" (Altman 1999, p. 560). He also states that global responses have focused more on altering behaviour of those at risk, rather than care and support for those PLWHA. Altman (1999) also stresses the need for a political economy approach which would recognise the significance of political and economic factors. In many parts of the world, the greatest problems are a combination of lack of political will, barriers against admitting the causes of infection, and addressing them in practical ways, stigma, and church opposition, access to pharmaceuticals, health budgets, military spending, corruption, and weak government responses.

The mass media can be a positive force in increasing knowledge, but not so effective in changing health beliefs rooted in cultural patterns (Airhihenbuwa, 1995). Journalists can be encouraged to facilitate presentation of material by informing and

not stigmatising. Finally, knowledge of culture and social mores is essential in designing programmes which will encourage change in beliefs.

15.4.3 Improvements in healthcare for women

Sensitisation and awareness programmes need to be provided for all healthcare workers from the cleaners upwards. They may need support because of their own *affiliate* stigma from working with PLWHA. Allopathic doctors have a particular status and authority, and can be effective conduits of appropriate information. In addition, they can positively influence IWLWHA, as well as the community. Nurses can be encouraged to play a more significant role, because of their strong links with patients and their gender. Alternative health practitioners need to be included, and have access to education regarding HIV/AIDS, so that their contribution is not lost.

Women accessing healthcare can be encouraged by the CHWs in the first instance. Women will need encouragement for them to put their needs forward. ART provision will lead to longer lives, and choices in this area need to be encouraged. Longer term counselling is another way that women can be supported. This requires some informal counsellors like the CHWs and psychologists to attend to more complex problems, or to work with the collaboration of CHWs, as suggested earlier.

15.4.4 Responsibility of men in the area of HIV/AIDS

In the literature reviewed, I found that there is very little research in changing men's attitudes and behaviour, beyond stating the demographics of high-risk populations such as intravenous drug users, brothel patrons, and mobile populations such as long distance drivers. Approaching this area may require more work in the cultural area – e.g. beliefs which are currently held, such as cooling the body down by frequent sexual intercourse can be reframed into producing a HIV-free child. Successful programmes such as those in Uganda can be used as best-practice models. Encouraging boys at school to attend gender-equity programmes is a start. Peer education amongst truck drivers has proved successful, and could be extended to other groups. Motivating men to change involves changing the social and cultural environment and belief structures, and encouraging them to take part in women's health initiatives. More research is indicated to explore men's extra-marital activities, and the effect of gender on beliefs and attributions. For example,

Tarakeshwar et al. (2006) found that women believed their HIV infection was due to their fate, or an external force such as God, or sins committed by their husband or family. In contrast, men felt punished for their transgressions.

15.4.5 Initiatives in the community for IWLWHA

Leaders in the slum communities could be approached to encourage them to include IWLWHA to participate in self-help groups and meetings, and to increase their awareness and knowledge of how stigma and discrimination affect women. IWLWHA can be supported to come together in groups to tell their stories, and document instances of stigma and discrimination. In these communities, the leaders carry authority and can influence the people. They may also be able to lobby politicians and governments for better conditions.

15.4.6 Economic and employment opportunities for IWLWHAs

It is important to improve women's economic position by education, skills training and employment opportunities. KJ Somaiya Hospital has collaborated with the Ra Foundation to set up a micro-credit scheme by which women can contribute and draw on small cash reserves in times of crisis and illness. This is a better option than moneylenders, or relying on family members to supply the shortfall. Employment possibilities are limited, because of caring duties of the women and their own health. The sewing group at the hospital is a start in providing women with a viable income particularly when they are widowed.

15.4.7 Human rights and advocacy for PLWHA

The Lawyers Collective, which advocates on behalf of all PLWHA, needs to be supported in its work towards protecting the rights of PLWHA. The Positive Peoples Network is another avenue for PLWHA to have a voice, as well as strengthening those who are infected and affected. It is necessary to lobby parliamentarians and politicians to keep women's issues in the public domain, and to continue to pressure policymakers and businesses. Another avenue is to lobby women with high profiles such as the new female President of India, celebrities, journalists and other media. There is a role for more active women in the community who have networks and contacts, to continually highlight women's needs.

15.5 Significance of the study

15.5.1 The study participants

This study has given the participants, who live in slum communities in Mumbai, an avenue to express their views. Monogamous women, in low socio-economic conditions, have been neglected in the literature. Each and every woman has been represented in this study, and therefore has a voice which represents her feelings, thoughts and experience in her own words. This is an acknowledgement of their resilience, and honouring the care that they provide to family members infected with HIV/AIDS.

15.5.2 KJ Somaiya Hospital and Medical College – the research site

This study also demonstrates that the home-based programme is successful in that it is appreciated and valued by the clients. The HIV/AIDS sensitisation and awareness programmes for the hospital staff have been successful. The participants reported that they did not experience discrimination at the hospital. The respect and power of doctors brings with it the responsibility to address the issues regarding HIV/AIDS with knowledge, respect and compassion. Ongoing sensitisation and awareness programmes are indicated.

The role of the home-based care programme is important and justified in its support of women who are overwhelmingly the “shock absorbers” of the disease in the community. In particular, the community health workers have an important role to play in health education, linkage to hospital services, and above all, sustaining and supporting women in the community. The development of micro-credit and income-generating activities is commendable. I will provide the opportunity to share this study with KJ Somaiya Hospital and Medical College.

15.5.3 Messages for policy makers

The HIV/AIDS epidemic in India is said to be preventable. The efforts to date have worked to a certain extent by targeting high-risk groups such as CSW, MSM, IDU. A new National HIV/AIDS Project has just been signed in July 2007, which aims to increase awareness in high risk groups to 80%. Resources need to be matched to key locations with matching of data and resources. Data from sentinel surveillance of

pregnant women does not include older women for example (World Bank, 2007). The needs of vulnerable groups, such as monogamous women, still need to be voiced and recorded.

Urgent funding is needed to increase the availability of ART, to strengthen the existing services, and to increase the medical services available to women and their children. Beyond that, the will to translate ideals in all facets of government instrumentality into action is essential. For example, the World Bank has made recommendations for capacity building, leadership and direction to government and NGOs. Training of doctors and health professionals in sensitive care can be a vanguard of strength against stigma and discrimination. The effect of this reaches beyond the hospital and into the homes and community. Home-based care is an efficient way of reaching women, dispelling fears and myths, providing education and awareness and support. Community health workers need to be encouraged and supported in their work, and can eventually train others in the field.

Emotional counselling is vital for women who are deeply affected by HIV/AIDS. Development of both formal and informal counselling is indicated. Psychologists provide counselling for more complex problems which have developed in response to HIV/AIDS. Increasing education will result in more psychologists in India, but in the meantime, there is the possibility of training for informal providers (i.e. community health workers). The cultural and social structures regarding women have to be addressed and changed. There is an untapped resource in women's resilience and coping, which, if strengthened, could lead to a formidable force of human capacity. The ray of hope is the success of policies and programmes such as family planning and eradication of famine in India.

15.5.4 The benefits for the researcher

I was very fortunate to be able to study for my own pleasure. The opportunity to research and interview these women was fantastic. The challenges that field research presented were approached with some trepidation, and yet I achieved my objectives, despite the difficulties, both physically and emotionally. This gave me an enormous boost in confidence. Looking back, I think my expectations to be included into Indian cultural and social world were unrealistic. I had lessons to learn in patience

and persistence, and these have proved useful for me. Experiencing stigma myself was new and valuable, and helped me in my research. It is only by having to dig deep into one's own resources in situations of stress that one finds core strengths. This has helped me in my work, and my understanding of other women. I have enjoyed the process and the discipline of the research, thanks to my excellent supervisor. This has been another way of meeting challenges and it has given me confidence to accept new challenges. Most importantly, I am inspired by those women I shall never forget. Always well-dressed and clean, always gracious and hospitable, they helped me to understand how to make the best of one's life.

15.6 Limitations of the study

15.6.1 Generalisability

The target group in this study were women in slum communities in Mumbai. Their low status is largely dependent on their caste, and economic status, and conditions. Status in India is very diverse, and varies from state to state, urban to rural, and caste to caste. Therefore it is evident that conclusions can only apply to similar groups of women in urban slum conditions.

15.6.2 Language and interpretation

The researcher did not speak any of the languages of these communities, and the participants lacked English. This necessitated the use of an interpreter, and raised questions regarding authenticity of the responses. This difficulty was addressed in part by back translation. There was a consistency in the responses which demonstrated that the interpreter was careful to adhere to the interview guidelines. The researcher was dependent on the interpreter and community health workers to establish rapport with the participants. Although she was young, the selected interpreter proved to be resilient, capable and efficient after the initial delays. There will always be limits to translation, in that it is dependent on the interpreter making sense of the answers, and the researcher re-interpreting the data.

15.6.3 Duration of study and financial costs

The priority was set on the interviews being completed in the required time. The required interviews were completed within the allotted time for field research;

however this left little space for focus group discussions and key informant interviews. It was difficult to foresee whether the interviews would be finished on time. As the study was not financed in any way, any extension of time could not be considered. The period of 10 weeks in the field was limited by leave from my job and personal finances.

15.6.4 Health of the participants

There were occasions when the intended interview could not take place because of illness of the participant, more pressing family issues, or presumed unwillingness when the person was not at home as arranged. We were interviewing in the only window of opportunity – early afternoon, when these women usually had a rest as they had to get up so early. It was understandable if they could not accommodate us.

15.6.5 Dependency on the SAHAS team and bias

Interviews were arranged by the community health workers in the team, and sometimes did not happen resulting in waste of time and energy. The researcher had no time or opportunity to interview apart from this source. As all of the participants were recipients of the KJ Somaiya Trust's home-based services, there could be bias in their responses, although they were all informed that they would not be penalised in any way.

15.6.6 Limited logistical, social and infrastructure support

The researcher's ability to cope was compromised to some extent by the accommodation, and lack of interface with the community. This limited access to more cultural knowledge and understanding. For example, it would have been useful to examine TV and DVDs as a source of information for women regarding HIV/AIDS.

15.6.7 Position of the researcher

My position as a white, middle-class, middle-aged foreigner carries with it biases and prejudices, and opens the criticism of being from another culture. However, it does not disqualify me from addressing this topic of these women's oppressive situation. In fact, I feel that I would be neglectful if I did not. I experienced some stigma

myself, which was helpful in some small degree to understand the dynamics and feelings in this area.

15.7 Final concluding statement

Despite all the difficulties in the area of HIV/AIDS, there are a few national success stories. Thailand has managed to reduce HIV prevalence in commercial sex workers (CSWs), army conscripts and pregnant women; and in Uganda, prevalence has dropped in pregnant women and young people. However, the decline is more to do with mortality in HIV positive people than active public policy. Ainsworth & Teokul (2000) conclude that non-government organisations (NGOs), civil society and the private sector can all help, but if the government is reluctant to act and denies the epidemic, then the spread will continue. Partly the epidemic needs to move into the general population before it can be generally treated, otherwise it can always be perceived to be someone else's problem, and a local epidemic. The long latent period of HIV infection is a problem, and also where there is a lack of a large scale operation.

This study resulted in diverse opinions in all areas. Stigma and discrimination and prejudice still exist for women in the community slums in Mumbai. The sources are their own families, and the communities in which they live. In order for illiterate women to access knowledge of AIDS and preventative strategies, information has to be delivered in an understandable form. Street plays, community events, and a judicious use of television have not been explored thoroughly. Strategies to address stigma and discrimination cannot be confined to raising awareness. There are religious, social and cultural systemic barriers to changing attitudes, and until these are addressed, the situation of poorer Indian women cannot improve. Deeper analysis of the problem needs to be undertaken in order to implement policies which will be effective. Strategies which acknowledge health beliefs and religion in particular, would have more success. These require detailed cultural knowledge of the diverse groups which co-exist in India.

There are signs of PLWHA mobilising and providing support to each other within peer groups. Any intervention must involve the people who are affected and infected. Collaboration with other programmes both inside India, and in other countries, is advisable both for cross-pollination of ideas and funding possibilities. The KJ Somaiya hospital programmes that I observed were functioning well. The use of Community Health Workers and a psychologist Co-ordinator is meeting some of the needs of the women. Finally, the plight of these women is ongoing, onerous and difficult. They showed remarkable resilience, courage and caring in their daily lives. Their sense of duty leads them to learn care giving, and they should be valued and supported. The sad thing is that once they fall ill, the whole household is deeply affected. The pragmatic and poignant words of the young rag picker Kalavati, who earned Rs 10-20 (27-56 cents) a day, ring in my ears:

“I will live as long as I can. Once I fall ill, critically ill, I will end my life. I don't want to be a burden to anyone. This is a bad disease. People die because of it. Someone should find a solution to it quickly.”

EPILOGUE

For months I have not been able to see the trees for the wood. I have certainly ‘immersed myself in the data’, and slowly, it has come together like an epic poem. I have enjoyed the challenge of different disciplines of writing – from macro to micro, from summarising to expanding, and back again, from data expressed in different ways, and the diversity of opinions, from researchers to participants. I have learned many new skills – how to make posters and Power Point presentations and how to deliver papers at conferences. Even if I lose things on the computer, I know I can survive, and I have nearly 700 references in my Endnotes library.

Apart from the research skills, are the valuable things I have learned about myself. Challenges come in many shapes and sizes – some physical and some psychological and some mental. The opportunity to engage in field research was irresistible. It proved to be more difficult than I had thought, despite modern conditions. I suspect that what I experienced is common to most researchers in the field, in any era. Entering another culture with preconceived ideas about time and work, and fitting my goals into an existing programme were all interesting experiences. My characteristics of patience and persistence proved to be invaluable, tried as they were to the very limit. Physically, and mentally what is needed is stamina and discipline. One cannot afford to fall by the wayside - particularly in the drains of Mumbai.

I am translating what I have learned in the research about human capacity to my work with women. I have always looked for the social and economic factors underpinning women’s issues. Now I add the threats and strengths to their coping ability and how we can build on the resources a woman possesses.

6.11.07

What an amazing journey I have had. Not only India, but within myself. Challenges come in many shapes and sizes – some physical and some psychological and some mental. I have not been found wanting. What an interesting journey I have made! The rewards are immense. Whatever comes next, I have found **my** voice, and that is important to me. I hope it is not the end of my journey. Tennyson (1892) says:

*“How dull it is to pause, to make an end,
To rust unburnish’d, not to shine in use!
As tho’ to breathe were life.....”*

I have succeeded in finishing. Time to look for the next challenge.....

REFERENCES

- Abbasi, RI 2006, *What has changed for girls in India in the decade since Beijing and Cairo?*
Retrieved August 10, 2007, from
www.bernardvanleer.org/files/crc/3.C%20Razia_Ismail_Abbasi
- Abdul, S, Yarnal, S & Loni, I 2003, 'Knowledge of AIDS among married Indian women of varied socio-economic status', *Indian Journal of Sexually Transmitted Diseases*, vol. 24, no. 2, pp. 68-73.
- Abrums, M 2000, "'Jesus will fix it after awhile": Meanings and health.' *Social Science and Medicine*, vol. 50, no. 1, pp. 89-105.
- Acharya, AK 2004 'Gender preferences and India's missing girls: Evidence from selected states in India'. Population Association of America, *Annual Meeting*, Boston, April 1-3. Retrieved March 10, 2008 from
<http://princeton.edu/download.asp.submissionID=42008>.
- Aggleton, P 2000, *HIV and AIDS-related stigmatization, discrimination and denial: Forms, contexts and determinants. Research studies from Uganda and India, UNAIDS Best practice collection*. Retrieved July 6, 2005 from
www.unaids.org/en/KnowledgeCentre/Resources/Publications/BestPracticesArchivePage4.asp
- Aggleton, P, Wood, K & Malcolm, A 2004, *HIV-related stigma, discrimination and human rights violations: Case studies of successful programmes, UNAIDS, Geneva*. Retrieved March 18, 2005 from <http://www.avert.org/aroundworld.htm>
- Asia Pacific Network of People living with HIV/AIDS (APN+) Human Rights Team. 2004, '*AIDS: Discrimination in Asia*'. Retrieved November 30, 2005 from www.gnpplus.net/regions/asiapac.html.
- Ainsworth, M & Teokul, W 2000, 'Breaking the silence: Setting realistic priorities for AIDS control in less-developed countries', *The Lancet*, vol.356, no. July 1, 2000.

- Airhihenbuwa, CO 1995, *Health and culture: Beyond the Western paradigm*, Sage, London.
- Ali, S 2005, 'Second chance: City based organizations find more takers for children who survive virus', *Indian Express*, 18 November, p.5.
- Ali, S 2006, 'Why a walk to school makes students ill', *Indian Express*, 19 January 2006, p.10.
- Alonzo, AA & Reynolds NR 1995, 'Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory', *Social Science and Medicine*, vol. 41, no. 3, pp. 303-315.
- Altman, D 1999, 'Globalization, political economy and HIV/AIDS', *Theory and Society*, vol. 28, pp. 559-84.
- Ambati, BK, Ambati, J & Rao, AM 1997, 'Dynamics of knowledge and attitudes about AIDS among the educated in southern India', *AIDS Care*, vol. 9, no. 3, pp. 319-30.
- Angel, RJ 2006, 'Narrative and the fundamental limitations of quantification in cross-cultural research', *Medical Care in a Multi-Ethnic Society*, vol. 44, no. 11, pp. 31-33.
- Angermeyer, M & Matschinger, H 2005, 'Labeling-stereotype-discrimination: An investigation of the stigma process', *Social Psychiatry Psychiatric Epidemiology*, vol. 40, pp. 391-395.
- Arunkumar, T, Sankar, P, Archana, R & Kochumuttom, J 2002, 'HIV/AIDS stigma and discrimination: A Kerala experience'. Retrieved April 4, 2005, from <http://www.thrani.com/pap2.pdf>
- Ashraf, S & Godwin, P 1998, 'Gender differentials and the special vulnerability of women', in P Godwin (ed), *The looming epidemic*, Hurst & Co, London, pp. 171-183.
- AVERT, 2005, 'Worldwide HIV & AIDS epidemic statistics'. Retrieved April 4, 2005, from <http://www.thrani.com/pap2.pdf>
- AVERT, 2007, 'Who is affected by HIV and AIDS in India'. Retrieved May 1, 2007, from <http://www.avert.org/hiv-india.htm>

- Baden, S & Wach, H 2006, *Gender, HIV/AIDS transmission and impacts: A review of issues and evidence. Briefing prepared for the Swedish International Development Corporation (SIDA)*. Retrieved December 14, 2006 from www.bridge.ids.ac.uk/reports/re47c
- Bahuguna, N 2004, 'India: Joining hands against HIV/AIDS', *Women's Feature Service*. Retrieved July 16, 2004 from proquest.umi.com/pqdweb?did=6520481/fnt=3&clientid=22212&RQT=3098VName+PQ
- Bailey, A & Hutter, I 2007, 'Cultural heuristics in risk assessment of HIV/AIDS', *Culture, health & sexuality*, vol. 8, no. 5, pp. 465-477.
- Bailey, P 1997, 'Finding your way around qualitative methods in nursing research', *Journal of Advanced Nursing*, vol. 25, pp. 18-22.
- Bajpai, N & Goyal S 2004, 'Primary health care in India: Coverage and quality issues', CGSD Working Paper No. 15, *The Earth Institute at Columbia University*. Retrieved June 5, 2005 from www.earth.columbia.edu.
- Balk, D & Lahiri, S 1997, 'Awareness and knowledge of AIDS among Indian women: Evidence from 13 states', *Health Transition Review*, vol. 7, pp. 421-65.
- Bartley, M 2007, 'Capability and resilience: Beating the odds'. Retrieved 1 August, 2008 from www.ucl.ac.uk/capabilityandresilience.
- Belsare, V 2003, 'The doctrine of purusartha: A gender perspective', Chap 9 in M Kelkar & D Gangavane (eds), *Feminism in search of an identity: The Indian context*, Rawat Publications, Jaipur, pp.164-177.
- Benatar, SR 2002, 'Reflections and recommendations on research ethics in developing countries', *Social Science and Medicine*, vol. 54, no. 7, pp. 1131-1141.
- Bennetts, A, Shaffer N, Manopaiboon, K, Sorapipatana, S, Yuvaseevee, C, Jalanchavanapate, S & Clark, L 1999, 'Determinants of depression and HIV-related worry among HIV

- positive women who have recently given birth, Bangkok, Thailand', *Social Science and Medicine*, vol. 49, no. 6, pp. 737-749.
- Bent, KN 2005, 'The people know what they want: An empowerment process of ecological community health', *ANS Frederick*, vol. 26, iss. 3, pp.215-227
- Berg, B & Pearson, A 2004, *Qualitative research methods for the social sciences*, 5th edn, Allyn and Bacon, Boston.
- Besemeres, M 2007, '*Other lives: The power of autobiography in History and Anthropology*'. Curtin University Lecture Series, Semester 1.
- Besley, A 2002, 'Foucault and the turn to narrative therapy', *British Journal of Guidance and Counselling*, vol. 20, no. 2, pp. 125-143.
- Bhagat, S 2006, 'Technology to the rescue of girl child', *Times of India*, 14 January, p. N/A.
- Bharat, S & Aggleton, P 1999, 'Facing the challenge: Household responses to HIV/AIDS in Mumbai, India', *AIDS Care*, vol. 11, no. 1, p. 31.
- Bharat, S 2004, *Challenging AIDS stigma and discrimination in South Asia*, UNAIDS, Mumbai. Retrieved August 6, 2005 from www.tiss.edu/TISSAIDSStrategy/Paper.pdf
- Bharat, S, Aggleton, P & Tyrer, P 2004, 'India: HIV and AIDS-related discrimination, stigmatization and denial', *UNAIDS*, Geneva. Retrieved September 2, 2005, from <http://www.unaids.org/en/KnowledgeCentre/Resources/Publications/BestPracticesArchivePage2.asp>
- Bhattacharya, G 2004a, 'Healthcare seeking for HIV/AIDS among South Asians in the United States', *Health and Social Work*, vol. 29, no. 2, pp. 106-115.
- Bhattacharya, G 2004b, 'Sociocultural and behavioral contexts of condom use in heterosexual married couples in India: Challenges to the HIV prevention program', *Health Education and Behavior*, vol. 31, no. 1, pp. 101-117.
- Bhavnani, K-K 1993, 'Tracing the contours: Feminist research and feminist objectivity', *Women's Studies International Forum*, vol. 16, no. 2, pp. 95-104.

- Bhugra, D, Mehra, R, de Silva, P & Bhintade, VR 2007, 'Sexual attitudes and practices in North India: A qualitative study', *Sexual and Relationship Therapy*, vol. 22, no. 1, pp. 83-90.
- Birbili, M 2000, 'Translating from one language to another', *Social Research Update* 31, pp. 1-7.
- Blumenfeld-Jones, D (1995) 'Fidelity as a criterion for practicing and evaluating narrative enquiry', In JA Hatch, & R Wisniewski, (eds) *Life History and Narrative*. The Falmer Press, London, pp.22-36.
- Bollinger, RC 2005 'Stop AIDS - keep the promise', *Indian Journal of Medical Research*, vol. 122, no. 6, pp. 459-461.
- Brimlow, D, Cook, J & Seaton, R 2003, 'Stigma and HIV/AIDS: A review of the literature', *US Department of Health and Human Services Health Resources and Services Administration HIV/AIDS Bureau*, Rockville, MD. Retrieved October 12, 2005 from <http://hab.hrsa.gov/publications/stigma/front.htm>.
- Brown, L, Macintyre, K & Trujillo, L 2003, 'Interventions to reduce HIV/AIDS stigma: What have we learned?' *AIDS Education and Prevention*, vol. 15, no. 1, pp. 49-69.
- Bruner, J (2004). 'Life as Narrative'. *Social Research*, vol.71, no.3, pp. 691-710. Retrieved July 31, 2007, from Academic Research Library database. Document ID: 738631461.
- Bruner, J (1990) *Acts of meaning*. Harvard University Press, Cambridge.
- Bruner, J (2004) *Life as narrative: Social Research*. Retrieved 1 February 2008 from http://goliath.ecnext.com/com2/gi_0199-3053562/Life_as_narrative
- Bumiller, E 1990, *May you be the mother of a hundred sons*, Penguin, New Delhi.
- Burns, J 1996, 'A wretched new class of infected untouchables', *The New York Times*, 22 September, p. 1.
- Burns, R 2000, *Introduction to Research Methods*, 4th edn, Longman, Sydney.

- Byrne, P 1999, 'Stigma of mental illness: Changing minds, changing behaviour, *British Journal of Psychiatry*, vol. 174, pp. 1-2.
- Casey, K 1993, *I answer with my life: Life histories of the women teachers working for social change*, Routledge, New York.
- Caste system in India* 2006. Retrieved 4 April, from www.anand.to/india/caste.html
- Catz, S, Gore-Felton, C & McClure, J 2002, 'Psychological distress among minority and low-income women living with HIV', *Behavioral Medicine*, vol. 28, no. 2, pp. 53-61.
- Cavaye, A 1996, *Case Study research: A multi-faceted research approach for IS*, Delft University of Technology, Delft, the Netherlands.
- Centre for Advocacy & Research, New Delhi, Positive Women's Network, Chennai 2006, *'Positive speaking: Voices of women living with HIV/AIDS*. Retrieved June 6, 2007 from www.unifem.org.in/PDF/Positive%20Speaking
- Chambers Dictionary 2008*. Retrieved July 21, 2008 from www.chambersharrap.co.uk
- Chandra, PS, Ravi, V, Desai A & Subbakrishna, DK 1998, 'Anxiety and depression among HIV-infected heterosexuals - a report from India', *Journal of Psychosomatic Research*, vol. 45, no. 5, pp. 401-409.
- Chandra, V 2007, *Sacred games*, Faber & Faber, New York.
- Chatterjee, A 2002, 'Power of shame', *Abstract Book of 14th International AIDS Conference on HIV Knowledge and Commitment for Action, July 7-12, Barcelona*. Retrieved April 10, 2007, from <http://shic.rcsha.org/viewRecord.aspx?fid=5341>
- Chatterjee, M 2006, *Women and education*. Retrieved February 2, 2007, from www.pitt.edu/super1/lecture/lec20691/006.htm
- Chatterjee, N 1999, 'They have not heard of AIDS: HIV/AIDS awareness among married women in Bombay', *Public Health*, vol. 113, pp. 137-140.

- Chatterjee, P 2004, 'Response to HIV/AIDS in India', 2003, *UNAIDS*. Retrieved February 4, 2005 from www.unaids.org.in
- Chesney, M & Smith, A 1999, 'Critical delays in HIV testing and care', *The American Behavioral Scientist*, vol. 42, no. 7, pp. 42-49.
- Chhatre, L 2003, 'Empowerment of women: The Buddhist perspective', in M Kelkar & D Gangavane (eds), *Feminism in search of an identity: The Indian context*, Rawat Publications, Jaipur.
- Clandinin, DJ & Connelly, F 1994, 'Personal experience methods', in NK Denzin & Y Lincoln (eds), *Handbook of qualitative research*, Sage, Thousand Oaks, Ca, pp. 150-175.
- Clandinin, DJ & Connelly FM 1992, 'Teacher as curriculum maker', in P Jackson (ed), *Handbook of research on curriculum*, Macmillan, New York, pp. 363-401.
- Cohen, J 2004, 'HIV/AIDS in India: Till death do us part', *Science*, vol. 304, no. 5670, p. 513.
- Cohen, L, Marmion, L & Morrison, K 2000, *Research methods in education. 5th ed*, Routledge-Falmer, London.
- Connelly, FM & Clandinin, DJ 1990, 'Stories of experience and narrative inquiry', *Educational Researcher*, vol. 19, no. 5, pp. 2-14.
- Corrigan, P & Penn, D 1999, 'Lessons from Social Psychology on discrediting psychiatric stigma', *American Psychologist*, vol. 54, no. 9, pp. 765-776.
- Corrigan, P, Watson, A, Gracia, G, Slopen, A, Rasinski, K & Hall, LL 2005, 'Newspaper stories as measures of structural stigma', *Psychiatric Services*, vol. 56, no. May 2005, pp. 551-556.
- Creswell, J 1994, *Research design: Qualitative and quantitative approaches*, Sage Publications, Thousand Oaks, California.

- Dalrymple, W 2006, *The last Mughal: The fall of a dynasty, Delhi, 1857*, Bloomsbury, London.
- Dandona, L 2004, 'AIDS in India', *The Lancet*, vol. 363, no. 9403, p. 177.
- Darak, S, Pant, R, Kulkarni, V & Kulkarni, S 2004, 'Burden of being discreditable; Fear of stigmatisation and its impact on people living with HIV/AIDS (PLWHA)', *Electronic Journal of the International AIDS Society*. Retrieved April 10, 2007, from <http://shic.rcsha.org/viewData.aspx/fid=358>
- Darell, R 2003, 'Working with teachers: Beliefs, experiences and the creative arts (drama)', *Annual Conference for the Australian Association for Research in Education, 29 November-3 December, 2003*. Retrieved May 9, 2008 from www.aare.edu.au/03pap/dar03394.pdf
- Das, S 1994, *Indian women*, Ess Ess Publications, New Delhi.
- DAWN, (Disabled Women's Network) Ontario. 'Women and HIV/AIDS Women's vulnerability to HIV/AIDS: An overview' 2007, Retrieved May 1, 2007, from http://dawn.thot.net/women_hiv_aids1.html
- D'Cruz, P 2002, 'Engulfing darkness: The impact of HIV/AIDS on the family', *Families in Society: The Journal of Contemporary Human Services*, vol. 83, no. 4, pp. 416-431.
- D'Cruz, P 2003, 'Moments of truth: The experiences of wives in HIV/AIDS affected nuclear households in Mumbai', *Journal of Comparative Family Studies*, vol. 34, no. 2, pp. 255-277.
- D'Cruz, P 2004, 'The family context of care in HIV/AIDS: A study from Mumbai, India', *The Qualitative Report*, vol. 9, no. September, pp. 413-434.
- D'Cruz, P 2005, 'The influence of HIV concordance and discordance on marital life: A study from Mumbai, India', *International Social Work*, vol. 48, no. 5, pp. 581-591.
- de Bruyn, T 1998, *HIV/AIDS: A discussion paper*, Canadian HIV/AIDS Legal Network and Canadian AIDS Society, Montreal. Retrieved August 15, 2005, from

<http://www.aidslaw.ca/Maincontent/issues/discrimination/discussionpapers/DISCdiv.html>

Denzin, N & Lincoln, Y 2000, *Handbook of qualitative research*, 2nd edn, Sage Publications Inc, California.

Deshmukh, R 1993, *History of Marathas*, Nimesh Agencies, Bombay.

De Souza, R 2007, 'The construction of HIV/AIDS in Indian newspapers: A frame analysis', *Health Communication*, vol. 21, no. 3, pp. 257-266.

Develotte, C & Rechniewski, E 2007, *Discourse analysis of newspaper headlines: A methodological framework for research into national representations*. Retrieved June 27, 2006 from <http://wjfms.ncl.ac.uk/titles.htm>

Devers, KJ 1999, 'How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research', *Health Services Research*, vol. 34, no. 5 (Pt 2), pp. 1153-3388.

D'sa, JL 2005, 'Violence against women: The Indian scenario', *Children's and Women's Rights and Violence*. Retrieved May 6, 2006, from http://222.fhs.mcmaster.ca/slru/ic2003/ABSTRACTS.Children_Womens_Rights.pdf.

Dushku, S 2000. 'Conducting individual and focus group interviews in research in Albania', *TESOL Quarterly*, vol. 34, no. 4, pp.763-768.

Duvvury, N, Prasad, N, Kishore, N, Agarwal, R & Dharmaraj, D 2006, 'Community led intervention research on HIV/AIDS stigma, and intimate partner violence', *Abstract Book of 15th International AIDS Conference*, Toronto, Canada.

Dwivedi, S & Holkar S D 2005, *Almond eyes, lotus feet: Indian traditions in beauty and health*, Eminence Designs Pvt Ltd, Bombay.

Earnest, J 2003, *Science education reform in a post-colonial developing country in the aftermath of a crisis: The case of Rwanda*, Digital Thesis, Curtin University of Technology. <http://adt.curtin.edu.au/theses/index.html>.

- Edwards, R 1998, 'A critical examination of the use of interpreters in the qualitative process', *Journal of Ethnic and Migration Studies*, vol. 24, no. 1, pp. 197-209.
- Ekstrand, M, Garbus, L & Marseille, E 2003, 'Country AIDS policy analysis project: HIV/AIDS in India', *AIDS Policy Research Center*, San Francisco. Retrieved 20 April 2005, from <http://ari.ucsf.edu/ARI/policy/profiles/India.doc>
- Elamon, J 2005, 'A situational analysis of HIV/AIDS-related discrimination in India', *AIDS Care*, vol. 17, no. Supplement 2, pp. S141-151.
- Eliot, E 1998, 'Changes in Mortality in Mumbai: Monitoring mortality to analyse the spread of HIV', in P Godwin (ed), *The Looming Epidemic*, Hurst & Co, London, pp. 62-93.
- Ellis, F & Biggs, S 2001, Evolving themes in rural development 1950's-2000's. *Development Policy Review*, vol. 19, no. 4, pp.437-448.
- Embassy of India 2007, 'Rights of the child'. Retrieved 10 August, 2007, from http://www.indianembassy.org/policy/Children_Women/rights_children.html
- Emihovich, C 1995, 'Distancing passion: Narratives in social science', *International Journal of Qualitative Studies in Education*, vol. 8, no. 1, pp. 37-48.
- Engenderhealth 2006, 'Transmission risk. Women's vulnerability and risk'. Retrieved July 7, 2006 from <http://www.engenderhealth.org/res/onc/hiv/transmission/hiv3p6.html>
- England, KVL 1994, 'Getting personal: Reflexivity, positionality and feminist research', *Professional Geographer*, vol. 46, no. 1, pp. 80-9.
- Erickson, F 1998, 'Qualitative research methods for science education', in BJ Fraser & KG Tobin (eds), *The international handbook of science education*, Kluwer, Dordrecht, The Netherlands.
- Farmer, T, Robinson, K, Elliott, SJ & Eyles, J 2006, 'Developing and implementing a triangulation protocol for qualitative health research', *Qualitative Health Research*, vol. 16, no. 3, pp. 377-394.

- Feldman, S 1998, in P Jeffrey & A Basu (eds), 'Appropriating gender:women's activism and politicized religion in South Asia', Routledge, New York.
- Flaskerud, JH & Tabora, B 1998, 'Health problems of low-income female caregivers of adults with HIV/AIDS', *Health Care for Women International*, Vol. 19, pp. 23-36.
- Fleming, V, Gaidys, U & Robb, Y 2003, 'Hermeneutic research in nursing: Developing a Gaderian-based research method', *Nursing Inquiry*, vol. 10, no. 2, pp. 113-120.
- Friedman S, 2006, 'Living on the outside', *Health and Development Networks*, p.50. Retrieved 21 February, 2007, from www.hdnet.org/library/stigma
- Gaitonde, VR 2001, *A thief in the night: Understanding AIDS*, East West Books (Madras) Pvt Ltd, Chennai.
- Ganesan, S 2005, 'A return to roots', *Sunday Times of India*, 4 December 2005, p. N/A.
- George, A & Jaswal, S 1997, 'Gender relations in urban households in Bombay: Challenges for HIV/STD prevention', *Arrows Change*, vol. 3, no. 1, p. 3.
- Gibson, D 2006, 'Sign of a Catholic split over stigmata 'miracle'', *The West Australian*, 25 March, p. 16.
- Gielen, AC, McDonnell, KA, Wu, AW, O'Campo, P & Faden, R 2001, 'Quality of life among women living with HIV: The importance of violence, social support and self-care behaviors', *Social Science and Medicine*, vol. 52, pp. 315-322.
- Giles, F 2007, 'TV Medicine: Heartthrobs and Health messages' *Medical Forum*, October, p.4.
- Gilgun, JF 2006, 'The four cornerstones of qualitative research', *Qualitative Health Research*, vol. 16, no. 3, pp. 436-43.
- Gillman, RR & Newman, BS 1996, 'Psychosocial concerns and strengths of women with HIV infection: An empirical study', *Families in Society: The Journal of Contemporary Human Services*, vol. 77, no. 3, pp. 131-41.

- Gilmore, N & Somerville M A 1994, 'Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming 'them' and 'us"', *Social Science and Medicine*, vol. 39, no. 9, pp. 1339-58.
- Goffman, E 1963, *Stigma: Notes on the management of a spoiled identity*, Simon & Schuster, New York.
- Gore-Felton, C, Koopman, C, Spiegel, D, Vosvick, M, Brondino, M & Winningham, A 2006, 'Effects of quality of life and coping on depression among adults living with HIV/AIDS', *Journal of Health Psychology*, vol. 11, no. 5, pp. 711-29.
- Government of India, 2008, 'AYUSH'. Retrieved 4 May 2008 from http://india.gov.in/health_family/ayush.php
- Graneheim, U & Lundman, B 2004, 'Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness', *Nurse Education Today*, vol. 24, pp. 105-112.
- Grenville, K 2005, *The secret river*, Text, Melbourne.
- Grbich, C 1999 (ed.), 'Approaches to health', *Health in Australia: Sociological concepts and issues*, Longman, New South Wales, pp. 4-9.
- Guba, EG & Lincoln YS 1994, 'Competing paradigms in qualitative research', in N Denzin & YS Lincoln (eds) *Handbook of qualitative research*, Sage Publications, London, pp.105-111.
- Gubrium, JF & Holstein J A (1999), 'At the border of narrative and ethnography'. *Journal of contemporary ethnography*, vol.28, p.561
- Gupta, GR 2002, 'How men's power over women fuels the HIV epidemic', *BMJ*, vol. 324, pp. 183-184.
- Hackl, K, Kalichman, S & Somlai, A 1995, 'Women with HIV/AIDS: The dual challenge of patient and caregiver', *HIV Infected Women Conference*, Washington. Retrieved 9 May, 2008 from <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102214922.html>

- Hadjipateras, A 2004, 'Unravelling the dynamics of HIV/AIDS-related stigma and discrimination: The role of community-based research. Case studies of northern Uganda and Burundi', *ACORD*. Retrieved 9 May 2008 from www.acord.org.uk/stigma.pdf
- Halli, SS, Ramesh, BM, O'Neil, J, Moses, S & Blanchard, JF 2006, 'The role of collectives in STI and HIV/AIDS prevention among female sex workers in Karnataka, India', *AIDS Care*, vol. 18, no.7, pp. 739-749.
- Hasic, T 2004, *Reconstruction planning in post-conflict zones. Bosnia and Herzegovina and the international community*, Royal Institute of Technology Press, Stockholm.
- Hatch, JA & Wisniewski, R (eds) 1995, *Life history and narrative*, The Falmer Press, London.
- Hayes, RA, Vaughan, C, Medeiros, T & Dubuque, E 2002, 'Stigma directed toward chronic illness is resistant to change through education and exposure', *Psychological Reports*, vol. 90, pp. 1161-1173.
- Health and Development Networks 2006, *Living on the outside*, Retrieved February 21, 2007, from www.hdnet.org/library/stigma
- Herd, G 2001, 'Stigma and the ethnographic study of HIV: Problems and prospects', *AIDS and Behavior*, vol. 5, no. 2, pp. 141-149.
- Herek, GM 1999, 'AIDS and stigma', *The American Behavioral Scientist*, vol. 42, no. 7, pp. 1106-1117.
- Hirschfeld, M & Lindsey, E 2002, 'Community home-based care in resource-limited settings: A framework for action', pp. 1-99. Retrieved May 22, 2007 from www.enro.who.int/aieff/web75.pdf
- Health and Development Network 2005. *HIV/AIDS eforum*. Retrieved December 16, 2005, from www.healthdev.org/eforums/cms/individual.asp. Gender-AIDSHIV eforum.
- Holroyde, P 2007, *An ABC of Indian culture: a personal padayatra of half a century into India*, MapinLit, London.

- Horton, M 2007, 'Health and home place: Close contact participatory research with Gypsies and Travellers', in A Williamson & R DeSouza (eds) *Researching with communities: Grounded perspectives on engaging communities in research*, muddycreekpress, Auckland, pp. 25-38.
- Human Rights Watch 2004, 'Discrimination against children affected by HIV/AIDS: Discrimination by health care providers'. Retrieved May 24, 2007, from http://hrw.org/reports/2004/india0704/5.htm#_Toc76445936
- Hutchison, S, Wilson, M & Wilson, H 1994, 'Benefits of participating in research interviews', *Journal of Nursing Scholarship*, vol. 26, pp. 161-164.
- ICRW 2006, 'Key findings on HIV/AIDS stigma and discrimination', Retrieved August 12, 2006, from <http://www.icrw.org>
- Im, E-O, Page, R, Lin, L-C, Tsai, H-M & Cheng, C-Y 2004, 'Rigor in cross-cultural nursing research', *International Journal of Nursing Studies*, vol. 41, pp. 891-899.
- Indian NGOs 2005, 'Assessing the socio-economic impact of HIV/AIDS in Maharashtra', Retrieved April 20, 2005, from <http://www.indianngos.com/issue/hiv/resources/india.htm>
- Inzlicht, M, McKay, L & Aronson, J 2006, 'Stigma as ego depletion: How being the target of prejudice affects self-control', *Psychological Science*, vol. 17, no. 3, p. 262.
- Iyer, M 2005, 'Blood safety being ignored: AIDS experts say storage banks are poorly equipped which violates Apex Court directive', *TNN*, 20 November 2005.
- Jayaraman K S 1998, 'Indian state plans compulsory HIV testing, segregation and branding', *Nat Med*, vol. 4, no. 4, p. 378. Retrieved June 3, 2005 from PUBMED database.
- Jha, US & Pujari, P 1996, *Indian women today: Tradition, modernity and challenge*. , Kanishka Publishers, New Delhi.

- Joseph, EB & Bhatti, RS 2004, 'Psychosocial problems and coping patterns of HIV seropositive wives of men with HIV/AIDS', *Social Work in Health Care*, vol. 39, no. 1-2, pp. 29-47.
- Joshi, P 2006, 'Rs98,00,00,00,00,000!' *Mumbai Mirror*, 4 January 2006, p. 9.
- Kapborg, I & Bertero, C 2002, 'Using an interpreter in qualitative interviews: Does it threaten validity?' *Nursing Inquiry*, vol. 9, no. 1, pp. 52-6.
- Karkaria, B 2006, 'Curdling up to AIDS', *Sunday Times*, 22 January 2006, p. N/A.
- Katz, 1960, 'The functional approach to the study of attitudes', *Public Opinion Quarterly*, vol. 24, pp. 163-204.
- Keller, 2007, *AIDS - Eforum*. Retrieved February 3, 2008 from www.healthdev.org/eforums/cms/individual.asp?sid=1016&name=Gender-AIDS
- Key, JP 1997, 'Qualitative research. Module R14, Research Design in Occupational Education', *Oklahoma State University*. Retrieved May 9, 2008 from www.okstate.edu/ag/agedcm4h/academic/aged5980a/newpage21.htm
- Khanna, A & Dhar, S 2004, 'The Gender Dimensions of HIV/AIDS: Challenges for South Asia', *UNAIDS & UNIFEM*, Geneva. Retrieved May 9, 2008 from www.unaids.org.
- Khaparde, SD 2006, 'Impact of education intervention programme on knowledge about HIV/AIDS adolescents in Mumbai slums', *Abstract Book of Joint National Conference of IPHA & IAPSM, January 21-24*, Tirupati, AP, India.
- Kingsley, E & O'Connor, PM 1991, 'Educating Alzheimer's Disease Association helpers to share the care', in D O'Neill (ed), *Carers, professionals and Alzheimer's Disease*, John Libbey & Company, London.
- Kippax, S, Tiller, G, Crawford, J & Cregan, J 1991, *Discrimination in the context of AIDS: Disease and deviance*, Macquarie University AIDS Research Unit. A unit of the National Centre for HIV Social Research, Macquarie University, NSW.

- Kitzinger, J 1995, 'Qualitative research: Introducing focus groups', *BMJ*, vol. 311, pp. 299-302.
- KJ Somaiya Medical College and Hospital 2002, *Project proposal for PLWAS*, Sion, Mumbai.
- KJ Somaiya Medical Trust 2007, *Integrated Community and Home-based Care Program for People Living with HIV/AIDS (PLHAs)*, Mumbai. Retrieved 30 April 2007, from www.somaiya.edu/SVVHIVPROJECT/team.htm
- Koch, T & Harrington, A 1998, 'Reconceptualizing rigour: The case for reflexivity', *Journal of Advanced Nursing*, vol. 28, no. 4, pp. 882-890.
- Kostermanis, K 2006, *Living on the outside*. Retrieved February 21, 2007 from: www.hdnet.org/library/stigma
- Kowshik, P 2006, 'Grit of a woman. Remembering Poonam Hindustani', *The Times of India*, 4 February 2006, p. N/A.
- Kozub, ML & FM 2004, 'Dealing with the power struggle in clinical and educational settings', *Journal of Psychological Status and Mental Health Services*, vol. 42, no. 2, pp. 22-31.
- Krefting, L 1991, 'Rigor in qualitative research: The assessment of trustworthiness', *The American Journal of Occupational Therapy*, vol. 45, no. 3, pp. 214-22.
- Krishna, VAS, Bhatti, RS, Chandra, PS & Juvva, S 2005, 'Unheard voices: experiences of families living with HIV/AIDS in India', *Contemporary Family Therapy*, vol. 27, no. 4, pp. 483-504.
- Krishnakumar, A 2005, 'AIDS: Promising microbicides.' Retrieved June 14, 2005, from <http://www.hinduonnet.com/thehindu/thscrip/print.pl?file=20040716001708600.htm>
- Krishner, F 2005, 'Indian Catholic Church HIV/AIDS policy.' Retrieved September 7, 2005 from <http://healthgroups.yahoo.com/group/AIDS-INDIA/messag/4918?threaded=1>

- Krueger, R & Casey, M 2000, *Focus groups: A practical guide for applied research*, 3rd edn, Sage Publications Inc., Thousand Oaks, California.
- Kshirshage, NA, Shinde, RR & Mehta, S 2006, 'Floods in Mumbai - impact of public health service by hospital staff and students', *Journal of Post-graduate Medicine*, vol.52, pp.312-314.
- Kubler-Ross, E 1969, *On death and dying*, Simon & Schuster, New York.
- Kulkarni, N 2003, 'The Satapatha Brahmana on women', Chap 8 in M Kelkar & D Gangavane D (eds), *Feminism in search of an identity: The Indian context*, Rawat Publications, Jaipur, pp.139-163.
- Kumar, S 2005, 'Govt may gift free drugs to the poor in new year', *Mumbai Mirror*, 30 December 2005, p. 22.
- Kumar, SS, Ananthan, S & Saravanan, P 2000, *HIV and AIDS related stigmatization, discrimination and denial: Forms, contents and determinants, research studies from Uganda and India*, UNAIDS, Geneva.
- Lacey, A & Luff, D 2001, 'Trent focus for research and development in primary health care: An introduction to qualitative analysis,' *Trent Focus*. Retrieved June 17, 2006 from Trentdsu.org.uk/resources_qualitative.html
- Lal, S 2003, 'Surveillance of HIV/AIDS epidemic in india', *Indian Journal of Community Medicine*, vol. 19, no. 1, pp. 3-8.
- Languages of India* 2008. Retrieved 2 March 2008, from www.ethnologue.com/show_country.asp?name=India
- Lannoy, R 1971, *The speaking tree: A study of Indian culture and society*, Oxford University Press, London.
- Lawyers Collective, 2006, 'Sex workers stage national protest for rights,' Mumbai. Retrieved 15 May 2006, from aidslaw1@lawyerscollective.org
- Lee, RS, Kochman, A & Sikkema, KJ 2002, 'Internalized stigma among people living with HIV/AIDS', *HIV/AIDS and Behavior*, vol.6, no.4, pp.309-19.

- Lewis, S 2005, 'Statement', *Third International AIDS Society Conference*, Rio de Janeiro, Brazil, pp. 1-5.
- Lewis-Beck, M, Bryman, A & Liao, T (eds.) 2004, *The SAGE Encyclopedia of Social Science Research Methods*, Sage, Thousand Oaks, Ca.
- Lincoln, Y & Guba EG 1986, 'But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation', in DD Williams (ed), *Naturalistic evaluation*, Jossey-Bass, San Francisco.
- Lindsey, E, Hirschfeld, M, Tlou, S & Ncube, E 2003, 'Home-based care in Botswana: Experiences of older women and young girls', *Health Care for Women International*, vol. 24, pp. 486-501.
- Loxley, W 1995, *Young injecting drug users and the risk of HIV/AIDS: Psychosocial and environmental constraints on safer drug using and sexual behaviour*, PhD Thesis, Curtin University of Technology.
- Majumdar, B 2004, 'An exploration of socioeconomic, spiritual and family support among HIV-positive women in India', *Journal of the Association of Nurses in AIDS Care*, vol. 1, no. 3, pp. 37-46.
- Mak, W, Poon, C, Pun, L & Cheung, S 2007, 'Meta-analysis of stigma and mental health', *Social Science and Medicine*, vol. 65, pp. 245-61.
- Mak, WWS, Mo PKH, Cheung, RYM, Woo, J, Cheung, FM & Lee D 2006, 'Comparative stigma of HIV/AIDS, SARS and Tuberculosis in Hong Kong', *Social Science and Medicine*, vol. 63, pp. 1912-22.
- Mandelbaum, D 1957, *India's villages*, Asia Publishing House, Bombay.
- Manohar, P 2006, 'A child of India's streets', *The Times of India*, 26 January, p.N/A.
- Marshall, A & SB 2003, 'Ethical issues in cross-cultural research', *Connections '03*, pp. 139-51. Retrieved May 3, 2008 from www.educ.uvic.ca/Research/conferences.connections2003/10Marshall105.pdf

Marshall, G 1998, *Oxford Dictionary of Sociology*, Oxford University Press, Oxford.

Marshall, P 2004, 'The environmental context,' Paper presented at 2004 Science, Technology and Society Conference, University of Wollongong, Australia. Retrieved May 12, 2008 from http://www.uow.edu.au/arts/sts/bmartin/classes/STS300_04/topessays/Penelope_Marshall.pdf

Martin, M 2005, *Children shunned, placed at high HIV risk*, Infochange News and Features. Retrieved August 24, 2005, from <http://www.infochange.india.org>

Mawar, N, Sahay, S, Pandit, A & Mahajan, U 2005, 'The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma and discrimination and future needs', *Indian Journal of Medical Research*, vol. 122, no. 6, pp. 471-85 Retrieved January 9, 2006, from <http://proquest.umi.com.dbgw.lis.curtin.edu.au/pqdlink?index=19&sid=1&srchmode=3&v>

Mays, N & Pope, I 2000, 'Qualitative research in health care: Assessing quality in qualitative research', *BMJ*, vol. 320, pp. 50-52.

Mehta, AK & Gupta, S 2007, *The impact of HIV/AIDS on women caregivers in situations of poverty: Policy issues*, UNIFEM South Asia Regional Office, New Delhi.

Menadue, D 2006, 'My STI shame', *Talkabout*, vol. 146, pp. 26-8.

Messinger, L 2001, 'Using a story-building approach to researching comprehensive community initiatives', *The Qualitative Report*, vol. 6, iss. 1. Retrieved July 23, 2008 from <http://www.nova.edu/ssss/QR/QR6-1/messinger.html>

Miles, MB & Huberman, AM 1994, *Qualitative Data Analysis: An expanded sourcebook*, 2nd edn, Sage Publications, Thousand Oaks, California.

Mishra, AD 1999, *Gender perspective: Participation, empowerment and development*, Radha Publications, New Delhi.

- Mohanty, M 2004, 'Conclusion: Social movements in a creative society', in M Mohanty (ed), *Class, caste, gender: Readings in Indian government and politics*, Sage Publications, New Delhi.
- Morris, M 2005, 'Indian women face peril of HIV', *BBC News*, 21 September, 2005.
- Mukhopadhyay, S, Nandi, R, Nundy, M & Sivaramayya, J 2001, *Living under a shadow: Gender and HIV/AIDS in Delhi*, Institute of Social Studies Trust, New Delhi.
- Mumbaispace* 2005. Retrieved 29.3.05, from
<http://www.mumbaispace.com/cityinfo/geography>
- Nabar, V 1995, *Caste as woman*, Penguin, New Delhi.
- NACO, *Report 2002-2004*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India. Retrieved January 10, 2006, from <http://nacoonline.org/annualreport.pdf>.
- NACO, 2004a, *Annual Report 2002-2003, 2003-2004*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India. Retrieved January 10, 2006, from <http://nacoonline.org/annualreport.pdf>.
- NACO, 2004b, *National baseline general population behavioural surveillance survey 2001*. Retrieved October 16, 2004 from
www.nacoonline.org/Quick_Links/Publication/ME_and_Research_Surveillance/Reports_and_Surveys/National_BSS_2001
- Nag, D 2005, 'Role of youth in preventing stigma and discrimination', *Indiatimes*, Fitness and Health. Retrieved May 25, 2005 from
<http://health.indiatimes.com/articleshow/329881.cms>
- Nagaraj, A 2005, 'Facing fear', *The Sunday Express*, 18 December 2005, p. 12.
- Naglzas, M 2007, 'New twist to royal story', *The West Australian*, 13 November, p. 7.
- Nairn, RG 2007, 'Media portrayals of mental illness, or is it madness? A review', *Australian Psychologist*, vol. 42, no. 2, pp. 138-46.

- Nath, M 2004, 'Gender relations: A central element of effective HIV/AIDS prevention strategies', *The Journal of Family Welfare*, vol. 50, no. Spl., pp. 43-8.
- National Family Health Survey, 2005, *National Family Health Survey, Chap 9. Quality of Care*. Retrieved October 13, 2006, from www.nfhsindia.org/data/india/indfctsm.pdf
- Nichols, S, Tippins, D, Bilbao, P, Barcenal, T, Castellano, M & Morano, L 2001, 'Using narrative inquiry to explore relationships of community, science teacher education and research', *National Association for Research in Science Teaching, March 25-28* St Louis, MO.
- Nussbaum, MC 2007, *The clash within: Democracy, religious violence and India's future*, Belknap Press of Harvard University Press, Cambridge, Mass.
- Nyblade, LC, Pande, R, Banteyerga, H, Bond, V, Kilonzo, G, Mbwambo, J & Kidanu, A 2004, 'Family and community level stigma impedes HIV prevention and care, and lowers the quality of life for people living with HIV and AIDS', *International Conference on AIDS, July 11-16*. Retrieved August 28, 2006, from www.icrw.org/docs/2005_report_stigma_synthesis.pdf
- O'Connor, PM & Kingsley, EJ 1991, 'The three directional benefit of in-home respite' in D O'Neill (ed), *Carers, professionals and Alzheimer's Disease*, John Libbey & Co, London.
- Ogden, J & Nyblade, L 2005, *Common at its core: HIV-related stigma across contexts*, Int. Conf. AIDS 2004. Jul 11-16, 15, abstract no.THPeD.
- Ojanuga, D & Gilbert, C 2002, 'Women's access to health care in developing countries', *Social Science and Medicine*, vol. 35, no. 4, pp. 613-7.
- Orner, P 2006, 'Psychosocial impacts on caregivers of people living with AIDS', *AIDS Care*, vol. 18, no. 3, pp. 236-40.
- Pagare, D, Meena GS, Jiloha RC & Singh, MM 2005, 'Sexual abuse of street children brought to an observation home', *Indian Paediatrics*, vol. 42, February 17, pp. 134-39.

- Pallikadavath, S, Jayachandran, AA & Stones, RW 2005, 'Women's reproductive health, sociocultural context and awareness in Northern India', *Journal of Health Management*, vol. 7, no. 1, pp. 109-28.
- Pallikadavath, S, Sreedharan, C & Stones, RW 2006, 'Sources of AIDS awareness among women in India', *AIDS Care*, vol. 18, no. 1, pp. 44-8.
- Paranjape, S 2003, 'Position and role of women in Rgveda', Chap 2 in M Kelkar & D Gangavane (eds), *Feminism in search of an identity: The Indian context*, Rawat Publications, Jaipur, pp. 38-49.
- Parkar, SR, Fernandes, J, & Weiss MG 2003, 'Contextualizing mental health: Gendered experiences in a Mumbai slum', *Anthropology and Medicine*, vol. 10, no. 3, pp. 292-308.
- Parker, R & Aggleton, P 2002, *HIV/AIDS-related stigma and discrimination: A conceptual framework and an agenda for action*, The Population Council - Horizons Program.
- Parker, R & Aggleton, P 2003, 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action', *Social Science and Medicine*, vol. 57, pp. 13-24.
- Patel, K 2007, 'The constitutional paradox posed by permitting polygamy in India'. Retrieved May 6, 2008 from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=965200.
- Patton, MQ 2002, *Qualitative evaluation and research methods*, Sage Publications, Newbury Park, Ca.
- Paulose, S, Langkham, B & John, KR 2005, *Health care needs of people living with HIV/AIDS in New Delhi*, Emmanuel Hospital Association.
Retrieved March 21, 2005, from <http://www.eha-health.org/research6.htm>
- Paxton, S 2004, 'Women's issues at Bangkok', *HIV Australia*, vol. 4, no. 1, pp. 14-16.
- Peel, J 1995, 'For who hath despised the day of small things? Missionary narratives and historical anthropology', *Comparative studies in society and history*, vol. 37, no. 3, pp. 581-607.

- Penzak, SR, Reddy, YS & Grimsley, SR 2000, 'Depression in patients with HIV infection', *American Journal of Health Systems Pharmacology*, vol. 57, pp. 376-86.
- Piot, P 2000, *Report by the executive director, Programme Co-ordinating Board, Joint United Nations Programme on AIDS*, Rio de Janeiro.
- Piot, P & Seck, AMC 2001, 'International response to the HIV/AIDS epidemic: Planning for success', *Bulletin of the World Health Organisation*, vol. 79, no. 12, pp. 1106-13.
- Poindexter, CC 2005, 'Family care in HIV/AIDS: Exploring lived experience', *AIDS Education and Prevention*, vol. 17, no. 1, p. 90.
- Polkinghorne, D 1995, 'Narrative configuration in qualitative analysis', in JA Hatch & R Wisniewski (eds), *Life history and narrative*, The Falmer Press, London, pp.5-24.
- Ponterotto, JG, 'Brief notes on the origins, evolution and meaning of the qualitative research concept: "thick descriptions," *The Qualitative Report*, vol. 11, 3, September, pp. 538-549.
- Pope, C, Ziebland, S & Mays, N 2000, 'Qualitative research in health care: analysing qualitative data', *British Medical Journal*, vol. 320, pp. 114-6.
- Population Foundation of India 2007, *HIV/AIDS in India - The hard hit states*. Retrieved 15 August, 2007, from <http://www.prb.org/Pdf/Maharashtra.pdf>
- Population Services International (PSI) India 2003, *The Saadhan Helpline: HIV/AIDS information and counseling in Mumbai: A case study*, Population Services International (PSI) India.
- Pradhan, BK & Sundar, R 2006 *Gender: Impact of HIV and AIDS in India*, UNDP. Retrieved April 4, 2007 from <http://mycii.org/library/Newarrivals/0702.htm>
- Pradhan, BK, Sundar, R & Singh, SK 2006, *Socio-economic impact of HIV and AIDS in India*, United Nations Development Programme, New Delhi.
- Preeti, R 2006, *We all have AIDS*, Retrieved February 2, 2006, from RPreeti@dnaindia.net

- Pryor, JB & Reeder GD 1993, *The social psychology of HIV infection*, Lawrence Erlbaum Associates Inc., Hillsdale, NJ.
- Pryor, JB, Reeder, GD & Landau, S 1999, 'A social-psychological analysis of HIV-related stigma', *The American Behavioral Scientist*, vol. 42, no. 7, pp. 1193-212.
- Quam, M D 1990, 'The sick role, stigma and pollution', in D Feldman (ed), *Culture and AIDS*, Praeger, New York, pp. 34-43.
- Rajaram, NS 1995, *The politics of history: Aryan invasion theory and the subversion of scholarship*, Voice of India, New Delhi.
- Rashid, T 2005a, 'Government attempt to ensure girls get married after 18', *Indian Express*, 21 November 2005, p. N/A.
- Rashid, T 2005b, 'Phase 1 trials for HIV/AIDS vaccine over. Officials say vaccine successful on healthy people, result expected in a month.' *Indian Express*, 3 December 2005, p. N/A.
- Ratnathicam, A 2001, 'AIDS in India: Incidence, prevalence and prevention', *AIDS Patient Care and STDs*, vol. 5, pp. 225-61.
- Riessman, CK 2005, 'Exporting ethics: A narrative about narrative research in South India', *Health and Social Work*, vol. 9, no. 4, pp. 473-90.
- Riessman, CK & Mattingly, C 2005, 'Introduction: Toward a context-based ethics for social research in health', *Health*, vol. 9, no. 4, pp. 427-9.
- Riessman, CK 1993, *Narrative analysis*, Sage Publications, California.
- Ritchie, J 2000, 'Not everything can be reduced to numbers', in CA Bergland (ed), *Health research*, Oxford University Press, Melbourne.
- Roberts, GD 2003, *Shantaram*, Scribe Publications, Australia

- Roche, E 2007, *India's first woman president savours victory*, ATP, New Delhi. Retrieved 24 July, 2007, from http://news.yahoo.com/s/afp/20070722/w1_sthasia_afp/indiapoliticspresidentvote_070
- Rodrigues, M, Patel, V, Jaswal, S & de Souza, N 2003, 'Listening to mothers: Qualitative studies on motherhood and depression from Goa, India', *Social Science and Medicine*, vol. 57, pp. 1797-806.
- Rogers, ME, Hansen, NB, Levy, BR, Tate, DC & Sikkema, KJ 2005, 'Optimism and coping with loss in bereaved HIV-infected men and women', *Journal of Social and Clinical Psychology*, vol. 24, no. 3, pp. 341-60.
- Rosen, A 2006, *What developed countries can learn from developing countries in challenging psychiatric stigma*, Refugees and Detained Populations. Retrieved August 28, 2006, from www.wpanet.org/education/docs
- Rosenwald, G & Ochberg, RI (eds) 1992, *Storied lives: The cultural politics of self understanding*, Yale University Press, London.
- Royce, RA, Sena, A, Cates, W & Cohen, MS 1997, 'Sexual transmission of HIV', *New England Journal of Medicine*, vol. 336, no. 15, pp. 1072-8.
- Sahai, NP 2008, 'Experts lift veil off purdah origin.' *The Times of India*, 19 June 2007. Retrieved 6 May 2008 from http://timesofindia.indiatimes.com/India/Experts_/rsasarticleshow/232555.cms
- Sakthi, S 2006, 'Gender perspectives on HIV/AIDS: Issues and challenges - an Indian experience', *Abstract Book of the XVI International Conference*, Toronto.
- Sarkar, P 2005, 'City to get AIDS care unit', *The Statesman*, 1 December 2005, p. N/A.
- Sartre, Jean-Paul (1964) *The Words*. Braziller, New York.
- Sayce L 1998, 'Stigma, discrimination and social exclusion: What's in a word?' *Journal of Mental Health*, vol. 7, no. 4, p. 331.

- Schaffer, TC & Mitra, P 2004, *India at the crossroads: Confronting the HIV/AIDS challenge*, Center for Strategic and International Studies, Washington. Retrieved August 8 2005, from www.csis.org/saprog/0401_hivindia.pdf
- Schensul SL, Mekki-Berrada A, Nastasi B, Sagguru N & Verma RK 2006a, 'Healing traditions and men's sexual health in Mumbai, India: The realities of practiced medicine in urban poor communities', *Social Science and Medicine*, vol. 62, no. 11, pp. 2774-85.
- Schensul, SL, Mekki-Berrada, A, Nastasi, BK, Singh, R, Burtleson, JA & Bojko, M 2006b, 'Men's extramarital sex, marital relationships and sexual risk in urban poor communities in India', *Journal of Urban Health*, June. Retrieved April 9, 2007, from www.infoforhealth.org/popreporter/2006/01-23.shtml
- Scholes, R 1981, 'Language, narrative and anti-narrative', in WJT Mitchell (ed), *On narrative*, University of Chicago Press, Chicago, pp. 200-8.
- Scrimshaw, EW 2002, 'Social support, conflict and integration among women living with HIV/AIDS', *Journal of Applied Social Psychology*, vol. 32, no. 10, p. 2022.
- Sehrawat, S 2005, 'The foundation of the Lady Hardinge Medical College and Hospital for Women in Delhi: Issues in women's medical education and imperial governance', in S Kak, & B Pati, (eds), *Exploring gender equations: Colonial and post-colonial India*, Nehru Memorial Museum and Library, New Delhi.
- Sen, A 2006, *The argumentative Indian: Writings on Indian culture, history and identity*, Penguin, London.
- Sen, G & Ostlin, P 2007, *Unequal, unfair, ineffective and inefficient - gender inequity in health: Why it exists and how we can change it. Final report to the WHO Commission on social determinants of health*, Women and Gender Equity Knowledge Network.
- Seshan, R 2003, 'Feminism and identity: Women saints and the question of identity', in M & GD Kelkar (eds), *Feminism in search of an identity: The Indian context*, Rawat Publications, Jaipur.

- Seshu, G 2003, 'Budget, women and the yawning gap', *India Together*, January 25, 2003, p. 1. Retrieved February 25, 2008 from www.indiatogether.org/2003/jul/women-genbudg.htm
- Shankar, AV, Sastry, J, Erande, A & Joshi A 2005, 'Making the choice: The translation of global HIV and infant feeding policy to local practice among women in Pune, India 1,2', *The Journal of Nutrition, Bethesda*, vol. 135, no. 4, pp. 960-6.
- Sharma, R 2001, 'More than a quarter of India's youngsters have premarital sex' *BMJ*, vol. 322, 10 March, p. 575.
- Sharma, M 2005, 'Globalisation with a female face: Issues from South Asia', in S Kak & B Pati (eds), *Exploring gender equations: Colonial and post-colonial India*, Nehru Memorial Museum and Library, New Delhi, pp. 463-90.
- Sharma, R 2001, 'More than a 1/4 of India's youngsters have premarital sex.' *BMJ*, 10 March, vol 322, p.575.
- Sharma, R 2005, 'Cautious, some men play it safe. Insist on sex workers taking HIV test before a night-out', *TNN/Times Nation*, 28 January 2006, p. 14.
- Sharma, R 2005, 'Desperate housewives to sex workers', *The Times of India*, 4 January, p. 14.
- Sharma, V, Sujay, R & Sharma, A 1998, 'Can married women say no to sex? Repercussions of the denial of the sexual act', *The Journal of Family Welfare*, vol. 44, no. 1, pp. 1-7.
- Shelton, JD, Halperin, DT, Nantulya, V, Potts, M, Gayle, HD & Holmes, KK 2004. 'Partner reduction is crucial for balanced ABC approach to HIV prevention', *BMJ*, April 10, vol. 328, p. 891-893.
- Shelton, JN, Richeson, JA, Salvatore, J, & Hill, DM 2006, 'Silence is not golden: The intrapersonal consequences of not confronting prejudice', in S Levin & C van Laar (eds), *Stigma and group inequality: Social psychological perspectives*, Lawrence Erlbaum Associates, Mahwah, NJ.
- Shridharani, K 1941, *My India, my America*, Duell, Sloan & Pearce Inc, New York.

- Sikkema, KJ, Kochman, A, Di Francisco, W, Kelly, JA & Hoffmann, GHR 2003, 'AIDS-related grief and coping with loss among HIV-positive men and women', *Journal of Behavioral Medicine*, vol. 26, no. 2, pp. 165-81.
- Simbayi, LC, Kalichman, SC, Strebel, A, Cloete, A, Henda, N & Mqeketo, A 2007, 'Internalized stigma, discrimination and depression among men and women living with HIV/AIDS in Cape Town, South Africa', *Social Science and Medicine*, vol. 64, pp. 1823-31.
- Singh, A 1999, 'Gender sensitization at grassroot. Chap 2', in AD Mishra, (ed), *Gender perspective: Participation, empowerment and development*, Radha Publications, New Delhi.
- Singh, MC 2005, 'Gender, medicine and empire: Early initiatives in institution building and professionalisation (1890s-1940s)', in S Kak & B Pati (eds), *Exploring gender equations: Colonial and post-colonial India*, Nehru Memorial Museum and Library, New Delhi, pp. 93-116.
- Singh, SB 2005, 'It's time MBCs got their due', *The Times of India*, December 2005, p. N/A.
- Sinha, K 2005, 'Now, condom vending machines at JNU, DU', *TNN/The Times of India*, 16 November 2005.
- Slater, J 2004, 'Back of the class', *Far Eastern Economic Review*, vol. 167, no. 28, p. 40. Retrieved April 4, 2006 from ProQuest Social Science Journals.
- Smith, BA 1999, 'Ethical and methodologic benefits of using a reflexive journal in hermeneutic-phenomenologic research', *Journal of Nursing Scholarship*, vol. 31, no. 4, p. 359.
- Smitha, F 2006, 'MacroHistory: India'. Retrieved October 6, 2006, from <http://www.fsmitha.com/h1/ch13.htm>
- Solomon, S, Chakraborty, A & Yepthomi, RDS 2004, 'A review of the HIV epidemic in India', *AIDS Education and Prevention*, vol. 16, no. supplement A, pp. 155-69.

- Somaiya CRS-HIV Project 2004, *Status report*, K J Somaiya Medical College and Research Centre, Mumbai.
- Somaiya Medical Trust 2004, *Somaiya CRS-HIV Project*.
- Somaiya Medical Trust 2005, *Integrated development of vulnerable children and youth*, Mumbai.
- Somaiya Medical Trust 2005, *Positive Programme Partnership*, K J Somaiya Medical Trust, Mumbai.
- Sporton, D (1999). Mixing Methods in Fertility Research. *The Professional Geographer* 51, no. 1 p. 68-76.
- Sridhar, L 2002, 'India: Getting HIV drugs free, along with rude treatment', *Global Information Network*, p. 1.
- Srinivasan, S 2005, *Mechanism by which HIV infects healthy cells uncovered*. Retrieved November 5, 2005, from <http://infochangeindia.org/analysis03.jsp>
- Stajduhar, KI & Davies, B 1998, 'Palliative care at home: Reflections on HIV/AIDS family caregiving experiences', *Journal of Palliative Care*, vol. 14, no. 2, p. 14.
- Stake, RE 1994, 'Case studies', in NK Denzin & YS Lincoln (eds), Chap 14 in *Handbook of qualitative research*, Sage, Thousand Oaks, Ca., pp.236-247.
- Stansbury, JP & Sierra, M 2004, 'Risks, stigma and Honduran Garifuna conceptions of HIV/AIDS', *Social Science and Medicine*, vol. 59, no. 3, pp. 457-71.
- Strang, AB & Ager, A 2007, *Building a conceptual framework for psychosocial intervention in complex emergencies: Reporting on the work of the Psychosocial Working Group*. Retrieved 10 January 2007, from www.ishr.org/conference/articles/strang.pdf
- Sudha, RT, Vijay, DT & Lakshmi, V 2005, 'Awareness, attitudes and beliefs of the general public towards HIV/AIDS in Hyderabad, a capital city in South India', *Indian Journal of Medical Sciences*, vol. 59, no. 7, pp. 307-16.

- Sulaimani, K 2005, 'AIDS cases up, prevalence rate down in Gujarat', *Indian Express*, 5 December 2005, p. N/A.
- Tanna, K 2005, 'HIV+ spouses face jail for causing hurt', *Times of India*, 10 November 2005, p. N/A.
- Tanna, K 2006, 'For a few rupees more', *Mumbai Mirror*, 25 January 2006, p. N/A.
- Tarakeshwar, N, Krishnan, AK, Johnson, S, Solomon, S, Sikkema, K & Merson, M 2006, 'Living with HIV infection: Perceptions of patients with access to care at a non-governmental organization in Chennai, India', *Culture, Health & Sexuality*, vol. 8, no. 5, pp. 407-21.
- Taylor, C 1987, 'Interpretation and the sciences of Man', in P Rabinow & WS Sullivan (eds), *Interpretive social science: A second look*, University of California Press, London, pp. 33-81.
- Taylor, SE, Klein, LC, Lewis, BP, Grunewald, TL, Gurung, RAR & Updegraff, JA 2000, 'Biobehavioral responses to stress in females: Tend-and-befriend, not Fight-or-flight', *Psychological Review*, vol. 107, no. 3, pp. 411-29.
- Temple, B 1997, 'Watch your tongue: Issues in translation and cross-cultural research', *Sociology*, vol.31, no. 3, pp.607-18.
- Tennyson, AL 1892, *The works of Alfred Lord Tennyson, Poet Laureate*, Macmillan & Co., London.
- The Psychosocial Working Group 2003, *Working paper*. Retrieved January 3, 2005 from www.forcedmigration.org/psychosocial/papers
- The World Bank Group 2005, *India's national AIDS control program*. Retrieved September 5, 2006 from <http://INweb18.worldbank.org/sar/sa.nsf/0/0c8bd13c927027ca3852567f4005394fc?>
- Thomas, D 2000, *The contribution of qualitative research to evidence-based medicine*. Retrieved May 5, 2005, from www.health.auckland.ac.nz/hrmas/resources/qual%20evidence.html

- Thomas, D 2003, *A general inductive approach for qualitative data analysis*, School of Population Health, University of Auckland, Auckland NZ.
- Thomas, J & Bandyopadhyay, M 1999, 'Ethnic minorities and their vulnerability to AIDS in a border state of India', *AIDS Care*, vol. 11, no. 1, p. 45.
- Thomas, BE, Rehman F, Suryanarayanan, D, Josephine, K, Dilip, M, Dorairaj, VS & Swaminathan, S 2005, 'How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India', *AIDS Care*, vol. 17, no. 7, pp. 795-801.
- Thresia, CU 2007, 'Interplay of gender inequities, poverty and caste: Implications for health of women in the cashew industry of Kerala', *Social Medicine*, vol. 2, no. 1, pp. 8-18.
- Tripathi, S 2000, 'Health seeking behavior: Q structures of rural and urban women in India with sexually transmitted disease and reproductive tract infection.' *The Professional Geographer*, vol 52, no. 2, pp.218-32.
- UNAIDS 2004a, *Challenging AIDS stigma and discrimination in South Asia: Report of an electronic discussion forum*. Retrieved March 4, 2005 from www.unaids.org.in/Album/Publications.pdf
- UNAIDS 2004b, *Report on the global AIDS epidemic*, UNAIDS. Retrieved March 29, 2005, from www.unaids.org/bangkok
- UNAIDS 2006a, *2006 Report on the global AIDS epidemic*. Retrieved February 20, 2007, from http://data.unaids.org/pub/GlobalReport/2006/2006_GR_CHOZ_en.pdf
- UNAIDS 2006b, *UNAIDS/WHO Epidemic Update: December 2006* Retrieved April 30, 2006, from http://www.unaids.org/ca/HIV_data/epi2006/default.asp
- UNAIDS 2007, *Epidemic update*. Retrieved February 22, 2008 from http://data.unaids.org/pub/EPIslides/2007/2007_epiupdate_en.pdf
- UNAIDS 2007, *FACTSHEET*. Retrieved 3 August 2007, from <http://www.unaids.org>

- UNAIDS 2007a, *Children and young people in a world of AIDS*. Retrieved 3 December 2007, from unaids.org/Publications/IRC-pub02/JC656-Child_AIDS_En.pdf
- UNAIDS/ UNFPA/UNIFEM 2004, *Women and HIV/AIDS: Confronting the crisis*. Retrieved May 16, 2006 from http://genderandaids.org/downloads/conference/308_filename_women_aids1.pdf
- UNAIDS/WHO 2006, *AIDS epidemic update December 2006*. Retrieved 2 November, 2007, from http://data.unaids.org/pub/EpiReport/2006/2006EpiUpdate_en.pdf
- UNAIDS/ WHO 2007, *Factsheet: 2007 AIDS epidemic update*. Retrieved 7 December 2007, from unaids.org/pub/EPISlides/2007/071118_epi_revisions_factsheet_en.pdf
- UNAIDS/WHO/UNICEF 2007, *HIV epidemic in India*. Retrieved 15 November 2007, from <http://www.unaids.org.in>
- UNDP/UNFA/WHO/World Bank Special Program of Research & Development and Research Training in Human Reproduction 2003, *HIV infected women and their families: Psychosocial support and related issues. A literature review*, UNDP, UNFA, WHO, WORLD BANK Special Program of Research Training in Human Reproduction, Department of Reproductive Health and Research, Family and Community Health, World Health Organization, Geneva.
- UNIFEM 2007, *Women, gender and HIV/AIDS in East and South East Asia*. Retrieved August 20, 2007, from [UNIFEMgenderaidskit.pdf](http://www.unifem.org/UNIFEMgenderaidskit.pdf)
- Uys, LR 2002, 'The practice of community caregivers in a home-based HIV/AIDS project in South Africa', *Journal of Clinical Nursing*, vol. 11, pp. 99-108.
- Vati, J, Walia, I & Sharma, S 2003, 'AIDS awareness among hospital class IV employees', *Nursing Journal of India*, vol. 94, no. 12, p. 276.
- Vincent, R 2005, 'What do we do with culture/ Engaging culture with development. Retrieved 2 November 2006 from www.healthcomms.org
- Waria, F 2006, 'Behind every memsahib is a bai', *The Times of India*, January 2006, p. N/A.
- Warren, K J 1996, *Ecological feminist philosophies*, Indiana University Press, Bloomington.

- Warren, KJ 1997, 'Taking empirical data seriously: An ecofeminist philosophical perspective', in KJ Warren (ed), *Ecofeminism, women, culture, nature*, Indiana University Press, Bloomington.
- Weiss, MG & Ramakrishna, J 2001, *Interventions: Research on reducing stigma*. Retrieved July 4, 2006, from <http://www.stigmaconference.nih.gov/WeissPaper.htm>
- Weiss, MG 2001, 'Cultural epidemiology: An introduction and overview', *Anthropology and Medicine*, vol. 8, no. 1, pp. 5-28.
- WHO 2004, *Country Health Profile - India: Trends in policy development*, World Health Organization Regional Office for South-East Asia. Retrieved March 2, 2005, from http://w3.whosea.org/EN/Section313/Section1519_6816.htm
- WHO/UNAIDS/UNICEF 2007, *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector. Progress Report, April 2007*. Geneva. Retrieved August 30, 2007, from www.who.int/hiv/universalaccess2010/en/
- WHO. 2008. *India*. Retrieved 14 March 2008 from: [who.int/countries/india/en](http://www.who.int/countries/india/en)
- Wight, RG, Aneshensel, CS, Murphy, DA, Miller-Martinez, D & Beals, KP 2006, 'Perceived HIV stigma in caregiving dyads', *Social Science and Medicine*, vol. 62, pp. 441-56.
- Williams, KD & Zadro, L 2005, 'Ostracism: The indiscriminate early detection system', in KD Williams, JP Forgas & W von Hippel (eds), *The social outcast: Ostracism, social exclusion, rejection and bullying*, Psychology Press, New York.
- Williams, RB 1997, 'The role of psychosocial factors in human disease: Lessons from animal models', *Acta Psychologica Scandinavica*, vol. 640, pp. 100-2.
- Women Priests 2008, 'The ordinance of women in the Roman Catholic Church'. Retrieved April 14, 2008 from www.womenpriests.org/index.asp
- World Health Organisation, 2002, 'Community home based care in resource-limited settings: A framework for action'. Retrieved 6 May 2008 from www.who.int/hiv/pub/prev_care/isbn9241562137.pdf

- World Bank 2005, *India: Country Assistance Strategy 2005-2008*. retrieved 10 May 2008 from www.worldbank.org
- World Bank 2007a, *HIV/AIDS in India*. Retrieved 13 September 2007, from www.worldbank.org/in
- World Bank 2007b, *HIV/AIDS South Asia, India: State of the epidemic*. Retrieved 15 November 2007, from <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/SOUTHASIAEXT/EXTSAREGTOPHEA>
- World Health Organisation, 2004, 'Country health profiles - India' Retrieved 2 March 2005, from http://w3.who.org/EN/Section313/Section1519_6816.htm
- Worth, D 1990, 'Minority women and AIDS: Culture, race and gender', in D Feldman (ed), *Culture and AIDS*, Praeger, New York, pp. 112-3.
- Wright, ER & Martin, TN 2003, 'The social organization of HIV/AIDS care in treatment programmes for adults with serious mental illness', *AIDS Care*, vol. 15, no. 6, pp. 763-73.
- Yamin F, Rahman, A & Huq, S 2005, 'Vulnerability, adaptation and climate disasters: A conceptual overview', *IDS Bulletin*, vol. 36, no. 4, pp. 1-14.
- Yasodhara P, Raghunath, M, Sreeramulu, D, Venu, L, Hemalatha, R & Krishna, T 2003, 'Local immunity in Indian women with bacterial vaginosis', *Journal of Reproductive Immunology*, vol. 70, no. 1-2, pp. 133-41.
- Zeller, N (1995) Narrative Strategies. In JA Hatch & R Wisniewski, (eds) *Life History and Narrative*. London & Washington, The Falmer Press, pp.75-88.

APPENDIX 1

RESEARCH PROJECT: INFORMATION SHEET

STIGMA AND DISCRIMINATION OF WOMEN LIVING WITH HIV/AIDS: PERCEPTIONS AND EXPERIENCES OF WOMEN IN MUMBAI, INDIA

INFORMATION SHEET FOR INTERVIEW PARTICIPANTS ENGLISH VERSION

My name is Pam O'Connor. I am a PhD student at Curtin University in Perth, Western Australia. I am asking for your help in my project which is to understand the stigma and discrimination which women face when they have HIV/AIDS. As well as this interview, I am asking groups of people about their experience of HIV/AIDS. Your help with this project is completely voluntary. It is important for you to know that if you decide NOT to take part in this project, the health care and services provided by the K J Somaiya Hospital will not be affected in any way. You will continue to receive the same care and services that you have been getting. There will NOT be any money paid to you for helping me. You can stop taking part in the project at any time.

The interview may take 60 minutes. So I can be accurate, I wish to record your answers on audiotape. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer *but your name will not be entered*. No-one will be able to match your name to the answers. If you are willing to help me with the interview, I will ask you to read the next page. After this, I will ask you to sign the consent form, or make your mark.

This research has been approved by the Human Research Ethics Committee, Curtin University of Technology. If you have any questions or concerns, please contact the

Office of Research and Development, Curtin University, GPO Box U1987, Perth,
Western Australia 6845, or email: S Darley@curtin.edu.au

My personal contact details are:

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Thank you very much for your time

APPENDIX 2

**RESEARCH PROJECT: STIGMA AND DISCRIMINATION OF WOMEN
LIVING WITH HIV/AIDS; PERCEPTIONS AND EXPERIENCES OF
WOMEN LIVING IN MUMBAI, INDIA**

CONSENT FORM

My name is _____

My address is _____

I have read the information sheet about this project (or the interpreter has read it to me) and I am willing to be interviewed. I am helping voluntarily and I understand that I will not be paid or given any sort of gifts for my help.

I understand that I can stop answering questions at any time, and I can ask questions about the project. I am helping with the project on the understanding that my answers will be kept confidential, and my name will not be associated with my answers.

I agree to the interview being taped.

I am happy for the researcher to use my answers to the interview questions in reports and publications as long as my wishes regarding confidentiality are followed.

Signed _____

Date _____

Please hand this sheet back

APPENDIX 3

SEMI-STRUCTURED INTERVIEW SCHEDULE

What language do you speak and understand?

How old are you?

Where do you live?

How long have you lived there?

Why did you choose to come here?

What made you come to Mumbai?

Where did you come from?

Where were you born?

What religion are you?

What caste do you belong to?

Have you been to school? To what level?

Did other members of your family go to school?

Can you read and write?

What do you live on? Your monthly income

Do you earn money?

Is there other money earned in the family?

How many people live in your household?

Who are they?

When did you first hear of HIV/AIDS?

Who told you about it?

What did they tell you?

What does the word HIV/AIDS mean to you

What did you know about it before the infection?

Do you have HIV/AIDS? Yes No

Are you looking after someone in your family with HIV/AIDS

Who told you that you have HIV/AIDS?

Were you alone?

How did you feel?

Have those feelings changed over time? How?

How has your family been treated by others?
Do you think people know s/he has HIV/AIDS?
How do they show that?
What have you noticed?
Do people around you treat you differently now? How
Do people help you or stay away?
Could people help you more?
What do you need now to help you to cope?
Do the doctors and nurses treat you differently if you have AIDS?
How, when and where?
Have you been able to get help? What sort? From where?
What about your son, brother. Husband (if infected). Do they get the same help as
you?
Have you been able to talk about your infection?
Who are your best emotional supports?
What helps you to cope?
Does your religion help?
What have you learned about yourself after the infection?
How has your experience helped/hindered you?
What do you think about the future?

APPENDIX 4

INTERVIEW PARTICIPANTS

The participants are represented here by the salient points in their histories. The names are in alphabetical order, with the number of the interview in brackets. The names listed below are pseudonyms which have been used for the purpose of the thesis.

Abha (17): Abha is widowed at 50 and dependent on her sister for support as she is often not well. She feels hopeless, does not believe in God, and is unable to share her troubles.

Aisha (18): When her husband was diagnosed with HIV/AIDS, Aisha became severely depressed, and had shock treatment twice. This was her second marriage, unusual in itself. Her husband was Muslim and she was Hindu. They experienced much discrimination in the community when the diagnosis was made known. She loved her husband and wanted to care for him as best she could.

Anju (45): Anju's husband died of HIV/AIDS, and she has been diagnosed also. She has three sons, and is presently working with a positive outlook.

Arwa (33): Arwa came to Mumbai when she was 7 and orphaned. She is Muslim, married to a Hindu. She is HIV positive and her husband. She became very depressed on learning her diagnosis, and suffered discrimination from her neighbours. Her husband abused her, and is in hospital. He told the owner of their house to throw her out which is a great worry to her.

Bidya (11): This 29 year old woman's husband is infected as well as herself. She was told during her second pregnancy. They have not told anyone because they fear discrimination. She worries about her children's future.

Charu (25): Charu had taken her sister-in-law to the hospital when she was continuously ill to be diagnosed, and then she managed her care until she died, as her own parents discriminated against her. Now she is bringing up her niece as her own.

Divya (7): Divya is 78 years old and cared for her son until he died of AIDS.

Fatima (22): Fatima is Muslim and her husband infected her after he had worked overseas. Their daughter is also infected. There are seven people in her family suffering from HIV/AIDS. They care for each other and try to make the best of their lives.

Gita (21): Gita is 40, from a scheduled caste, and has ten people in her household. Her brother-in-law and his wife had died from HIV/AIDS leaving their children orphaned. One child is mentally retarded, and difficult, and another maladjusted. They are not seen as a burden.

Irfa (29): Irfa is only 18 years old, and nursed her mother who had HIV/AIDS and also became paralysed. There are five children and her father to care for, and she is trying to study at school.

Jwala (16): A widow of 26 years, Jwala and her two children are dependent on her brothers for support. She misses her husband and finds his absence terribly unsettling. Her mother-in-law is a great support to her

Kalavati (9): This 65 year old woman came to Mumbai when she married. Her son in-law infected her daughter who was treated like an “untouchable” so her mother brought her home to be nursed until she died of AIDS.

Kamla (1): Kamla lived in Chembur and came from a scheduled caste. She became the breadwinner after her brother died of AIDS and left 3 children to care for.

Kavita (36): Kavita is 35, and from a backward caste. She and her husband are HIV positive. They have three children. At present, both are still working and healthy and happy taking one day at a time.

Keya (27): Keya is 35 years old, widowed, and earns Rs 10-20 a day as a rag-picker. She does not tell anyone as she thinks people will think wrong about her. When she becomes critically ill, she plans to end her life so she will not be a burden on the family.

Latabai (8): Latabai is 67 years old. She had lost all her sons to HIV/AIDS. There are no men left in this family and the daughter-in-law is infected so that leaves her to care for the grandchildren.

Leela (44): In Leela's family, all five people are infected with HIV/AIDS. She and her daughter are the only ones who are ill. She stays positive and wants to live long enough to see her children independent and well settled.

Lina (34): At 25 years old, Lina has just learned that she is HIV positive. Her husband is already infected. She fears discrimination, as she has observed it happening and says they will have to leave their home and that no-one will help them.

Mina (37): Mina believes her husband was infected by donating blood. She has not told anyone because she fears discrimination as they had to vacate their previous residence, when the community learned of her husband's diagnosis. She is dependent on her two children for support as she is also HIV positive.

Munira (28): Munira is Muslim and migrated to Mumbai. Her children have not gone to school since her husband's death. She is HIV positive, and dependent on her brother for support for herself and her three sons.

Neela (14): Neela is a 31 year old widow who lives under a bed with her three children. She is infected with AIDS and not well. She is grateful for a roof over her head as she knows there is worse discrimination. She feels very alone, but still trusts God to improve her conditions.

Nirmala (13): Nirmala is 50 years old, and married. Her daughter-in-law is widowed and affected by HIV/AIDS, as is her 11 year old daughter. They have not told their neighbours. Their household consists of 4 children, one son and his wife, one daughter-in-law and her daughter.

Pooja (32): Pooja came to Mumbai when she was 25 to be married. She cares for her HIV-positive husband who is often ill. She is scared of the future, raising her two children by herself.

Priya (5): Priya is 24 years old, from a backward caste, lives with her husband and two children and her father. Her 7 year old sister has been diagnosed with HIV/AIDS. She is afraid of discrimination, and will not reveal her sister's status.

Pushpa (23): Pushpa is from a scheduled caste, and Buddhist. She cared for her mother who had AIDS until her death. This was difficult as she was angry with her mother who had married three times; her husband did not like her mother, and she found the nursing was onerous as she was a young woman in her early twenties.

Reema (42): Her husband is ill with HIV/AIDS and cannot work. She is not HIV positive, because they always had safe sex. She has two children and they have not told anyone in the neighbourhood.

Rekha (30): Rekha's unmarried brother contracted HIV/AIDS and lives with her family, as everyone from her mother's side of the family are deceased. She asks her family to "adjust a little" and help her care for him.

Rita (43): Rita is a young married woman who has just been diagnosed. As her husband is negative, she is shocked and unable to explain the infection. All she says she wants is a baby. She has no other aim in life.

Ritu (31): Ritu is 45 years old, infected with HIV/AIDS and widowed. She makes shoes to support her four children

Rukhsama (35): Her husband has been diagnosed with HIV/AIDS, and she feels it strongly as he is the backbone of the family. She has not told anyone as she does not want to damage his reputation. She does not know her own status and says her sons will decide whether she gets checked or not.

Rupa (41): Rupa believes her husband was infected as he worked as a hospital laboratory technician. She is now widowed and fears discrimination from the community so she has only told her daughters. She is still working at present.

Saras (26): Her husband had become very depressed when he was diagnosed with HIV/AIDS and tried to commit suicide. She nursed him until he died. She did not receive any help from the people in the community.

Sarita (39): At 38, Sarita is already widowed. She lives with her brother and her brother's brother-in-law. She is not HIV positive as her marriage was never consummated, but she cared for her husband until he died. She faces harassment from men who knew about her husband.

Seema (18): Her husband was diagnosed first, then herself. She has three children all negative. They have not told anyone as they fear discrimination towards the children. Her religious faith helps her to cope.

Shamla (2): Shamla was widowed at 36 with two sons to raise. She has HIV/AIDS herself, and was severely malnourished. She has a strong faith which helps her cope.

Sheela (24): Sheela is widowed at 25 years old. She cared for her husband until his death. Her own mother discriminates against her and will not let her sit with the family to have meals, but she forgives because her mother has taken her and her son into her household.

Shobha (38): Shobha is only 26 years old. She and her husband and 4 year old daughter are all HIV positive. The little girl has been sick since birth, and on medication, although they cannot afford that now. They have not told anyone outside the family as they fear discrimination.

Shuja (40): Shuja is newly diagnosed with HIV/AIDS. She learned about it during the delivery of her second baby. She was teased in the hospital by the nurses. Her husband is also HIV positive.

Sita (20): Sita is married, and cared for her son over five years. She believed that anyone with HIV/AIDS should be loved and cared for. They are feeling the effect of losing the breadwinner of the family.

Smitha (6): Smitha learned that she had HIV/AIDS for the first time during her pregnancy, and “had to” abort the child. She still has not got over it, and is withdrawn from other people.

Suruchi (12): This 30 year old widow has two sons and a daughter she has sent home to her mother. She has AIDS, and she has not told anyone as she fears discrimination.

Tara (3): She is a widow. Her husband had left her for another woman, became infected and returned to infect her. She was shattered by her diagnosis of HIV/AIDS, and without children or relations. She has not told anyone of her diagnosis.

Usha (10): This 57 year old widow cared for her son who had AIDS for two years until his death. Her strong religious faith helped her to cope.

Veena (15): Veena’s sister is infected with HIV/AIDS. She is fortunate her husband is supportive, but she has had to pawn her wedding necklace to pay for a nurse and medicines. She has not told anyone because she does not want to harm her husband’s reputation.

Vijaya (4): Vijaya is a widow at 24, with two daughters. She is proud that she nursed her husband well. She is not infected.

APPENDIX 5

PHOTO COMMENTARY

The photographs in this section are my personal photographs; they capture contextual images, and characterize the human element of the lives of the women. The inclusion of these 'photographic pieces' I hope will contribute to the overall 'sense' of the study. As it has been said – every picture tells a story and one picture tells a thousand words (Hasic, 2004, p xiv)

APPENDIX 5A

THE POLLUTION OF MUMBAI & THE ENTRANCE TO A COMMUNITY SLUM



Mumbai (formerly Bombay) is a mega city of over 15 million people. An ancient port, it borders the Arabian Sea. Unfortunately, the city itself cannot expand along the coast and therefore sprawls inland. The central business district is pleasant enough, with gracious colonial buildings, and tree-lined streets, and cool, sea breezes. As one travels further from the centre, the trucks, taxis and auto-rickshaws choke the highways. The roads have deep ruts and potholes, and the air is heavy with pollution from industrial factories and old vehicles.

This photo was taken from the student hostel where I lived. The greenery is unusual, and is part of the K J Somaiya University campus. Beyond are the high-rise buildings which house the ever-burgeoning population. The unhealthy air results in chronic respiratory health problems for Mumbaiites; for example, children have a high prevalence of chest and bronchial conditions like asthma, as they are exposed to pollution travelling to and from school. Tuberculosis is an added threat for people living with HIV/AIDS, and the pollution affects these people. Illegal dwellings were continuously being demolished alongside the highway, which added to the dust and dirt. Plants growing along the roads could not survive the coating of grey dust. Ghatkopar, the suburb where I lived, is also one of the sites for the city's garbage burning. In addition, every morning the apartment was filled with black soot from the rubbish students threw from the windows being burned during the night.

This slum community had grown up around the hospital, which served its inhabitants. A dirty stream separated the dwellings from the hospital, and it was approached by this makeshift bridge. Women in saris could easily trip and fall into the water below, although I was the one more likely to do so. The rubbish heaps were common, and the community leader said that sanitation and rubbish collection were major problems for the community. The dwellings, consisting of one room, were adjoining and bordering a central "road" only navigable by auto-rickshaws, and then with difficulty, as it was very rough.

I was always surprised by the number of tiny shops selling all manner of things, but always sweets in small quantities. Barrows sold poor quality vegetables like carrots and potatoes, and there were piles of chillies drying in the sun. People were accepting of my presence, and greeted me warmly as I tried out my Hindi. As they were mostly speaking Marathi, and with my accent, my attempts were usually not understood. One could feel the inevitable sharing of the community as they lived so close and their dwellings were windowless which forced people into the open street. I did not witness any fighting or loud voices. I wondered how women could manage to keep their illness secret in such circumstances.

Women moved easily, chatting to neighbours and passersby, as they watched their children, or pounded their spices in mortars on the ground. There were always dogs, cats, hens and chickens, and in other communities, pigs in the street. I was cautioned to avoid an obviously rabid cat, slavering at the mouth.

The rubbish heaps, dirt and squalor encouraged flies, mosquitoes and rats which I saw. The obviously unhealthy conditions were repeated in other slum communities I visited, and this community was one of the better ones.

APPENDIX 5B

THE SAHAS TEAM ENJOYING THEIR LUNCH



Each day, I would travel with the young interpreter, shown standing in this photo, to the hospital where the SAHAS team had their office. The dimensions of the office can be seen. It was often crowded with up to 12 people when clients from the service visited, or new clients were interviewed. There was little confidentiality possible in the small space. Clients were issued with food rations if they were on the Nutrition programme, or mats to replace those lost in the floods, and sometimes clothing. The office was often hot in the afternoon, as there was no air conditioning, but no-one complained, except me.

The three community health workers, and the two outreach workers would arrive from their morning visits. The Co-ordinator, shown on the right, would join them for lunch. Their food was carried in small, shiny, metal containers, and shared out amongst themselves, and eaten neatly in their fingers. They drank only water in the Indian style without touching the rim of the bottle with their lips. The women were always neatly dressed, hair tied back, and without makeup. They laughed, and

shared their experiences and their lives, in this manner. They spoke in Marathi, which I could not understand, but were always polite, and tried to include me in their conversations. Their smiling faces show their relaxed manner with me.

After the meal, arrangements would be made for me, and the interpreter to accompany one, and sometimes two, of the CHWs into a community to interview women participants in the study. The visits sometimes took up the whole of the hot afternoons, as we travelled from one community to another seeking the women who had agreed to be interviewed. I would then return with the interpreter to our homes by auto-rickshaw.

APPENDIX 5C

THE INTERIOR OF A DWELLING & A STEEL KITCHEN



This dwelling was the home for a widow, her two daughters and the child of one of them seen sleeping on the bed. Meals are taken in this way, on a mat on the floor. Bedding is rolled out at night, so the floor space is used very economically for sleeping, meals and even preparing food.

Dwellings had electricity which enabled people to have an electric light, usually a fluorescent tube, a fan and a television set. This family also have a refrigerator, which was unusual. On the wall, is a garlanded photo of this lady's guru. Often,

widows had photos of their deceased husband on the wall. This photo shows the mode of interviewing. The interpreter, outreach worker and CHW sat with the participants, whilst I sat observing from a plastic chair. Interviews took approximately one hour, and were recorded and later transcribed.

This steel kitchen is a fine example of an Indian woman's pride and joy. It implies some status to own so many articles and are displayed so that everyone can see. At the same time, it is very utilitarian. Every article is used and important in the presentation of food. It requires much elbow grease and effort to maintain utensils in this state when water is not always available. Women have to rise early each morning, to fill their pots with water for use during the day. This collection was the most comprehensive I saw.

APPENDIX 5D

HALDI KUM KUM DAY IN THE COMMUNITY



This celebration is held on several festive days of the year. There is no religious or historical significance, but it provides an opportunity for women to come together, and celebrate their femininity. It can take the form of a hostess distributing bangles, sweets, flowers, betel leaves and nuts, or more open, friendly gatherings.

In this case, I was invited to the haldi kum kum in the community. After a long wait, the women started appearing, a little self-consciously at first, in their special Maharashtrian saris. These are longer than the usual sari, in traditional patterns, very bright and colourful. They also wore their *mangalsutras* (wedding necklaces).

I was seated at a table and one by one, five women each anointed me with three colours – orange, red and white. After 15 daubs, I could feel it trickling down my cheeks. The community leader gave a speech welcoming me to their community, and then they presented me with a clock which I will always treasure. I felt very

honoured to be part of this special celebration. We shared some special sweets associated with the festival.

In this photo, the group of brightly dressed women are seen against the backdrop of their dilapidated houses, and bleak conditions. They are listening to the community leader, whose speech is broadcast through the speakers in the background.

APPENDIX 5E

KJ SOMAIYA SEWING INITIATIVE



Whilst I was at the hospital over the period of my research, I was able to witness the inauguration of this project. Funds had been obtained to purchase six sewing machines and place them in a room at the hospital so that women could be trained to sew, and therefore earn some income. Income-generating activities are vital as women affected by HIV and widows are left destitute, and without a government social security system, they are plunged into even more poverty.

The group commenced as the Positive Community Polytechnic with some training in the use of sewing machines and sewing, and they commenced by producing gowns for the hospital patients. These were well received, and as I was leaving, they were receiving new contracts which would bring revenue. The participants will be taught tailoring, embroidery, bag-making, Mehndi tattooing and crocheting. In this photo, the treadle machines which have long since disappeared in our country are being used to not only increase income, but also to raise self esteem, and independence. Bringing women together also helps them to cope, and spreads skills which they can pass on to other women.

APPENDIX 5F

A WOMEN'S CO-OPERATIVE



In the grounds of the college where I lived was a small women's co-operative. This had been going for many years. They produced several products such as very thin, crisp pancakes to be sold in the shop. There was a farm outside the city which provided some produce to be sold here, and also vegetables which I always tried to buy from the barrow man in the grounds of the University.

In this photo, women can be seen cooking on spirit stoves. On the left the woman mixes her dough, whilst the middle one pats it out, and cooks and the third one packs the cooked pancakes for sale. The manager of the shop is in the background, supervising. I was always welcomed to the shop, and despite my lack of language, was able to purchase fresh, clean snacks which I enjoyed. The women laughed and chatted as they worked, so the atmosphere was always pleasant and productive.