In Sickness and in Health: Redefining Self, Community, and Health within the Illness Experience of HIV-Positive Women in Chennai, India.

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Declaration

I, Caitlin Mariah O'Grady, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

This thesis investigates the evolving nature of the illness experience of HIV-positive women in Chennai as they redefine their concepts of self, community and health in light of their interactions with a local HIV clinic. It is through their ongoing relationships with the other patients and staff members within the Clinic that this thesis examines the state of liminality experienced by participants while they move through the different stages of their illness experience. In particular, their interactions and opinions at each stage of coming to terms with their diagnosis are discussed with regards to the concept of personal agency and the relationship this has to overall health and wellbeing. The thesis has three main areas of concern. The first explores the role that culturally-based stigmas and traditional schemas of women's positions within the family have in creating specific health-related vulnerabilities among these women. The second area of concern attends to the role of the family and the ability of HIV/AIDS diagnosis to alter the expectations of the sick role amongst individuals and family members. The experiences of stigma and fear discussed by participants highlight the redefining of what constitutes health and point to a definition of community that is expanded to include Clinic staff and other HIV-positive individuals while maintaining relationships with family and friends wherein HIV status is concealed and denied. The third area of concern continues this theme by exploring the actions of the Clinic staff and their ability to enter this expanded community definition by taking on roles traditionally held by family members while battling against the negative experiences patients have had at other medical facilities. Ultimately, this thesis details the intimate relationships experienced by these individuals and the Clinic staff at the intersection of traditional social values and the modern condition of HIV/AIDS.

CONTENTS

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Introduction:

Patient History: HIV/AIDS in India

"India is the single most important country with regard to the history of the global epidemic. If we lose the fight in India, we lose the fight globally"

- Richard Feachem, Epidemiologist, The Global Fund[1]

"It is not possible to control the overall HIV epidemic if it is out of control in India. Whatever success is recorded in India will immediately have an impact on the overall world situation just because of the sheer numbers."

- Denis Broun, Country Coordinator, *UNAIDS in India*[2]

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[1] Cohen, John. 2004. "HIV/AIDS: India's Many Epidemics." *Science*. Vol. 304 (5670) pp. 504-509

[2] Steinbrook, Robert. 2007. "HIV in India – A Complex Epidemic." *New England Journal of Medicine.* Vol. 356, pp. 1089-1093.

This thesis maps the illness experience of women who contract the Human Immunodeficiency Virus (HIV) in Chennai as they move from the diagnosis of their condition to personal acceptance[3]. It is through the detailed discussion of their illness experiences from their pre-diagnosis lives to the present that this thesis explores the ways in which the reality of their condition differs from that of their male counterparts, the role that social pressures and culturally-created vulnerabilities have in hindering risk assessments, and the impact that involvement with a local HIV/AIDS organisation has had on the definitions of self, community and health experienced by participants[4].

By investigating the intersection of socially-constructed vulnerability and the unique position of the Clinic, the thesis highlights the way HIV serves to divide the self into private and public versions and the steps individuals take to reconcile these two elements. This period of uncertainty, when the individual is coming to terms with their diagnosis and the impact it will have on their public, social self is therefore a key focus of the thesis and is intended to highlight a specific liminal state that individuals must pass through before fully accepting their new lived reality. This thesis seeks to investigate the coping methods used by participants to adapt their lives to their condition and their condition to their lives. Ultimately, this thesis intends to use this liminal period to demonstrate the impact personal agency and interaction with the Clinic has in mediating the experience of social inequalities and to shift the focus from a dialogue of suffering to one of empowerment.

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[3] For the purposes of this thesis, the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome will be known by their acronyms of HIV and AIDS.
[4] In order to maintain the privacy of my participants, the organization where this thesis is centred will be referred to as the Clinic.

In this way, this thesis seeks to expand the narrative around decision making highlighted by Cecilia Van Hollen through her work in South India. The focus on the positive impact of the Clinic follows Van Hollen's (2007) assertion that "the discourse of positive living" provided by HIV-positive networks creates a framework that women can use to their benefit in navigating their condition (Van Hollen, 2007). The Clinic is then provided as a physical space wherein this framework is displayed and engaged with. However, while her work has been centred on decision making around reproductive health and childbearing, this thesis broadens the discussion through an examination of the elements at work within the acceptance of diagnosis and the period of transition individuals face. For example, while the social and cultural elements are examined, they are viewed through the lens of their impact on the need for a liminal period and the effect this has on personal agency and acceptance. Furthermore, this thesis is focused on the changing relationships demonstrated within the liminal period rather than on the area of decision making itself.

The main element of HIV diagnosis that this thesis seeks to attend to is the illness experience. This is defined within this thesis as the patient's interactions as a result of their condition and their perception of it rather than focusing on the virus itself. For example, the interviews with staff members around the Clinic, and in particular those with medical staff, tended to focus on the virus' impact on an individual's health and the medications used to combat this influence. Meanwhile, the interviews and discussion with the patients themselves were more focused on social elements or the difficulties they had in their day to day activities as a result of their condition. These ranged from fears about disclosure resulting in isolation or eviction from their rented accommodation to concerns about how

their status might negatively impact their children or family members due to the established stigma relating to the condition.

An additional benefit of focusing on the illness experience for these participants is the ability to examine not only their reactions to diagnosis but also the change over time as they move towards accepting their condition. Often, discussions about HIV-positive individuals can become overly medicalized wherein the patient becomes a representation of the virus, rather than someone who changes and adapts to their new status. However, this approach overlooks the pre- and post-diagnostic influences that continue to act on the individual and can alter their perception of the condition. For example, Byron Good (1977) has highlighted the importance of acknowledging that a person's suffering is both a 'medical fact' and a 'socio-historical' fact. This has proven true in the case of HIV illness experience as public perception of the epidemic and those who are living with the virus continues to impact participants and has led to the adoption of the liminal state after diagnosis (Sontag, 1989).

In order to assess the illness experience of HIV-positive women, this thesis benefited from a methodology designed to allow for the inclusion of the Clinic as a whole, which included staff members, patients and the general public. The two main methods involved were general observation and semi-structured interviews. The general observation took place both within the Clinic and around the compound where it is located. I was interested to see how individuals arrive at the site and who they choose to bring with them, as well as their general attitude upon arriving, while waiting to be seen and finally when leaving. For example, by observing the waiting areas, it was possible to investigate the level of interactions patients have with each other and the staff members. The participant

interviews were designed to go deeper into the illness experience by asking a range of semi-structured questions, which allowed participants to share what they felt was the most important about their personal histories. These were conducted with HIV-positive women who volunteered to take part and with staff members at every level of treatment within the Clinic[5]. The methodology used within the fieldwork component of this research was designed as a result of the ethical concerns involved with a focus on such a stigmatized condition and also the desire to maintain sensitivity to the experiences of participants. Therefore, the location of this research within the medical facility of the Clinic was necessary as it was the only area of the city where HIV-positive individuals felt comfortable discussing their condition.

The terminology included within this thesis was chosen with regards to the different roles individuals played during the fieldwork process. *Staff members* were considered to be anyone who was employed at the Clinic or at the sister location of the Kitchen. When discussing a given individual, such as through interview quotations, their specific position will be identified although they will have been assigned a pseudonym to protect their identity. *Clinic visitors*, also referred to as *visitors*, includes all individuals who were involved in the general observation in and around the Clinic. This included time spent observing the waiting areas and other spaces within the Clinic and the immediate location. Additionally, this term also refers to individuals who were present during my observations of counselling sessions. Finally, *interview participants*, also referred to as *participants*, indicates the women who agreed to more formal interviews wherein they were asked a

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[5] The fieldwork methodology, and the reasoning behind it, are discussed in greater detail in Chapter Two.

specific set of semi-structured, open ended questions that had been approved by the ethics boards in India and at University College London.

Background of the Epidemic

The approach to gaining an overview of the HIV/AIDS epidemic within India for the purposes of this thesis has mirrored the steps taken by HIV-positive individuals as they come to understand their diagnosis. In the same way, this chapter seeks to unravel the "patient history" of the epidemic within India itself. The three steps of testing, counselling and disclosure, were chosen to not only match the stages of understanding undertaken by individuals, but also to demonstrate the knock-on effects the decisions made by policy makers and government officials at the beginning of the epidemic have had on the problems of awareness and stigma facing HIV-positive individuals today.

When an individual begins their journey through the illness experience of HIV, the testing stage is the most direct with the bare bones of the condition laid out before them. What is HIV and what does it mean to test positive? In applying this stage in diagnosis to the patient history of the epidemic, the first step of this study started with the statistics and history of the local HIV/AIDS epidemic within India and, more specifically, within Chennai, the capital of Tamil Nadu. In addition, a comparison between the local epidemic within India and the global pandemic was examined to highlight both the denial of the virus' existence in India and the delay in official action on this epidemic by the government.

The next step for individuals who have received a positive test result involves post-testing counselling. This step extends into the lifestyles of most patients as the reality of living with the condition often brings up questions that counsellors can help to answer. This process is in effect the merging of the medical elements of the condition with the

practical and therefore combining the illness details with the daily concerns for patients, such as traditional ideas about health, public misconceptions of the condition and social interactions. Within the patient history of the epidemic within India, this stage meant looking beyond the medical statistics to the bigger picture issues that impact on the perception of the epidemic and the way individuals react to their diagnosis. In particular, this stage highlights the way the remnants of early denial within the official discourse and the resulting delay in improving awareness has resulted in an environment that is ripe with misunderstandings and misconceptions that encourage the creation and propagation of stigmatizing ideas and actions. This then leads into the final stage in coming to terms with a diagnosis: disclosure.

When examining this stage from the point of view of the epidemic as a whole, disclosure involves adapting to the forces laid out in the previous two sections in order to move forward. For the epidemic, this forward momentum includes increasing numbers of infections as, despite the attempts by policy makers, international donors and non-governmental organizations, the epidemic continues to expand within India although its pace has slowed in recent years. This expansion has been made possible by taking advantage of a created vulnerability, which has resulted from the combination of cultural traditions and social preconceptions about the condition. Therefore, within the patient history of the epidemic in India, the disclosure stage allows for the discussion of the India-specific cultural factors that continue to create social vulnerability within the population.

Testing

The testing stage in the patient history can be viewed as the necessity of gathering data and understanding the official discourse surrounding the condition. Just as doctors

focus on the methods of transmission and testing stages for patients, statistics and country-wide reports are used to construct the overall picture of HIV/AIDS. When approaching the local epidemic in India one of the first steps is to differentiate the condition within the subcontinent from the global HIV/AIDS pandemic.

Global Pandemic/Local Epidemic

The necessity of examining issues within a social or cultural context through the inclusion of both their unique and general features was highlighted in 1971 by Evans-Pritchard, who theorized that although social anthropology is often seen as being more comparative and, in particular, more focused on the similarities between cultures than other social sciences, wherein the goal of research is to determine the differences between subjects, the reality is that all social research must acknowledge and consider both elements in order to be valid (Evans-Pritchard, 1971: 4). Within HIV/AIDS, the different versions of the condition seen in the global pandemic compared to the local epidemic offer important insights into the way culturally specific elements impact the illness experiences of individuals.

Originally detected in the United States in 1981, HIV/AIDS has gone on to become a global pandemic. However, the effect of local epidemics has varied. While some western countries were able to adapt previous public health campaigns to slow infection rates, the same cannot be said of the developing world. With the pandemic in its fourth decade, India has distinguished itself as a particularly complex case study as infection rates rise in some states and fall in others (Avert, 2016).

The United States Centers for Disease Control began the fight against the spread of HIV/AIDS by defining the virus and its subsequent conditions and circulating information

on the symptoms to doctors around the world (Kuller and Kingsley, 1986: 57; Fox, 1986: 7; Adelman and Verbrugge, 2000: 351). By 2008, there were 33.4 million HIV-positive individuals globally, with the majority living in developing countries (AVERT, 2010). During the intervening two decades, the virus spread from the isolated communities it originally affected, such as men who have sex with men, commercial sex workers and intravenous drug users into the general public. However, these origins continued to follow the pandemic and labelled sufferers as a part of communities considered socially liminal. This alienation of sufferers led to the public considering HIV/AIDS as a disease of 'others' and therefore not a concern for themselves (Hymes et al 1981: 598-599; Sontag 1988: 25; UNAIDS, 2001).

This shared perception of the condition has been supported by the official discourse in countries, such as the United States, where targeted campaigns aimed at those considered a part of 'high risk' groups has led to successes in awareness, behaviour change and condom use. These countries have therefore maintained a low infection rate. As a result of this success and due to the fact that the United States is one of the leading donors of international efforts to stem the spread of the virus (through the President's Emergency Plan for AIDS Relief – PEPFAR), this approach focusing on identified 'high risk' groups has been circulated to other countries via international aid programs (PEPFAR, 2011). However, this program design was specific to the culture, tradition and history of the United States and therefore has not been as successful in other settings. As epidemiologists and public health program managers have been joined by sociologists, anthropologists and social workers in the study of the virus, cultural competency has becoming a focus point for future planning (Balmori, 2003).

The virus itself, through its spread into previously unaffected communities, has created the need for new approaches to local epidemics. Of the Second Wave countries, India represents the biggest threat to the global HIV/AIDS pandemic as its large population, consisting of one and a half that of the continent of Africa, means that any increase in the infection rate could have massive repercussions (Steinbrook, 2007). With the population set to surpass China's to be the largest in the world over the next decade, the threat from HIV/AIDS is still a major concern (Population Reference Bureau, 2015). The epidemic in India has had several important differences compared to that experienced by western nations. Perhaps the most important involves the mode of transmission within the population. In India, heterosexual intercourse has been the driving force of the epidemic whereas homosexual intercourse and intravenous drug use were the most common transmission routes in countries like the United States (Fee & Fox, 1989; Farmer & Kleinman, 1989; Sontag, 1989; Ghosh, 2002: 114; Amin, 2004: 6; Cohen, 2004). As a result, women have been a major part of the epidemic from the start, with women making up 39% of current infections (Amin, 2004: 6; Pallikadavath & Stones, 2003; AVERT 2011; Paranjape & Challacombe, 2016). Although HIV/AIDS is often discussed as an India-wide problem, the virus has been largely contained within six Indian States: Andra Pradesh, Mizoram, Karnataka, Manipur, Tamil Nadu and Nagaland. This geographical disparity highlights the importance of acknowledging the localized impact of the epidemic (Desai, 2005; Cohen, 2004; Datta & Misra, 2000; Mitra, Hate & Schaffer, 2007; Steinbrook, 2007)[6].

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[6] Although these states have consistently been the worst effected, there are new states that have seen their rates rise while the more traditional locations have seen theirs

Although infection rates over the past two decades have caused alarm among international researchers, the epidemic within India began comparatively late. As one of the 'second wave' countries along with Russia, Nigeria, Ethiopia and China, India's first HIV case was diagnosed in 1986 and the 1990s saw the epidemic increase significantly (Dietrich, 1995). This delay was echoed by the official response to the epidemic. From 1986 to 1992, the official discourse actively sought to downplay the possibility that India was home to a growing HIV/AIDS epidemic as economic concerns such as tourism were prioritized. However, this decision by the national government allowed rumours and misinformation to solidify within the general public.

The last two decades have seen India take important steps within industry, politics and healthcare in order to become a major player on the international stage. The epidemic's delay was important within the response to HIV/AIDS as the Government of India was able to examine the approaches undertaken by countries viewed as having successfully controlled their epidemics, such as the United States and United Kingdom. However, as previously stated, the example set by these countries cannot be directly applied to a country as complex as India, where different religions, languages and geography combine with one of the largest populations on earth. At present, there are currently over two million people living with HIV in the country which is less than half the number estimated in 2006 (Avert, 2016). Although this represents a recent drop in infections, India continues to have the third largest HIV epidemic in the world with a prevalence rate of 0.26%. Therefore, India remains at a critical junction where HIV/AIIDS must be combated not only as a subject for

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lower. For example, Uttarakhand, Jharkhand, Odisha, Assam, Punjab, Delhi, Haryana and Chattisgarh have all seen rising prevalence rates (Paranjape & Challacombe, 2016)

biomedicine but also through recognition of the fears and beliefs surrounding the local understanding of the condition (Pisani 2000: 64; Steinbrook, 2007; Farmer, 2003; Kleinman, 1980; Avert, 2016).

A diagnosis of HIV infection impacts more than just an individual's mental and physical health. Instead, the virus invades all aspects of daily life as sufferers face socio-political stigma, economic hardship resulting from the disclosure of their status, and isolation from family support (Alderman & Verbrugge, 2000; Aggleton & Homans, 1988; Bolton, 1995; Chandra et al, 2006; Cohen 2004; Dworkin, 2005). Too easily written off as a disease of 'others,' HIV awareness and knowledge within the general Indian public remains low despite attempts to increase levels of understanding (Eaton, 2008; Farmer & Kleinman, 1989; Ghosh, 2002; Kimberly, Serovich & Greene, 1995; Van Hollen, 2013; WHO, 2006).

Although the statistics and country-wide reports have highlighted the differences between the global pandemic and the local Indian epidemic, the Government of India has continued to focus its strategies on prevention, treatment and research among designated risk groups modelled on those of other countries (Bhat, 2004; Datta & Misra, 2000). The 'at risk' groups have been defined as commercial sex workers, intravenous drug users and those attending sexually transmitted disease clinics, despite the fact that these risk groups are only targeting a small proportion of the population (Kumarasamy, 2005; Rodrigues et al, 1995). Although the epidemic in India is particularly concentrated within these groups, the evidence of HIV's spread into the wider population via "bridge groups" indicates that

targeting all heterosexual sex, the main driver of new infections, would be a beneficial addition to the overall prevention strategy (Population Foundation of India, 2003)[7].

This difference between the government defined characteristics and the reality of the situation means that government officials or nongovernmental organization staff members will often find their campaigns falling on deaf ears as individuals who do not view themselves as part of those groups ignore them. In addition, this focus ignores the fact that some groups, such as commercial sex workers, will be more loosely defined by the public. Further, an approach that targets commercial sex workers themselves, rather than the industry as a whole, will bypass the individuals who are active in this area as clients. This bridge group has proven to be a significant element of the spread of the virus. For example, one study on HIV-positive women in South India found that 81% were married housewives. Of these women 89% reported heterosexual intercourse as their only risk activity and 90% indicated a history of monogamy (Cohen, 2004; Rodrigues et al, 1995; Bailey & Hutter, 2006: 469; Desai, 2005: 145). Therefore, their lack of inclusion in risk groups and their unknown vulnerability to the virus highlights the need for greater awareness within the general public.

Healthcare in India

A country as complex and diverse as India is unsurprisingly complicated when it comes to healthcare. Faced with a large population spread over a diverse geographic area, the Government of India has spread its resources as evenly as possible while trying to focus

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[7] A bridge group is defined as a population who carry the virus from an at risk group to the general population. One of the most common examples is men who contract HIV from commercial sex workers and then pass the condition on to their wives. The focus on these bridge groups has been steadily growing due to the high rate of HIV infection among women in antenatal clinics (Population Foundation of India, 2003).

on problem areas (Dyson 2003: 429). With current estimates highlighting the continuing varied nature of infection rates and a national need to maintain a strong work force, the official strategy has been to try and prove these estimations wrong by rolling out ambitious plans to expand access to care and improve adherence to medication (USAID 2010; Pisani 2000: 64). However, the difficulties in the approach itself have been exacerbated by a decentralized implementation, the majority of the funding coming from external sources, and a lack of preparedness among local healthcare facilities and practitioners. In order to give an overview of healthcare in India and the implications for the local epidemic, this section has been divided into two subject areas: organization and preparedness for HIV/AIDS.

Organization

In its approach to the control of the epidemic, the government of India has divided its strategy into five year plans with the third iteration taking place between 2007 and 2012 (Mitra, et al, 2007: 5)[8]. Viewed as more 'ambitious' and complicated than previous plans, the third phase of the National AIDS Control Program (NACP-III) focused on preventative interventions, increased treatment levels and extending awareness programs to isolated communities in order to try an educate more individuals about their potential risk (Mitra et al, 2007: 5-6, Bhat 2004:12). This included extending the 'at risk' groups to include truck drivers and migrant workers who have traditionally proven difficult to target due to their continuous movement, which means they are often absent from population surveys. In

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[8] India has since entered the fourth phase of the National AIDS Control Programme which continues the focus on intensifying and consolidating prevention services with at risk groups and expanding awareness campaigns to target women and young people more directly (NACO, 2015)

addition, 380,000 health personnel were to be trained in specific HIV/AIDS healthcare. Finally, in the most ambitious goal, the government hoped to have 300,000 additional people on antiretroviral treatment. While this number seems low given the estimates of the epidemic, a previous goal of 100,000 people on treatment had only managed 60,000 by 2007 (Mitra, Hate, & Schaffer, 2007: 5). The primary obstacles to this goal have been the difficulty in reaching patients in rural areas, the shortages within community outreach and follow up care, and the problem of "brain drain" which sees many of India's highly trained individuals migrating to other countries and leaving clinics and hospitals understaffed (Mitra, Hate & Schaffer, 2007: 5).

In many developing countries the government approach to the local HIV/AIDS epidemic is augmented by international donors who support nongovernmental organizations in local cities. This is true within India with international donors and organizations demonstrating an increasing footprint within HIV/AIDS treatment and care. (Halmshaw and Hawkins, 2004: 37). This creates new problems as the funding provided is critical to the fight against the epidemic but there are disagreements on how the funds should be distributed. For example, many donors, such as PEPFAR, refuse to engage in needle exchange despite the fact that this has been shown to be an effective means of lowering HIV infection rates. An added obstacle is that the requirements for successful disbursement, such as a local clinic or access point, may not necessarily be in place in all areas of the country, leading to problems and obstacles that keep the supplies from reaching the intended populations (Lieberman 2009: 216).

These funds from international donors make up a significant proportion of those available within India and are critical to prevention and treatment activities. For example,

the overall budget for the second five year plan, NACP-II, was $300 million (Amin 2004: 6). Of this, the Government of India contributed $38 million while the World Bank supplied $191 million in loans to the country, and the remaining contributions were made by other international agencies such as the United States Agency for International Development (USAID), the British Department for International Development (DFID), the Canadian International Development Agency (CIDA), the Australian Agency for International Development (AUSAID), and the Bill and Melinda Gates Foundation (Amin, 2004: 6; Pisani, 2000: 64). Another issue is the uneven distribution of international funds among the most affected states. For example, the United States donated the largest amount of assistance with $42 million in Maharashtra, spread over seven years, and $10 million, over five years, in Tamil Nadu (Amin 2004: 6, Lieberman 2009: 232). Finally, much of the international involvement has to be filtered through local non-governmental organizations. For example, USAID has its main offices in New Delhi and therefore, in order to reach other regions and communities, has reached agreements with local groups.

While the third phase, NACP-III, has been straightforward in its goals and programming, the implementation was more complicated as the focus moved from national planning offices to local program managers. At the national level, the National AIDS Control Organization (NACO), set up in 1992, and the newer Public Health Foundation of India, which began in 2006, are the two main organizations responsible for the creation and dissemination of the country's national AIDS plan (Mitra et al, 2007: 6; Bhat 2004: 11-12). This division between two separate organizations often creates unnecessary confusion and contradictions in programming. Although NACO operates directly under the Ministry of Health and Family Welfare, both organizations coordinate the implementation

of the national health programs on the state level. After the plans have moved from the national stage to the states, they are further divided amongst the State Secretary of Family Welfare and the Commissioner or Director of Health, who then implement policies through a variety of state run clinics, hospitals and treatment centres along with non-governmental agencies (Bhat 2004: 12). In addition to the state organized system, patients also have options among traditional medical systems, such as Ayurveda and Unani, as well as modern homeopathic medicine, such as Naturopathy (Jeffrey, 1988). In total, India's public health system makes up around twenty percent of available healthcare with the other eighty percent being made up of private sector providers (Bhat, 2004: 12). The desire on the part of the government to use a decentralized approach was well-meaning as it was intended to allow states to personalize the implementation of programming in order to best support their populations. However, the reality has been confusing for participants as they navigate through the multitude of treatment options.

Preparedness for HIV/AIDS

Although this level of decentralization within program implementation may seem overly complicated and unwieldy, it is critical in a country the size of India. The diverse population also means that a decentralized approach is more likely to be successful since each state's local government is able to adjust the program to suit its population (Ghosh, 2002: 122; Lieberman, 2009: 215). However, this does not mean that the system is problem free. For example, some offices have complained that the way new programs are introduced is impractical as the programs are presented as an entirely new package that then has to be implemented immediately, regardless of whether local governments have been given the necessary tools (Datta & Misra, 2000: 24). In addition, this lack of preparedness stretches

into the medical communities as well. Within some local medical settings, stigma and discrimination against patients with HIV is still common while the hospitals and clinics themselves may be physically underprepared. For example, a high proportion of 'AIDS wards' in both private and public hospitals include only one or two beds, usually relegated to an isolated and less cared for section of the building (Mitra et al, 2007: 5). This treatment only increases the feelings of isolation and shame already present within the HIV-related stigma, which is the subject of the following section.

Counselling

The counselling stage of the epidemic's patient history focuses on understanding the lasting impact of the early official discourse and the resulting stigma and discrimination. HIV-positive individuals are constantly aware that the social perception of their condition means they could face abuse or isolation if their status was to be revealed. This expectation of maltreatment haunts HIV-positive individuals and has a direct impact on their illness experience. Therefore, understanding how to approach stigma in this context was a key element of this research. The stigma studies examined here have offered two approaches to the ways societal pressures act upon individuals within the context of illness. This research proposes that a combination of these theories is the most useful in understanding how socio-culturally-based stigma has impacted the epidemic in India. Therefore, this section lays the groundwork for the examination of more India specific factors within the disclosure section.

HIV/AIDS is, by nature, a complex condition to study. As a constantly changing epidemic, HIV has been examined by researchers from a variety of specialisms during the past thirty years. These studies have differed as local epidemics across countries

demonstrated unique and diverse challenges. However, the overarching theme has been the private nature of the illness experience and how this is often tied to the stigma individuals navigate through in order to research an understanding of their own condition. By seeking out more information about their illness, individuals are better equipped to maintain their health, privacy and to avoid infecting others. Within the literature on illness experience, one definition proves crucial to the study of individual suffering. Leon Eisenberg's (1977) distinction between illness and disease demonstrates the unique influences individual's feel while coming to terms with their condition. A disease is defined as something a physician diagnoses and treats based on physical symptoms. An illness, in contrast, is centred on the patient's experience of the disease (Eisenberg, 1977; Radley, 1994: 3). Within the study of HIV, the different ways of approaching the epidemic, either as a disease or illness, can create varied results. For example, focusing on the epidemic as a disease does not allow for an investigation of the complex social and cultural issues brought on by diagnosis (Sontag, 1989:16). By viewing the condition as an illness, the individual and their needs become the priority rather than the virus and medication.

When considering the definition of stigma and the role it plays in the lives of HIV-positive individuals, it is useful to think of it as a reaction to a threat placed on social bonds. In this way, HIV can be viewed as a threat to the existing social relationships and the stigma relating to it can be viewed as the result of the expectations and assumptions placed on the individuals within these relationships being disrupted. This concept of stigma is useful for this thesis and the interplay between private suffering and public discrimination. In particular, the participants in the fieldwork presented here found their understanding of

their condition was greatly impacted by their awareness of the stigmatising public perception of the condition.

In understanding stigma for these individuals, Erving Goffman's (1963) threefold definition of stigma presents a useful guideline for understanding the complex field of potential stigma faced by participants and the steps researchers must take to negate these risks as much as possible. Goffman begins by first distinguishing three distinct types of stigma that individuals may face. The first focuses on the visible differences or physical deformities. The second form involves the unseen deformities of character, which are concealed within the morals and perceived weaknesses of the individual. Finally, the third type is what Goffman terms the stigma of race, nation and religion. With this final type of stigma, Goffman indicates the ability for negative impressions and shame to contaminate all members of a given group, whether that is a family, community or workplace (Goffman, 1963).

While this definition is useful in separating the different elements at work within HIV/AIDS stigma, the complex ties between them must be acknowledged as they combine to form the whole of stigma today. When HIV/AIDS was first detected in the early 1980s, the original patients created an initial negative impression of the condition that continues to the present. Early sufferers often presented with symptoms of Kaposi's Sarcoma, a form of cancer that creates lesions on the skin of sufferers. This visible sign of illness remains the stereotype relating to HIV today and creates the expectation that someone with HIV will look unquestionably sick. Meanwhile, the stigma of character surrounding HIV/AIDS also maintains links to the original outbreak of the condition. The first patients were those on the outskirts of society as their lifestyles and actions were seen as immoral or unnatural.

In addition, due to the sexual nature of the condition and the high rates of infection among commercial sex workers, the virus was seen as resulting from illicit behaviour. This view is still prevalent within public perceptions of HIV/AIDS and, combined with the physical expectations of illness, form the third type of stigma highlighted by Goffman (Goffman, 1963). While HIV status is neither a nation nor religion, it does form a community of individuals who face collective stigma from those outside the group. Due to the negative stereotypes associated with the physical and character stigma, anyone who discloses their HIV status risks being placed in this group and therefore assuming the stereotypes associated with it.

Goffman's three elements of stigma have combined within the local HIV/AIDS epidemic in Chennai, and similarly around the world, to create an atmosphere where individuals refuse to disclose their status because the expectation of discrimination is so ingrained and where health workers actively fight against this perception of the condition with both their patients and the general public. However, this approach to stigma studies has been criticized by anthropologists and social researchers for the passivity it places on sufferers, the vagueness of the theories and the individual approach that limits the application of results to larger communities or social factors (Good, 1977; Kleinman, 1980; 1995; Phelan and Link, 2001).

In the face of this backlash, Phelan and Link (2001) have offered an alternative view of stigma as "the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination" (Phelan and Link, 2001). They go on to address the need for social power to be involved in order for stigma to have the ability to impact the individual negatively. Phelan and Link further maintain the need for social scientists

who are interested in addressing "life chances" disparities within a social group to study stigma within their given population (Phelan and Link, 2001).

Although this thesis focuses on the illness experience of HIV-positive women in a very specific setting, the approaches to stigma demonstrated by Goffman, Phelan and Link will be used to ensure the concepts examined are applicable to wider social influences rather than pertaining solely to the individual. Within this research, Goffman's blueprint was used to frame the overall picture of HIV-related stigma while the method described by Phelan and Link clarified the details within, which will be examined in later chapters (Goffman, 1963).

In the past, conditions such as venereal disease and Tuberculosis were seen as social diseases due to the nature of their transmission and the added vulnerability caused by low economic status, poor housing and other social factors. HIV has, since its first instance, been solidly placed within this social disease category. This is true not only due to its transmission via sexual intercourse but also through the uneven spread within social groups with those who are already vulnerable to disease due to poverty, malnutrition and geography being among the first to be infected. HIV has the added factor of extreme stigma, which therefore makes it even more difficult for individuals to get adequate treatment. These social factors and the co-occurrence of the components of stigma impact local HIV epidemics in ways that anthropology is uniquely positioned to uncover. The following section examines how anthropology's socio-cultural approach identifies the big picture influences, including historical factors such as the caste system and its' impact on Indian society, the economic inequality inherent in a stratified society and the traditional expectations and social norms individuals navigate through on a daily basis.

Disclosure

While the majority of research into HIV has been in the realm of public health and epidemiology, anthropology has proven it has an important role to play in understanding the social and cultural pressures individuals face which impact their awareness of the condition and adherence to medication. In addition, a major justification for HIV/AIDS as an anthropological subject can be found within the final stage of diagnosis: the disclosure to family and friends. Disclosure involves bringing the illness to the local environment and making sense of the tensions and confusion caused by this merger. Anthropology allows for a detailed study of the culturally specific conditions that inform the reaction to disease. This is particularly important given HIV/AIDS status as a global pandemic wherein the day-to-day reality of living with HIV can be vastly different between countries, cities and even neighbourhoods.

Arthur Kleinman (1988) and Byron Good (1994) have led the way for social scientists to focus their attentions less on the biomedical element within the experience of sickness and instead move towards seeking to understand the role an individual's cultural background plays in their overall health. With biomedicine, the virus or pathogen is considered as an object in order to study it in isolation from other areas of health. However, by following a traditional anthropological approach, the condition is instead viewed in the context of the individual's beliefs and cultural norms regarding health and illness (Fassin, 2007: 238). This focus allows for a more holistic view of the epidemic within the lives of HIV-positive individuals.

In addition, by allowing for the inclusion of socio-cultural factors into the discussion of the local epidemic, the ties between an individual's health and their community's social

expectations and understanding can be examined. For example, Link and Phelan (1995) highlighted the importance of 'identifying the mechanisms linking social conditions to disease' and in particular the ability this approach has for accounting for the social patterns of distress, an element within the illness experience of many of my participants. The constant fear of discovery and the stigma that would entail is, as mentioned in the previous section, a major concern and obstacle for health for many of the participants in this research.

HIV-positive individuals are often faced with the decision about whether or not to reveal their status and what the implications of this disclosure might be. For example, on the one hand, this may allow them to receive the moral and social support that is often granted to those who are ill. In this case, family members may step in to help with economic concerns or social responsibilities so that the individual has time to recuperate. However, there is also the potential for individuals to find their disclosure results in increased suffering and isolation rather than support. This is a possibility that is not necessarily unique to HIV/AIDS but is heightened due to the public perception of the condition. In this way, individuals are faced with the social fears relating to the contagious nature of the condition and the stigma around sufferers. This ability for HIV to disrupt the interpersonal obligations that come with social ties is a subject that has received particular attention.

Social researchers such as Kleinman, Kapferer and Eaton have all drawn their readers' attention to the ability for those who are, or perceived as, ill to be essentially removed from the social bonds in order to allow for the severing of treatment and care expectations by other members of their community (Kleinman, 2009; Kapferer, 1979; Eaton, 2008). Kapferer (1979) focused on the different processes whereby a "Self" is first

created within the social bounds and then dismissed according to those same social bounds. This negation of the "normal Self" allows those around the individual to change the expectations society has placed on them because the individual is now seen as an 'abnormal non-social self' and therefore does not require the same care and consideration (Kapferer, 1979: 110).

Kleinman (2009) furthers this discourse by describing the perspective of family members who have 'run out of the energy, patience and funds' which they need to fulfil their social obligations. By changing the disabled or sick individual's social status, their support system can be withdrawn. In order to accomplish this, the affected individual must become "non-human" in their status, which allows them to become a 'target for abuse, discrimination and ultimately rejection." This change is driven by the inability of the individual to be a productive member of the community and therefore they have lost their social value (Kleinman, 2009: 603).

An approach that considers the social value of an individual must also investigate the social forces that determine that individual's place. The theory of structural violence characterized a split away from the more traditional approach to HIV/AIDS and sought to look beyond the biomedical to the bigger picture issues in order to understand how political or economic elements impact on sufferers. Addressed by Paul Farmer, the elements within this theory can be viewed as determining "who falls ill and who has access to care" (Farmer et al, 2006).

The term structural violence, first created by Johan Galtung as a way to describe a force that kills indirectly and "undramatically" compared to more direct violence, has been expanded by Paul Farmer and other anthropologists into a theory focused on the cultural

causality of disease (Farmer et al, 2006; Galtung 1971). In the context of Farmer's research in Haiti, this concept centred on the healthcare structure and its financial drivers that exclude patients from poorer communities and the larger social, economic and political factors which connect Haiti to the United States, France and other developed countries (Farmer, 2001). In general, this umbrella theory represents the inner workings of social structures and their impact on those least able to navigate within the created areas of vulnerability. These structures include all aspects of social and cultural life, such as economic, political, legal and religious areas. In the global history of HIV/AIDS, religion and the legal system combined to impact the pandemic through the labelling of homosexual activities and anything associated with them as abnormal and sinful. This served to colour the entire condition, regardless of later changes in victimology that now include heterosexual individuals, as unnatural and outside culturally specified norms, which led to a lack of sympathy and suspicion and fear directed at sufferers.

Within the patient history of the epidemic in India, the main social factors that have impacted the victimology and access to care have been economic and political. The remnants of the caste system can still be seen within Indian society although caste was often played down within discussions with participants. This history has created deep economic divisions, which leave a large population in a position where vulnerability to the virus is increased as women turn to commercial sex work for income support, husbands are forced to work long hours away from home (and therefore may turn to sex workers out of loneliness) and individuals are unable or unwilling to use condoms due to their cost. This is then compounded after diagnosis as individuals are forced to choose between either spending a large portion of their monthly income to travel to a private clinic where they

are guaranteed safety and privacy but also have to pay the high cost of medication, or giving up their privacy and taking a chance with their local public hospital where treatment is free but care can often be indifferent or uncharitable.

The factors at work within this patient history continue to have a lasting impact on the HIV-positive individuals within India. Therefore, it is important to acknowledge these overarching issues because just as they affect those who are living with the condition being studied, so too will they influence the data and analysis by the researcher. For example, if an individual faces a higher vulnerability to HIV as a result of their position in society or their economic status, this might also impact the availability of the individual to participate with a study that is dependent on being present in a private clinic.

As a result of these combined factors, research into HIV in a given location that neglected to address the socially and culturally created vulnerabilities and obstacles for patients would be incomplete. Therefore, this thesis seeks to address this subject by considering both the patients' perspectives and beliefs about their condition and the overlying factors that have directly or indirectly contributed to their vulnerability to the virus.

Chapter Outlines

The chapters in this thesis have been organized to direct the reader through the liminal period in a way that mirrors the process that individuals undertake when coming to terms with their diagnosis. To that end, the thesis begins with a chapter focused on the theory of liminality and the reasons why it proved to be a useful overarching theme for this thesis. This chapter serves to present a holistic view of the theory through the following sections: the history of the concept of liminality, liminality as it relates to HIV/AIDS illness

experience, social suffering, women within the local epidemic and self, identity and the liminal period. This chapter is intended to set the scene for not only liminality's use throughout this thesis but also to provide background information regarding the focus on HIV-positive women and the gender-based obstacles they face. The following chapters are then organised to represent the process individuals experience in coming to terms with their condition as they acknowledge and address these obstacles.

The second chapter focuses on the fieldwork methodology that informed this thesis. The approach used for this research was entirely determined by the subject and its associated environment of stigma and discrimination. The main concern was in relation to the protection of participants' privacy (specifically the maintenance of the status quo regarding the knowledge of their HIV status). Not only was I researching their experiences of living with HIV, I was also charged with avoiding accidental disclosure of their status as this could lead to further discrimination or mental anguish. Therefore, the methodology allowed for several limitations that could not be avoided. These included the smaller participant pool, the inability to gain insights from family and friends and the necessity of a female focused approach.

Chapter three focuses on the role of the Clinic in the diagnosis process for participants. This involvement extends beyond the biomedical interventions expected within a medical setting to include a large element of social care as individuals begin to come to terms with the reality of their condition. The liminal period experienced by participants was heavily influenced by their interactions with the Clinic and the positive networks found therein. The biosociality of the Clinic is developed to understand the

coping process undertaken by participants, with particular interest in the impact this has on the liminal period.

The final three chapters outline the experiences of individuals within the period of liminality and the interactions they have, both positive and negative. In this way, the thesis demonstrates the methods of acceptance and areas of redefinition that ultimately give individuals a better understanding of their condition and the new position they find themselves in, which in turn signals the end of the liminal period.

Chapter four addresses the complicated nature of the Indian medical system, wherein patients are faced with a myriad of public, private and charitable organisations. Unfortunately, the treatment received at different locations has not always been as positive an experience as patients had anticipated. In particular, many participants reported maltreatment and abuse in local hospitals at the hands of doctors, nurses and other patients. Therefore, the Clinic staff members are forced to actively rebuild the social trust between doctor and patient. This chapter examines the role of the Clinic through the eyes of both patients and staff members and compares the experiences here with those found in other medical sites. In addition, this chapter follows the theme of redefinition through an examination of the concept of health and healthcare.

Chapter five focuses on the changing definition of community experienced within the liminal period and the impact this has on individuals. In particular, this chapter uses the issue of disclosure to highlight the difficult decisions individuals make. Individuals must choose between accepting the sick role, which should entitle them to the familial care afforded to the ill but may also involve opening themselves up to potential abuse or discrimination, and avoiding it entirely. The second option allows for greater privacy but

can also be isolating in its own right. This chapter examines what is at stake when patients either choose to disclose or conceal their condition from those around them. Additionally, this chapter explores the subject of community as staff members of the Clinic begin to take on additional roles, which are more traditionally reserved for family members. The new view of community, adapted to include the patients and staff members at the Clinic, is seen as a method of coping with the HIV diagnosis and another step towards the end of the liminal period.

Finally, chapter six investigates the role of personal agency and the self within the liminal period by reviewing the pre-diagnosis awareness held by participants and the personal adaptations that take place as their understanding of the condition improved. This chapter begins with a discussion of the awareness of public perception that participants had prior to their diagnosis and the social setting that has contributed to the created vulnerability described by individuals. This vulnerability to the virus has its roots in socio-economic traditions that meant participants did not feel they had the personal agency to attend to decisions regarding their health. This chapter then moves into the results of the changing levels of personal agency through an examination of the adaptation required within the liminal period that allows for its closure.

Chapter One:

Liminality in Context

"One of the best ways to fight stigma and empower HIV-positive people is by speaking out openly and honestly about who we are and what we experience"

- Alex Garner, HIV Activist[9]

"AIDS occupies such a large part in our awareness because of what it has been taken to represent. It seems the very model of all the catastrophes privileged populations feel await them."

- Susan Sontag, Author and Political Activist[10]

"The greatest forces lie in the region of the uncomprehended."

- George MacDonald, Author[11]

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[9] Garner, Alex. 2012. "Out About HIV." *The Huffington Post.*[Internet] Published September 13, 2012. Updated February 2, 2016.

[10] Sontag, Susan. 1990. *Illness as Metaphor and AIDS and its Metaphors.* New York: Farrar, Straus and Giroux.

[11] Macdonald, George. 1996 [1893]. *A Dish of Orts.* Whitethorn, C.A.: Johannesen Publishing and Printing.

The theory of liminality is a useful tool in understanding the complex processes that take place when an individual is undergoing a transition. The term "liminal" refers to this state of uncertainty wherein the transition itself is the focus. Defined by Victor Turner as an "interstructural situation", the liminal period represents a period of time when the individual is outside of the prescribed bounds of their given society (Turner, 1967: 93). As a result, they are seen as being in a marginal position where they are no longer in possession of their previous identity but have not yet moved into their new position (Turner, 1977: 37). This liminal period exists for the duration of the transition, which can vary according to the situation. For example, the liminal period may be permanent in the case of individuals who choose to live outside of the usual social settings while being much shorter in other situations where the state of liminality begins and ends in a single action.

Originally applied to ritual events in tribal villages, the concept of liminality has since been expanded to include a wider range of transitional situations. For example, Lloyd Warner (1959) demonstrated that in all societies, the entirety of an individual's life can be seen as a rite of passage. In this way, life as the most prominent ritual of passage is interpreted as "the movement of a man through his lifetime, from a fixed placental placement within his mother's womb to his death and ultimate fixed point of his tombstone and final containment in his grave as a dead organism – punctuated by a number of critical moments of transition which all societies ritualize and publicly mark with suitable observances to impress the significance of the individual and the group on living members of the community" (Warner, 1959: 303). Warner furthered this thought by identifying the most important periods of transition as "birth, puberty, marriage, and death" (Warner, 1959: 303).

This thesis contends that the moment of HIV-positive diagnosis can be placed alongside these life events as an important liminal period. This is due to the transitional nature of diagnosis where the individual is forced to leave their pre-diagnosis state to take on the new, unwanted designation of HIV-positive and all of the social pressures and suspicions that accompany it. Within the context of this thesis, the liminal period represents this sudden break with the past and covers the process of adaptation that individuals undergo. The liminal period for participants of this research represented a step back from their perception of society that allowed them to come to terms with their condition. This was achieved with the assistance of their involvement with the Clinic, which acted as a liminal place wherein HIV-positive individuals were able to gain a greater awareness of their condition and a clearer understanding of how the diagnosis would, and would not, impact their lives. In this chapter, the history of the theory of liminality is discussed in order to clarify its usefulness in understanding the illness experience of HIV-positive women in Chennai. Additionally, the concepts of social suffering and identity construction are used to demonstrate the environmental factors that inform risk awareness and personal agency for women. This is intended to set the scene for the empowering benefits of the liminal period as experienced by the participants of this research, which are discussed in the following chapters.

History of Liminality

When investigating the history of the theory of liminality, most researchers direct their readers to Victory Turner and his 1967 work, *The Forest of Symbols: Aspects of Ndembu Ritual*. However, Turner himself points to Arnold van Gennep and his 1909 manuscript, *Les Rites de Passage*, as the source of his inspiration (Turner, 1967;

Thomassen, 2009: 14). Therein, van Gennep laid out a classification system that he believed could be applied to any existing rite. Of particular focus were the rites of passage for individuals, which he divided into three sub-types: separation, transition and incorporation (Van Gennep, 1960 [1909]). These three sub-types represented the journey an individual takes during the rite of passage as they leave their current position and move into the next. For example, for a boy to become a man, there is a point in the ritual where he ceases to be a boy but is not yet a man. However, the transition is not always immediate and therefore van Gennep included this as a separate sub-category, which he called the liminal period (Van Gennep, 1960 [1909]).

Initially Turner used the theory to assist his analysis of the rituals of the Ndembu people of north-western Zambia. In particular, he focused on the potential for the liminal period to act as a catalyst in refreshing the societal organisation (Turner, 1967; Thomassen, 2009). This was made possible through the liminal period as it allowed individuals the structural distance and freedom to open themselves up to creativity and new ways of thinking. When they re-entered their society after the incorporation period of the ritual, this creativity came with them and the society as a whole benefited (Turner, 1967). In this way, Turner extended van Gennep's initial theory of liminality by realising it could be applied not only in highlighting the periods of being "betwixt and between" experienced by individuals, but also to the reactions individuals had to the liminal period itself (Turner, 1978; Thomassen, 2009).

This extension also allowed Turner to apply the theory of liminality to modern societies through his work on Christian pilgrimage (Turner, 1978). This work focused on the pilgrimage as a liminal period and the impact this had on participants. For example, as

individuals took on the mantle of pilgrim, they left behind their existing social positions. Therefore, the pilgrimage itself became a liminal period. Within this period, there was an equalising of statuses, which in turn helped to create the strong sense of shared purpose or communitas.

Throughout his work, Turner highlighted the varying nature of the liminal period and the ability for this theory to be more widely applied in different settings. The main characteristic of liminality that allows the theory to be so universal is the flexibility that allows it to cover everything from periods of time to particular places or even to individuals. For example, Turner described liminality as being applicable to everything from individuals, groups, villages to whole civilizations. This unique flexibility has allowed the theory to be the overarching theme in studies from a variety of disciplines and this thesis contends that it provides a useful framework for understanding not only the illness experience of HIV-positive women in Chennai but within wider HIV/AIDS studies as well.

Liminality within HIV/AIDS

Within the illness experience of HIV, the moment of diagnosis marks the shift as individuals move from one social position to another. In this moment, they become a 'structurally indefinable transition-being" and find themselves having to reassess their understanding of the world around them while adapting this new condition to their lives (Turner, 1987: 6). Individuals suddenly find themselves within a category, that of HIV-positive patients, which they have previously been only vaguely aware of in a negative light. Therefore, when they find themselves on the other side of the coin, going from being able to consider the virus a condition for 'others' to receiving their own diagnosis, it can

be extremely alienating. The moment of diagnosis starts the process of liminality as individuals begin to put up mental barriers between themselves and their family and friends. These barriers allow for privacy as they struggle to come to terms with the ways that their condition will begin to impact their day-to-day lives but also serve to disrupt the process of care and support that would be traditionally offered to the sick individual.

The narratives of illness experience shared by the participants of this research can be viewed as confirmation of the ways in which the official discourse on the condition and the misinformation prevalent within the public perception of the condition continue to directly impact individuals living with HIV. Liminality can be viewed as being stateless as a result of being partially within two distinct states, which in this case involve both the HIV-positive and negative states. Participants found themselves navigating the complex nature of their condition while remaining within their previous social positions, wherein they were receiving reinforcement of the public perception of the epidemic. In particular, the expectations held regarding the character and behaviour of HIV-positive individuals served as a reminder of the judgments they would be risking if they disclosed their status to others.

Although this period of liminality can be seen as isolating, this thesis contends that this state allows individuals the distance they need from society in order to reassess their needs and their methods of coping with their condition. For example, the chance to step back and reassess their own position within their households and society, without physically leaving their current roles, allows for the reconsideration of social pressures and traditions that had previously been accepted without question. Additionally, the liminal period is assisted by the presence of the Clinic and the positive networks and support

groups that are interwoven through the waiting rooms and hallways therein. By presenting an alternative society wherein HIV is normalized, the Clinic is able to act as a transformative space for participants. The liminal period is then inadvertently given a positive spin as individuals are able to pick and choose between their two societies in order to protect their privacy while simultaneously receiving the treatment and care they require. As a result, individuals often experience an increase in their level of personal agency post-diagnostically. This can also be aided by a shift in these roles caused by the ill health of a spouse or due to increased tensions within a joint family. In this way, participants often found themselves in new positions, such as breadwinner or single parent, wherein their condition had inadvertently resulted in their empowerment.

Social Suffering

Kleinman, Das and Lock (1997) have defined social suffering as the way in which a combination of political, economic and institutional power impacts individuals and defines their ability to address social issues (Kleinman, Das and Lock, 1997). This thesis attends to the intersection of these social pressures and the individual experience of HIV. The impact and source of these outside pressures have been a topic for many disciplines and have evolved over the last few decades in particular. Michel Foucault (1990 [1976]) tied his concept of the self to these discourses of power through a view of the individual as being essentially a product of the meta-narratives of a given society (Foucault 1990 [1976]: 92). This approach was quite similar to the concept of personhood wherein an individual was seen as indisputably socially-based and viewed as the summation of "society's understandings and laws regarding how an individual will be represented and treated" and "the degrees of autonomy or dependence he or she will possess" (Janzen, 2002: 138).

Within the study of HIV/AIDS specifically, the theory of structural violence opened up the possibilities of looking beyond the classic scope of study within the subject and allowed for an examination of the wider issues that were influencing the behaviour and risk assessment of individuals. Originally coined by Johan Galtung (1971) as a way to identify these social forces that place enormous pressure on individuals and can ultimately cause injury or even death, the concept was later expanded upon by Paul Farmer in the context of HIV/AIDS in Haiti (Galtung, 1971; Farmer et al, 2006). While this approach is included to underline the obstacles to awareness and the culturally created vulnerabilities experienced by participants, this thesis also intends to follow the lead of researchers such as Joao Biehl, Amy Moran-Thomas, Stefan Ecks, and Susan Reynolds Whyte in examining the new forms of intimacy that have emerged within communities that revolve around HIV/AIDS treatment (Biehl, 2007a; Biehl and Moran-Thomas, 2009; Ecks, 2005; Reynolds White, 2009) Referred to by Biehl (2007) as the "pharmaceuticalization of public health," this approach examines the concepts of community and kinship through the lens of health technology (Biehl, 2007b). This thesis seeks to investigate this phenomenon through the arena of the Clinic and the "therapeutic companionship" found therein, which has influenced the transition from individual suffering to group identity and empowerment (Nguyen 2005: 127).

One of the pitfalls of examining the illness experience of individuals is the potential ability for the issues found therein to be viewed through a lens of individualization. For example, Chuengsatiansup (2001) has highlighted the potential for the "personal version of healing suffering" to be brushed off as a problem for individuals, rather than seen as demonstrating a collective problem. Therefore, this thesis includes a discussion of the

social forces at work within the local epidemic, such as the meta-narrative of sufferers and the official discourse on the subject, while also identifying pre-diagnosis elements that create vulnerabilities in a given population. The thesis attempts to draw attention to the reality of living with HIV as demonstrated by the participants of this research in order to examine the ways in which women have not only been marginalized as a result of their HIV-positive status but also to invite discussion regarding their wider marginality within society (both a cause and a result of their new condition). However, this thesis intends to argue that the liminal period and the interactions with the Clinic create an environment where individuals are able to alter their marginalized state and to shift their individual experience into a collective source of power and support.

The view of HIV/AIDS as being a shameful condition has been present since the origins of the global pandemic (Farmer and Kleinman, 1989; Sontag, 1989). However, when viewed within the Indian context, the added element of the history of the caste system brings additional concerns for individuals. Within the caste system, there was a constant flow of competition between castes, with each viewing themselves as being better than their neighbours. One element of use within this competition was the amount of prestige a caste could claim through the actions of its members (Srinivas, 1962). HIV, with its associated stigma, would be viewed as highly dangerous to the group prestige. The official delay in acknowledging the condition's presence in India is demonstrative of this concern for prestige as political and economic concerns were given precedence. This competitive approach is at odds with the original view of the caste system as a strict hierarchy understood by all castes, as pronounced by Louis Dumont (1970) who categorized the caste system as a hierarchy (Dumont, 1970: 2). Although this proposal has been widely criticized

as being ethnocentric, it would be wrong to dismiss this idea outright. Srinivas admits that, by looking at the caste system either from the very top or the very bottom, it would indeed look to be hierarchical. However, the middle castes are much less rigidly defined in their positions (Srinivas 1962: 66). In fact, Dumont's ideas about hierarchy echo the importance placed on rankings and the competitive nature of these castes (Beteille, 1992: 14). Gupta (2004) has furthered this idea by describing the caste system's 'hierarchy' as being constantly contested by the castes themselves (Gupta, 2004: 411-412).

Even low caste groups will engage in this 'competitive assertion', focusing on their usefulness to society (Srinivas, 1962). For example, Berreman found that leatherworkers were proud of their ability to handle the dead animal hides, highly polluting for other castes, as they recognized that without their leather many goods that other castes relied on would not exist (Berreman, 1960: 126). This self-belief within castes causes them to seek out acknowledgement of their rising position in society. The main ways of doing this are through wealth and prestige (McHugh, 1998: 165). Prestige can also be viewed as respect, which is necessary to obtain from other castes in order to prove the deep held belief that one's caste does not deserve its low placement within society (Reddy, 2005: 43). And two of the best ways to gain respect or prestige is through 'appropriate moral behaviour' and the maintenance of honour (Reddy, 2005: 42). Therefore, caste can be viewed as providing a framework for defining the social role for individuals.

As previously mentioned, a source of contention for many societies is women's sexuality. This is seen has needing to be protected from outside sources as it can lead to disruption of honour if it is not sufficiently controlled. Within HIV diagnosis and the associated suspicions of inappropriate behaviour, there is the potential for the whole family

or community to face sexually-based dishonour or shame. This issue brings in the need to acknowledge the remnants of the caste system when discussing HIV/AIDS in India and the social stigma faced by sufferers.

Within HIV/AIDS, the role of the individual within the caste system has important echoes within contemporary India. In 2002, Syed Ali reported that, in his belief, the caste system had shifted from 'group identities' to 'individual identity' and therefore, in the present, an individual's actions had little effect on their caste group (Ali, 2002: 599). However, within the study of caste and HIV/AIDS, and as evidenced by Isabelle Nabokov's (2002) fieldwork within India, this view of society is not entirely correct. In fact, Nabokov found that individual behaviour had the power to impact the honour of not only the individual but that of their family and wider kin group (Nabokov, 2002). As she explains, the caste system and the Hindu religion are centred around the question of who an individual is (Nabokov, 2002). Within the answer lies the connection to family, community and caste group as these are the societal categories at work. With HIV/AIDS and its connections to behaviours that are outside the social norms, it would not be uncommon for an individual to find themselves removed from these connections in order to stop the flow of dishonour and shame. These social norms, such as expectations relating to partner choice, revolve around one main belief: the need to avoid spiritual pollution in order to protect the individual and the caste group. Therefore, when considering caste as a process of defining the social role for individuals, the consequences of exclusion from this system would be dramatic for those involved.

Temporary, or external, pollution is caused by contact with or proximity to, lower caste individuals and objects viewed as unclean (Dumont, 1970: 131). These include bodily

fluids, certain foods, and even menstruating women (Thurston & Rangachari, 2001: 20).

Pollution of this kind is dealt with through bathing, with some high caste members bathing

multiple times a day in order to remove this pollution. On the other hand, permanent

pollution is internal and cannot be removed (Dumont, 1970). While this primarily refers to

the hereditary pollution gained from family member's castes, it can also be seen through

the response to the permanence of HIV/AIDS. Just as pollution can be viewed as an

invading element, designed to negatively affect the sufferer, the same mentality is applied

to the epidemic (Dumont, 1970; Sontag, 1989).

The caste system, and the element of spiritual pollution, has been described as a

'ghost' hovering over modern, progressive India (Dirks, 2001: 276). Just as other countries

have continued to experience the repercussions of previous belief systems, India still

struggles with the cultural schemas informed by caste despite the fact that the system as a

whole has become less restrictive (Srinivas, 1957: 531). Viewed by some as a remnant of

the colonial administration, the focus on the religious and spiritual aspects of caste, such

as pollution, has been criticized (Sharma, 1999: 1). Referred to as the 'Western legend of

Hindu spirituality,' this approach has been seen as too attentive to a small element of caste

while ignoring the overall picture (Beteille, 1992: 155). Therefore, in order to study

HIV/AIDS in contemporary India, it is necessary to view pollution as a concept informing

risk assessment and behaviour modification among all residents regardless of their religion

(Singh, 2005: 124). While the local understandings of the HIV/AIDS epidemic and the

official government approach may not directly include caste and pollution, this ingrained

social schema is still present at the subconscious level. Despite attempts to move away

from these traditional beliefs, these concepts still colour the way issues are perceived (Dirks, 2001).

During my time in India, it was extremely difficult to discuss caste and pollution outright with any of the individuals involved in my fieldwork. This included friends outside the Clinic and Clinic staff who seemed almost annoyed at the mention of this subject. Although the topic of caste was one that my participants shied away from, it is clear in the stigma and discrimination faced by patients that the remnants of the system are still very active within society. This avoidance of the subject is partially related to the government's attempts to stamp out caste-based discrimination, which has in turn meant that the caste system has retreated from the forefront of society. Although it is not directly indicated in interactions around the city, the principles still remain. In particular, although the term *pollution* was never used, the stigma against visible signs of illness and the view of the virus as something "illegal" that infects the person with the shame of joining the ranks of those affected has interesting parallels to the past focus on pollution. The disconnect to society that individuals feel when they are diagnosed is directly informed by the stigmatizing public perception of the condition and results in the state of liminality they experience.

Women within the Local Epidemic

Within India, the current adult prevalence rate across the country stands at 0.26 percent, although the distribution of the virus has varied greatly. While some states reported extremely low prevalence rates, others such as Manipur (1.15%), Nagaland (0.78%) and Andhra Pradesh (0.66%) were much higher than the national statistics. In Tamil Nadu the rate is currently estimated to be over 0.26% which places it among the highest effected

states (NACO, 2017). However, the rate within the state has maintained its levels after falling from the high of 0.63 percent seen in 1994 due to improvements in targeted intervention programs among high-risk groups such as commercial sex workers, truck drivers and men who have sex with men. Therefore, Tamil Nadu is viewed as having one of the most successful HIV/AIDS programmes.

Country-wide, women over the age of fifteen currently make up approximately 35% of HIV infections with the total number standing at 750,000. Additionally, the most recently available statistics indicate a female prevalence rate of 0.22%, while the rate for their male counterparts is 0.3% (NACO, 2017). Although women make up a lower number of infections, they continue to experience a higher level of stigma as many women are diagnosed prior to their husband through visits to antenatal clinics where testing is undertaken for all pregnant women as a result of government policies enacted in 2009. As a result, women are often left vulnerable to the social consequences of their diagnosis such as abuse, isolation, stigma and abandonment (Van Hollen, 2013).

This thesis seeks to attend to the participants' narratives of illness experience, as expanded upon in the following chapters, as they indicate the many obstacles women in India face as they navigate the complicated setting of post-diagnosis life. Through a combination of social and economic factors, pre-diagnosis awareness among women is particularly low. This was especially true at the time of diagnosis for my participants while school children today have HIV/AIDS information included in the curriculums of Tamil Nadu schools. The limited awareness that my participants were able to share was primarily gleaned from those around them and often included the common types of misinformation

or rumours that continue to propagate within the public perception of the condition[12]. The lack of awareness was particularly gender-based as many of the participants in interviews and visitors to the Clinic felt that their positions within the household meant that they experienced constrained agency when it came to making decisions about their health. For example, economic dependency often proved to be a direct obstacle to accessing healthcare as women were unable to act without their husbands' consent because they controlled the funds needed to pay for prescriptions or transportation to the Clinic.

The concept of constrained agency is important as it helps to set the scene for why women find themselves at the mercy of socially constructed vulnerabilities when it comes to their health and awareness of personal risk. Bandura defines personal agency as the belief that the actions one takes can directly alter the environment around them (Bandura, 2008). As a result, individuals find themselves with the incentive to take action. When this personal agency is constrained, individuals feel there is very little reason to try to act, as they do not trust that their wishes will be followed or they may feel that they are not in a position to make these decisions in the first place. This may be as a result of economic dependency on their partners or joint family members but could also be the result of social conditioning, which places more controls over women's behaviour than on the behaviour of their male counterparts. Therefore, Ahern's (2001) definition of agency as "the culturally constrained capacity to act" was more helpful in understanding the constrained nature of agency with regards to HIV-positive decision making among women. This perception of personal agency is also useful in assessing where the liminal period (and the

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[12] Examples of these rumors follow the common stereotypes of assumptions regarding promiscuity or scandalous behavior that have been seen within HIV/AIDS epidemics in other countries (Sontag, 1989).

public/private division therein) may be beneficial to women in particular as it allows them to reassess their expectations regarding decision making.

This research is an attempt to follow the example of Banerjee and others who have sought to highlight the position of women within contemporary India (Banerjee, 2002; Sanghavi, Bhalla and Das, 2001). Gender-based violence continues to be seen in a variety of situations. For example, Sanghavi, Bhalla and Das have demonstrated, through an examination of the fire related deaths in 2001, that young women were three times more likely to die in fires than young men (Sanghavi, Bhalla and Das, 2001). The higher frequency of young women in these findings was attributed to issues such as domestic violence. Further, Banerjee (2002) demonstrated the continued control exhibited on women's sexuality by society, which in turn results in women feeling less appreciated within society and the labour market (Banerjee 2002: 61). Although many more women are finding work outside the home, their concept of personhood is still directly related to their position within their family and household, wherein the traditions of joint household residency meant that women were dependent not only on their husband but also their mother-in-law. As a result, women are particularly vulnerable to the social suffering that accompanies their HIV diagnosis.

Self, Identity and the Liminal Period

This thesis examines the extent of the social component of suffering and investigates the particular impact and alienation felt by the female participants of this research. This gender-based focus led to questions regarding the diagnostic journey and areas of transition seen within the process of coming to terms with their HIV status. In particular, the ability of this diagnosis to act as a catalyst for change beyond the inclusion

of medication became a central theme. In this way, this thesis follows the assertion made by Turner regarding the ability of the transitional nature of the liminal period to create lasting impacts on the individuals who experience them (Turner, 1967; 1978).

The changes seen within the illness experience are centred on the concept of the self held by participants. The redefining that takes place involving individual's understanding of community and health discussed in later chapters is only made possible through the adaptation of the post-diagnosis self. In essence, this thesis sought to chart the process participants undertook within the liminal period to renegotiate their identity in the wake of their HIV diagnosis. Therefore, a particular area of interest was the question of how the self is defined and how individuals perceive of their place within society.

For example, Marcel Mauss (1985 [1938]) put forward the concept of society as a cast of characters, or "personnages". In this approach, the community roles are seen as predetermined with each individual fulfilling one of these positions (Mauss 1985 [1938]). This approach to the self is also found within the works of Michel Foucault who viewed individuals as the products of overarching networks of power and influence (Foucault 1990 [1976]: 92; Sokefeld 1999: 418). Within this thesis, the narratives of illness experienced expressed by participants has demonstrated the validity of a holistic focus, which allows for the inclusion of the social and cultural elements that have led to pockets of vulnerability within the population. As mentioned previously, these include gender-based obstacles to health and unequal power distributions found within society, such as economic disparities and traditional roles within the family and household.

One of the biggest elements within the concept of the self is the question of identity and the ways individuals build this sense of purpose and place within society. Identity has

been described as "constantly under construction" as individuals interact with those around them (Ybema et al, 2009). These interactions offer the information needed to cultivate the distinctions between self and other which becomes a central point of the individual's identity. For example, by determining the labels and characteristics associated with the self, the individual is able to separate themselves from anything not associated with the self. This "othering" has been a central obstacle within HIV/AIDS awareness as it was very easy for individuals to convince themselves that they were not at risk. This in turn has fed into the negative stereotyping of the HIV-positive community, which is then transferred onto anyone who is seen as part of that group.

This ability for a label to directly impact an individual's identity is a key element within the development of the self for HIV-positive individuals. Strauss (2009) has highlighted the ability of a name, or label, to reveal not only information about the person who has been assigned it but also about those who have informed it (Strauss, 2009: 17). For example, the designation of HIV-positive is not only indicative of the presence of the condition but, for the public, it is also seen as a marker regarding the individual's character and behaviour. At the same time, the propensity of the public to place these assumptions onto the bearer of the label directly impacts the way the individual sees themselves. This is, as mentioned previously, the most difficult element of HIV diagnosis as the individual must come to terms with how this label will define them in the future. This is particularly true within the process of disclosure as they are risking being viewed in a negative light by those around them, who may not give them a chance to explain the reality of the condition and how it differs from the public perception.

In this way, identity can be viewed as a bridge between the individual and society, wherein these links are continuously being assessed and reassessed (Ybema et al, 2009: 301). This social identity is therefore a result of the push and pull between self-presentation and labelling by others, which is particularly true within the illness experience of HIV-positive individuals. The moment of diagnosis, and therefore the assigning of the label of HIV-positive, marks the beginning of the liminal period as individuals struggle to accept this term and the associated position within society. Through their interaction with the Clinic, the liminal period then becomes a space where individuals are given the tools to understand the relationship between the private view of their selves and the public, social view of HIV-positive individuals. This then allows them to manage the flow of information, through the maintenance of their privacy and the selective disclosure of their status. This period further enables the individual to move away from the isolating nature of their initial diagnosis and into the "community or comity of comrades" within the Clinic, which is made possible through this experience of liminality (Turner, 1987). The following chapters will demonstrate the transformative nature of the liminal state through an investigation of not only the Clinic itself but also the reassessments that take place through individual's interactions with it.

Chapter Two:

Methods and Limitations of Fieldwork in Stigmatised Setting

"If at the end of the twentieth century… one were inventing a method of enquiry by which to grasp the complexity of social life, one might wish to invent something like the social anthropologist's ethnographic practice."

– Marilyn Strathern, Anthropologist[13]

"The lived is only another word, if you like, for experience: but we have to find a word for that."

– Raymond Williams, Political Scientist[14]

"It involves the application of the full range of methods available to any researcher in a way that is obvious to common sense, is close to the way we all make sense of the world around us in our daily lives, and yet can be scientifically rigorous and systematic at the same time."

– Karen O'Reilly, Sociologist[15]

"Go and sit in the lounges of the luxury hotels and on the doorsteps of the flophouses; sit on the Gold Coast settees and on the slum shakedowns; sit in the Orchestra Hall and in the Star and Garter Burlesk. In short, gentlemen, go get the seat of your pants dirty in real research."

– Robert Ezra Park, Sociologist[16]

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[13] Strathern, Marilyn. 1999. "The Ethnographic Effect." *Property, Substance and Effect.* London: Athlone Press.

[14] Williams, Raymond. 1981. *The Sociology of Culture*. Chicago: University of Chicago Press.

[15] O'Reilly, Karen. 2005. *Ethnographic Methods*. New York: Routledge.

[16] Prus, Robert. 1996. *Symbolic Interaction and Ethnographic Research: Intersubjectivity and the Study of Human Lived Experience*. Albany: State University of New York Press.

In undertaking the fieldwork component of this research, the determination of elements such as location and timeframe were heavily influenced by the overarching concerns relating to ethical considerations, the emotional wellbeing of patients and practical issues. This chapter borrows heavily from Victor Turner and Arthur Kleinman to develop the methodology needed to undertake fieldwork on the illness experience of HIV-positive women in Chennai. In particular, the methods for this research manoeuvre around the necessary obstacles and concerns that had to be addressed in order to understand the complex nature of the local HIV epidemic and the reactions of the individuals involved. This methodology seeks to add insight into what I'm defining as the visible and concealed of the here and now. Within this chapter, the 'here' and 'now' make up the visible influences while the concealed elements reference the unspoken and hidden areas within this research, which will be discussed in greater detail in later chapters. This thesis seeks to demonstrate that these elements combine within the illness experience of HIV-positive individuals in Chennai and therefore influences their acceptance of the diagnosis, their fear of stigma and the ultimate cultivation of a post-diagnosis self within the parameters of their socio-cultural backgrounds.

Methodology in an Unorthodox Location

A central element of this research involves the role of the Clinic as a transformative space, which acts as a refuge for HIV-positive individuals from the stigma and discrimination found within the general society. By creating a space where HIV status is normalised, individuals are able to freely discuss their concerns regarding their status and the impact it has on their lives. The inclusion of HIV as an anticipated element within the social interactions found within the Clinic's walls creates a new orthodoxy within the

discourse regarding the local epidemic as seen by those most directly involved (Turner, 1969). This new orthodoxy represents a direct challenge to the existing metanarrative of HIV/AIDS within Chennai, wherein those infected are seen as having brought the infection upon themselves through inappropriate behaviour.

Upon receiving their HIV diagnosis, individuals find themselves burdened not only with that knowledge but also with a more detailed understanding of their condition, which ultimately pits them against the general perception of HIV/AIDS. This abundance of new information, such as the reality of living with the condition and details of medications and life expectancy, creates a distance between the individual and their family and friends. This distance is caused by the difference between the expectations for their futures (such as marriage and children) and their new concerns for their futures, which in turn places them in their liminal state. This mental space between themselves and those around them continues to grow as they debate disclosing their status. This distance is inhabited, and perpetuated by, the meta-narrative of the shared expectations regarding the characteristics of HIV/AIDS sufferers.

This public perception of the condition is based on the images of early AIDS patients and forms a shared understanding of how individuals with this condition will look or act. Expectations include a low moral character and engagement with activities such as commercial sex work and drug use. With this meta-narrative swirling around them, many HIV-positive individuals choose to not disclose their status. This then places them into their liminal state as they reassess their current position within their families and communities – i.e. married, unmarried, with children, without – and how their status now places this position in jeopardy. This simmering phase is internal to the individual but still

has a critical impact on their awareness of self within the social narrative. The conditions of this non-space and the resulting cultivation of a new, post-diagnosis self will be addressed more fully in later chapters. Therefore, this chapter focuses on the methodology used in completing the fieldwork for this research and the conflicting elements found within a clinic setting.

Fieldwork: Chennai, India

From January to September 2012, I conducted research in the Clinic[17], an organisation that provides diagnosis, treatment and care for HIV-positive individuals, located in Chennai, Tamil Nadu. This research was based on semi-structured interviews with Clinic staff members, patients and visitors. Additionally, participant observation in and around the Clinic was used to inform this thesis which focuses on the journey from diagnosis to acceptance as demonstrated by the individuals taking part in this fieldwork. This journey through the illness experience highlighted the redefinitions that take place for the participants, and in particular those in relation to their selves, health and communities, which are the overarching interests of this thesis. The Clinic, in its setting on the Health Concerns Compound[18], represents the focus point of HIV/AIDS awareness in Chennai. Run by Dr. S[19], the doctor who first identified the HIV virus in the city and within India, the Clinic's reputation is fairly well known among certain segments of the population, including not only HIV-positive individuals but also members of the middle and upper classes who have interacted with institutions, such as the Clinic, as part of their charitable endeavours.

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[17] The Clinic is a pseudonym used to protect the staff and patients.
[18] The name of the compound has been changed to maintain the Clinic's anonymity.
[19] This names of staff members have been changed to protect their privacy

In many ways, the origins for this project were founded in three very different experiences: my time spent working with the United States Agency for International Development (USAID) in Moscow, Russia; London-based research on HIV/AIDS for my MSc thesis; and my childhood years spent in Chennai, where my family has close friends who would ultimately be my starting point for this research.

During my time with USAID, I often found myself attending meetings with government officials or staff members of local non-governmental organisations, drafting reports on the countrywide HIV/AIDS environment and engaging in site visits to hospitals or community centres. These experiences highlighted not only the uphill battle many HIV-positive individuals face as far as their access to medications and their overall health are concerned, but also demonstrated the importance of history, place and local metanarratives about the condition. I would watch, often saddened and frustrated, as denials regarding the local epidemic expressed by government officials translated into misinformation and a complete 'othering' of the condition amongst the local populations, who would use their perceived distance to the condition as a basis for ignoring their potential risk of infection. As a result, many of the messages put forward by non-governmental organisations, backed by USAID, would fall on deaf ears as the infection rates continued to climb. This experience highlighted some of the reasons a universal approach to the global pandemic may not be equally effective across different nations and the importance of understanding the social and historical forces that inform the local audience's perception of HIV/AIDS.

My second area of previous experience came during my fieldwork for my MSc thesis. I conducted a study of the illness experience of HIV-positive women living in North London, which ultimately informed the methodology and approach for this research. I had

been intrigued by the so-called 'feminization' of HIV, wherein the role of women as a uniquely involved group worthy of study in its own right has been stressed. In the past, women were often included under other umbrella groups such as commercial sex workers or with regards to maternal and child health. This initial work allowed me to begin to explore issues within women's illness experiences such as gender-based differences, questions of personal agency and power, and the role of support groups within the acceptance of the condition. Further areas of study involved the experience and fear of HIV-related stigma and discrimination as well as the conundrum of disclosure faced by many of the participants. For example, many participants reported that their fear of negative reactions and the potential isolation they would face after disclosure was overshadowing their desire for moral support and a feeling of inclusion that is normally offered to those who are ill through the care of those around them. This initial work formed the basis for my fieldwork in India and the themes of this thesis by demonstrating the critical role that cultural background and traditional social norms play in constructing heightened vulnerabilities for individuals and the degree of personal agency in health felt by participants.

In determining a location for my research, Chennai, the capital of Tamil Nadu, stood out for a variety of reasons as the city where I could most effectively conduct this fieldwork. With a population of over nine million within the greater metropolitan area, Chennai is regarded as the sixth major city with the fourth most populous urban area of India, following New Delhi, Mumbai and Kolkata (Government of India Ministry of Home Affairs, 2011). The urban setting represented an opportunity to explore the issue of acceptance around HIV diagnosis and the obstacles women face when incorporating this

new condition into their complex communities in a bustling city. Additionally, researching within a city, as opposed to a more rural setting, allowed for a greater sense of participant anonymity, which was critical for the success of this fieldwork. For example, the city offered far more opportunities to interact with individuals without the fear of being overseen by prying eyes. As many of my participants had not yet divulged their condition to neighbours or friends, this was an absolute necessity in order to ensure their cooperation with this study.

Chennai also holds the unfortunate title of having been the first city in India to detect HIV infection within the population. While this has been seen by many as a dubious distinction, with concerns regarding tourism or the economy being foremost in many minds, I found this to be a benefit as I was able to discuss the local epidemic's changes over time and to interview those who were involved from the very beginning. This information was paramount as my participants revealed the social and political stigmas around the condition as well as the hard fought first steps that had led to vast improvements within the official approach to the condition.

This element was another reason why Chennai proved to be an appropriate location for this research as, at the time of fieldwork and continuing to the present, the city, and Tamil Nadu as a whole, is experiencing a reduction in the number of HIV diagnoses. Formerly one of the top three states in India with regard to HIV infections, Tamil Nadu has now fallen to fifth with 154,000 HIV-positive cases behind Karnataka (245,000) and West Bengal (167,000). This change has resulted from the admirable focus of HIV campaigners and policy makers who have sought to heighten public awareness of the risks of infection. By centring my research in Chennai, I was able to hear the descriptions of these challenges

first-hand from those directly involved. As noted in the previous chapter, this was by no means an easy feat with initial responses to the virus ranging from denial to anger on the part of politicians and community leaders. These responses originated out of fear for the reputation of Tamil Nadu as it was suggested that the local population would be viewed negatively and therefore the state would struggle to attract the visitors and industry needed to continue growth and development.

My own personal history with Chennai also played a very large part in determining the location for this research. As the information above has demonstrated, Chennai has a very complex local epidemic as a result of its complicated history with the condition. However, I was also drawn to Chennai due to my childhood years there and the widespread network of contacts that I already had through my parents' professional interactions and personal friendships. From 1986 to 1989, my father served as a consular officer with the United States Consulate in Chennai. This position, with its focus on visa applications and interviews, meant he had constant interactions with the local public. In addition, my mother served as the community liaison officer for the consulate, which in turn meant she was often setting up outreach programs and events to try and facilitate the sharing of cultural knowledge between the consulate's staff and communities within Chennai. As a result of these positions, my parents were able to expand their personal network across the city and have maintained these ties over the twenty-five years since we left Chennai. Taking this network into account during my upgrade proceedings, I felt Chennai would be the best location for my research as trust would be an important element within the fieldwork. For example, with the serious ethical concerns embedded within this research, having

references and contacts willing to vouch for my character and passion for this subject would be crucial to secure a place within a local institution.

In setting up the fieldwork in Chennai, my first port of call for planning this research was a close friend of my parents, Rafiq. As the owner of several successful businesses in Chennai, Rafiq was well versed in the charity sector as he had participated in several fundraising events. During my upgrade, as previously mentioned, it had been stressed that, due to the ethical concerns involved in research into HIV/AIDS, the involvement of a local nongovernmental organisation would be beneficial. As a result, I asked Rafiq to put me in touch with anyone he knew who could recommend an HIV/AIDS clinic where I could focus my research. Over the course of several conversations, my contacts all focused on the same organisation and therefore I began my interactions with the Clinic.

Ethics Approval Process

Before beginning fieldwork in Chennai, there were several steps that had to be completed in order to obtain ethics approval for this research. A main concern of the ethics boards was the potential for any negative consequences that my participants might face as a direct result of their involvement with this fieldwork. The first step involved the ethics board at University College London, wherein the study was put through several questions regarding the privacy protection available to participants. An additional component involved protecting participants from potential mental anguish through insensitive or difficult questions. Part of this process involved submitting the interview questions and the consent forms in advance so that they could be approved along with the research brief.

Once in India, this process was then repeated with the Institutional Review Board associated with the Clinic. This involved several rounds of submitting my research

proposal and methodology and then receiving suggested changes or requests for additional information. These additions most often involved further clarification of my proposed participant pool or alterations to my list of interview questions. An additional component of this process involved having the interview questions and consent forms translated into both Tamil and Telugu prior to submission of the application. A final element of the process involved the presentation of the research design to the IRB board, wherein the members of the board were able to question different sections of the methodology. It was at this stage that the intention to interview friends and family of participants was questioned as the review board members felt this would cause undue stress for participants, particularly if they had not disclosed their status.

The ethics approval process highlighted the varied concerns involved with undertaking research of this nature within a medical setting. The main concern of the board members was that I maintain the level of privacy and respect that patients had come to expect from the Clinic. This was intended to avoid causing anxiety on the part of participants and to avoid unintentional consequences for them as a result of their involvement with this research. Additionally, the review board members served as a sounding board for the practical concerns of data collection as they were able to judge my methodology and suggest alterations, which would enable the participation of a more streamlined participant pool.

While the review process itself, both in London and in Chennai, brought up questions about the inclusion of HIV-positive women within categories of ethical vulnerability, it also served as foreshadowing over how complicated HIV/AIDS research would be in the field. Without the involvement of the Clinic's staff members and their

acceptance of my presence within the waiting rooms and counselling sessions, this research would not have been possible. In particular, the trust shown in myself and my research methods by the staff members directly translated into the involvement of my interview participants as they felt comfortable taking part as a result of Clinic's endorsement.

The Clinic

The Clinic was born out of a growing need for a concentrated centre that would provide medical testing, patient treatment and social care such as counselling and nutritional guidance for HIV-positive individuals within Chennai. This new medical centre, set up as a non-governmental organisation, a public charity and an institution within its parent institution's trust, provided a safe and secure location for individuals while also offering a non-state run health treatment option for patients. Headed by Dr. S, the Clinic's goals were to continue the public education programs she had previously engaged in during her time with the AIDS Research Cell and later with the AIDS Resource Group. Both of these organisations had been a part of the Madras Medical College and had been focused on improving HIV/AIDS awareness among young people, raising the profile of HIV-positive individuals and their rights, and highlighting the need for increased public policy relating to HIV/AIDS.

Since 1993, the Clinic has been at the forefront of tackling the HIV epidemic in Chennai and has become well known as a destination for HIV-positive individuals who are in need of medical or social advice and care. The stated objectives for the organisation include building awareness of HIV infection and of safe and responsible behaviour; the provision of counselling, testing and care for all individuals; and to continue advocating

for equal legal rights and treatment for HIV-positive individuals and others who are directly affected by the local epidemic.

This methodology follows in the Lefebvrian example by aiming to assemble a "critique of everyday life" as seen through the veil of HIV diagnosis. Morris defines this arena of study as 'an investigation of particular ways of using culture, of what is available as culture to people inhabiting particular social contexts, and of people's ways of "making culture"' (Lefebvre, 1990; Morris, 1994: 43). Within this thesis, the term "community" is used as a catch all for the product of the social interactions of everyday life. The choice to use this term to describe this social element outside and within the Clinic's walls is an attempt to place this research alongside past researchers, such as Williams, who defined culture as a social product, wherein the 'lived experience' was the foremost concern (Williams, 1958).

In this way, the placement of the women participants of this research within the local epidemic and their lived experience of their diagnosis is constituted by and is constitutive of this social element found within their day-to-day interactions (Gray, 2003:2). This thesis seeks to integrate the role of culture within the individual's assessment of the local epidemic by focusing on the culture of the Clinic, informed by the social norms and understandings of south India, and the adaptations needed to include the local epidemic. More so, this thesis seeks to identify the participating individuals as the "body-self site" for contrasting the different influences on their illness experiences through a study of the coping methods and acceptance employed post-diagnosis and the steps taken to reach this understanding (Kleinman, 1995: 193).

The ethnographic nature of this research follows the recommendation of Kleinman in seeking to 'create another world' by following the methods participants and visitors to the Clinic have engaged in to redefine their selves, their health and their communities. In so doing, they are shaping the culture of the Clinic to one where HIV is a normative element within everyday life. This in turn then acts to inform their view on their communities outside the Clinic's walls and their interactions therein. The location of the Clinic presents a unique view of the local epidemic through a window of "individual suffering in a place of social suffering" (Kleinman, 1995: 210; Farmer, 2001: 106). The medical lens used in this focus on a clinic setting was chosen to follow previous medical ethnographies to view social life by way of its "health-relevant aspects" (Frankel, 1986: 60).

Continuing with Frankel's blueprint, this thesis uses his focus on diagnosis, illness experience and treatment as the building blocks for understanding the way participants have come to terms with their diagnosis in ways that informed their daily life among their communities (Frankel, 1986: 72). First, HIV diagnosis is viewed as the point of breaking away from normative social expectations and being placed into a position of liminality. Next, illness experience becomes the journey to come to terms with this diagnosis and to understand the obstacles to normative social life reflected within their new situation. Finally, treatment is identified as the acceptance of diagnosis and reinventing of society to fit with their new vantage point while also allowing a readmission into their original communities. This then ends their period of liminality, although they were primarily undertaking the journey internally without their friends, family or neighbours' knowledge.

While my research within the Clinic was not the natural setting for any of the participants, it was the only place research of this nature on such a sensitive subject could

take place. In their homes, people were not open to discussing HIV for fear of reprisals. Within the Clinic, this was the opposite as they came to the Clinic with the express desire of talking about their health and the impact HIV was having on their lives. As a result, my research interprets the expression of local culture that is found within the Clinic's walls and seen through this lens of HIV infection. The interview participants and visitors to the Clinic operate with a greater understanding of the local epidemic than the rest of the Chennai public and therefore their perspectives are very different to those found in the general population. There is an element of reflectiveness within these perspectives as they are able to reinterpret previous experiences, such as the reactions of friends and family to awareness campaigns, with the knowledge of their current HIV status.

Just as Alex and Heidemann have made evident that the status of local 'tribes' or adivasis remains contentious, this research has found the same to be true for the local HIV epidemic (Berger and Heidemann, 2013: 10). When interviewing individuals connected to the Clinic, either through their work or as patients, the view of the epidemic is much richer than that found outside the Clinic's walls and therefore offers a level of detail that was not known among the general public. Additionally, the complex nature of the epidemic within India, which ranges from severe to almost non-existent across different states, meant that while the data collected within this research fieldwork is useful for an examination of the epidemic local to Chennai, the issues and obstacles described herein may be less common in other regions.

My fieldwork began with several months of getting my bearings within the Clinic and the overall HIV/AIDS setting in Chennai. As a result, this thesis draws its main body of information from the interactions I had within the Clinic's walls, with patients and staff

members, although I also drew from my non-Clinic discussions with friends and others around the city. These examples of the public perception of the condition helped to inform my areas of interest within the illness experience of participants as they demonstrated the uphill battle many individuals face as they try to navigate the post-diagnosis environment where stigma and misinformation is rife. During this time, I focused on building relationships with staff members as they were invaluable in helping to guide my interactions with individual patients, an area where ethical concerns and the maintenance of well-being are critical.

The ability of anthropological fieldwork to centre its focus on this 'present actuality' proved to be a critical element of this methodology (Auge, 2009: 8). As stigmatised and feared as HIV/AIDS is within Chennai communities, the Clinic setting of this research was absolutely necessary. Many of my participants explained that they had not yet shared their status with family or friends, despite some of them having received their diagnosis several years prior to my interviews. Disclosure is one of the main elements of the illness experience for HIV-positive patients and the decision to open themselves up to the mercy of others by acknowledging their status is not something taken lightly. As a result, any attempt to conduct fieldwork within the homes of my participants would have been refused immediately. My obvious foreign appearance and sudden presence in their neighbourhoods would have brought undue attention on my participants and could have led to negative consequences for them. Therefore, the Clinic served as a safe location to meet and interact with participants.

Research Methods

At the Clinic, my methodology focused on participant observation at this nexus of interaction: patient to doctor, doctor to doctor, counsellor to patient, patient to patient, and patient to family member. During this observation, I was dependent on the kindness of staff members who guided me through the Tamil discussions, offering translation and commentary. These nuggets of interpretation offered not only a greater understanding of the patients but also of the staff members themselves, such as their concerns and opinions about their patients and the epidemic as a whole.

However, what enabled this fieldwork was not simply the medical setting. Far more important was the fact that this Clinic is exclusively focused on HIV/AIDS. Although the staff members treat many of the secondary infections associated with HIV/AIDS, such as tuberculosis, patients know that upon entering the building they are amongst other HIV-positive patients. This has an immediate calming effect, as they are able to let go of their protective shell, which is always tuned to immediately dispel any suspicions of those around them. Additionally, they are able to see the reality of the condition, which is that most of the other patients seem perfectly healthy without any of the visible signs of the condition that many new patients fear.

The Clinic serves as what Turner refers to as an "arena", wherein HIV status is the norm (Turner, 1969). This in turn allows individuals to focus on the day-to-day issues of their illness experience. This may include fears about losing their housing if their status became known to their neighbours or issues relating to their children's education or futures. As a result, individuals allowed my presence in counselling sessions and in the waiting rooms when they would have been less comfortable in a different setting.

Now that the Clinic has been established as the 'here' in this research, it is possible to move on to the 'now'. Patients who have been seen previously return to the Clinic at six-month intervals. These visits are designed to act as a check-up where patients can discuss their overall health, side effects from medication and attend counselling sessions. As a result, this fieldwork was a very literal interpretation of Auge's "present actuality" with participants sharing their impressions, concerns and opinions about their illness experience in a particular moment. Therefore, the methodology for this research focused on participant observation, volunteering with a sister organisation of the Clinic and conducting detailed interviews with HIV-positive women, Clinic staff members and local Ayurvedic practitioners.

Participant observation for this fieldwork was divided into two forms: general and specific. General observation was conducted within the waiting rooms and shared spaces of the Clinic, such as the courtyard. The aims of this method were to understand the way patients interact with the Clinic as a space, whether the atmosphere was comfortable or tense, and also to note who (if anyone) patients chose to bring with them. For example, many patients come alone or in couples. While this demonstrated a lack of disclosure for some, for others it was indicative of the level of comfort they felt within the Clinic. As a result, they did not feel the need to bring moral support with them.

A secondary location for general observation came during volunteer work with an organisation tied to the Clinic. Although I had applied to be an intern with the organisation, my work focused almost entirely on my research aside from my volunteer activities with the Kitchen. The link between the Kitchen and the Clinic, as both are part of the same parent organisation, is well known in Chennai as a result of several interviews and articles

that have appeared in the media since the Kitchen opened. As a result, this experience allowed me to gain a greater understanding of how the organisation and its activities are received. During my time with the Kitchen, I was involved in several areas of their work, including spending time getting to know the staff members while also visiting different work sites.

The Kitchen is headquartered in a huge, eco-friendly facility in the south of the city and focuses on helping to create independent entrepreneurs within the vulnerable communities in Chennai. Reached by way of the East Coast Road, the building is set in a rural and tranquil location, far from the chaos and noise of the city. Comprised of three main programs, the Kitchen provides corporate meals, charitable meals and a means of support for vulnerable women in the city. The three programs are intertwined and allow the kitchen to be entirely self-sufficient. For example, the corporate meals are delivered via contracts with different companies and office buildings. In return for a regular fee, the Kitchen supplies and runs the office canteens. This corporate fee is then used to subsidise the other two programs. The first is the charitable meal program, called Kathir Dahn. This program involves taking in donations from the public to be used to provide meals to vulnerable communities. For example, an individual can donate a set amount and choose an orphanage or another location for their donation to be spent.

Finally, the goal of the third program was to create opportunities for vulnerable women within Chennai. Women who are vulnerable due to economic hardship or seeking to move away from commercial sex work are trained to increase their business skills and given a roadside stand where they sell pre-packaged lunches to the general public. The women purchase the meals from the kitchen at a very low rate (which is subsidised by the

corporate program) and then sell them on to customers for a profit, which they keep. In this way, the organisation seeks to help women combat the socio-cultural forces that have placed them in their state of vulnerability. Involvement with this organisation demonstrated the many issues, such as unequal power dynamics within families and marriages, which combine to create an inability for individuals to control and improve their health.

My duties with the Kitchen involved the creation of a training manual for the servers who would be taking part in the corporate catering program. This involved several site visits to the corporate customers to see the layout of the kitchens, the serving tables and buffets, and to gain a greater understanding of the expectations of the customers. On these visits, I was accompanying one of the younger members of staff and our time spent together allowed for further discussions of her opinions on life in Chennai as a young woman. These insights furthered my understanding of the traditional social norms and the role young women have within their households.

The visits to the corporate customers were mirrored by a Kathir Dahn event I accompanied her to. Held in one of the more economically deprived areas of the city, this event involved serving lunch to the residents of the neighbourhood and was paid for by charitable donations made through the Kitchen. It was through these visits that I became acquainted with the different stresses and concerns for different social groups in the city. For example, the interactions I observed at the corporate sites differed greatly from the individuals I met during the Kathir Dahn event.

In comparison, specific participant observation involved attending counselling sessions with patients to better understand the relationship between themselves and staff members. These were conducted primarily with one of the senior counsellors, Lakshmi,

who acted as both intermediary and translator. Sessions ranged from twenty minutes to forty-five minutes as patients were encouraged to share any questions or concerns they had. These issues included those directly related to their HIV status, such as confusion over medication or worries about side effects, and those that were more indirectly related, such as fears about disclosure or worries about the suspicions of neighbours.

While the semi-structured interviews for this research were the most difficult element of fieldwork to arrange, the counselling sessions offered the most uncomfortable setting. Although I was extremely grateful to be given the opportunity to observe the private discussions between patients and Lakshmi, I was also acutely aware of a feeling of trespassing. These meetings were intended to allow for more in-depth discussion of any issues or concerns the patient may be experiencing and therefore these were inherently personal interactions. As I was conscious of the need to avoid overstaying my welcome with Lakshmi, I tried to spread out the days I would sit with her. This was primarily due to the fact that my presence created additional work for her (as she would need to translate for me while giving her full attention to the patient) and also slowed down each session. Knowing how important these sessions were to these individuals, I wanted to avoid taking too much of their time.

On days when I would sit with Lakshmi, I would arrive at the Clinic around nine in the morning to meet Lakshmi and double check that it was alright for me to join her for the day. Occasionally, she would have already started the first session and therefore I would wait for her to finish before joining her in the small office. Part of my discomfort in these sessions came from the ease with which the patients accepted my presence. While I took great pains to ensure they understood that I was neither a doctor nor a medical student (and

that they had the right to refuse me request to remain), I still felt I was being considered in that light. Through discussions with my friends in Chennai, I realised part of this feeling stemmed from the language barrier that was often in place between myself and the patients. As was pointed out by multiple friends, it is hardly unusual to have students present while meeting with a doctor – particularly in the case of attending teaching hospitals. However, being unable to personally clarify my position with the individuals attending these sessions made me feel out of place and anxious that I might be intruding.

Despite my concerns, the patients were very accepting of my presence and would even pause to make sure I understood while they were discussing their situations with Lakshmi. These meetings represented a normal part of their Clinic visit and made up just one of the sessions they were required to attend (in addition to a check-up with a nurse to take blood pressure and other body measurements before finally meeting with a doctor to discuss their medication and any test results.) During sessions, I was able to inquire about a range of topics including thoughts on traditional healthcare's role in combatting HIV/AIDS and their decisions regarding disclosure. In addition, this setting involved my only direct contact with male patients as the more focused interviews were conducted with only female patients. The reasoning for this was primarily due to the feelings of staff members that male patients would not feel comfortable discussing such an intimate and sensitive topic as their sexual health with a young woman. Therefore, in order to avoid causing this distress, female participants were exclusively sought.

Semi-Structured Interviews

The interviews for this research were semi-structured and designed to let the participant focus the discussion on the issues that were the most important to them.

Interviews with HIV-positive women ranged from forty minutes to an hour and a half and were dependent on how much the participant wanted to share. In total, there were fifteen participants who represented a unique cross-section of the local epidemic (fig. 1). Recruitment for these interviews was undertaken primarily through word of mouth. In my first months in the Clinic, I endeavoured to get to know the staff members and to clarify the aims and objectives of my research in order to build a level of trust with them that would encourage the promotion of my work. Counsellors would mention this research to their patients and offer to arrange the interview if they found a willing participant. However, since these interviews often meant participants would have to stay longer at the Clinic than they had intended, it was unsurprisingly difficult to recruit large numbers of individuals.

For the women who volunteered to take part in this study, the process of the interview was as straightforward as possible to ensure they were made comfortable and any questions were answered before we started. First, they were given a translated copy the research description and consent form[20]. This was then discussed to answer any queries and completed. Next we moved into a semi-structured discussion based around the interview prompts that had been previously approved by the Institutional Review Board of the Clinic.

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[20] Please see appendices A – C for examples of these documents.

Pseudonym	Age	Marital Status	Children (Age)	Education	Occupation	Diagnosed
Diya	29	Widowed	Son (5)	11th Std	Garlic and Spices seller (since husband's death)	2006
Shruti	38	Widowed	Daughter (15)	4th Std	Domestic help (since husband's death)	2002
Avani	38	Married	Daughter (12) Son (11)	SSLC	Health worker (doing home visits for HIV+ people)	2005
Riya	33	Married	Son (12) Son (8)	HSS	Housewife	2005
Aarohi	28	Married	Daughter (8) Daughter (7)	11th Std	Housewife	2008
Priya	31	Separated	Daughter (13) Daughter (11)	8th Std	Outreach worker (formerly a cook)	2005
Siya	35	Married	N/A	2nd Std	Housewife	2006
Saanvi	34	Married	Daughter (11) Son (1)	8th Std	Outreach worker	2002
Pari	37	Married	Son (14) Daughter (10)	10th Std	Outreach	1999
Prisha	34	Married	Son (13)	9th Std	Housewife	2002
Akshara	34	Widowed	Daughter (13) Daughter (12)	8th Std	Housewife	2001
Ameena	46	Remarried	N/A	BA Tamil Literature	Housewife	2006
Kalpana	46	Widowed	Son (17)	10th Std	Shop keeper	2009
Jyoti	32	Married	Son (10) Son (5)	10th Std	Housewife	2010
Madhuri	31	Separated	Son (10) Son (4)	10th Std	Housewife	2010

Fig.1. Semi-structured interview participant details.

The questions were designed to span the entirety of their illness experience, including pre-diagnosis awareness of the condition to new definitions of self and community. However, participants were free to take the conversation in any direction they wanted to focus on and therefore each interview was focused on the illness experience of the individual. For some participants, this meant a more detailed discussion of their diagnosis and the steps that lead up to it while others had more information based on their experiences with the health system.

For the interviews with staff members and Ayurvedic practitioners, the format was also semi-structured although the questions focused on changes in the local epidemic over time, concerns they had regarding patient adherence and general difficulties they faced in dealing with the public perception of the condition. These participants included counsellors, doctors and administrative staff wherein interviews conducted during their breaks. The Ayurvedic practitioners were based at the nearby training facility located within the Health Concerns Compound. These interviews focused on the treatment of symptoms and side effects and their opinions on the different strengths offered by biomedical and traditional health systems.

Limitations of Fieldwork

There were of course limitations within this research as a result of the methodological approach. As mentioned previously, the need to focus the in-depth interviews solely on female participants meant that my participant pool was more limited than expected. Additionally, the methodology had to adapt to unexpected changes as the research progressed. For example, when arriving at the Clinic, my original plan involved interviewing the friends and family members of participants to get a more holistic view of the condition from those around the individual. However, I was informed very directly that this would not be possible as the issues with disclosure and privacy were the main concern.

Additionally, the Clinic setting offered a particularly complex environment for fieldwork as I was required to not only navigate the intricacies of dealing with a stigmatised condition but also the politics of a highly supervised arena. While the Clinic's staff members were exceptionally warm and welcoming to me, I was also aware that their primary goal was the protection of their patients and therefore my presence was not to be taken for granted. As a leading private treatment facility, the Clinic is very familiar with the elements involved when hosting a visiting researcher. In this way, the process of gaining approval from the Institutional Review Board was very clear and my eventual presence was not alarming for the individuals attending the Clinic for treatment. This was the primary benefit of researching in a closed environment; once approval had been granted I was immediately accepted by the staff and patients. Therefore, I was able to tour the facility, meet with staff members and arrange my participant observation and interviews.

However, I also felt that I would not be able to study the Clinic itself as any change in our relationship might have resulted in my exclusion and inability to recruit participants. Therefore, my research focused entirely on the illness experience of the individuals who interact with the Clinic rather than the Clinic itself. While I felt this narrowed approach was useful given the scope and limitations of this thesis, I believe the Clinic would be an interesting and appropriate subject for future research. Despite the potential for interference, the Clinic setting offered positive elements as well. As mentioned above, my presence was easily accepted and the staff members were readily available to offer help where needed, such as within the interviews and counselling sessions.

Within the semi-structured interviews, there was one overarching issue: language. Although I attempted to familiarise myself with Tamil, the serious and stigmatised nature of the condition meant that I was uncomfortable attempting to interview participants in anything other

than English as the potential for inadvertently causing distress with an incorrectly chosen term or phrase was too high. With the staff interviews or those with other medical practitioners, this was not a problem. However, many of the HIV-positive participants felt more comfortable in Tamil and therefore it was necessary to employ translation services. During interviews and while sitting in on the counselling sessions, my primary translators were members of staff from the Clinic. Although this was an absolutely necessary step which allowed me to fully understand my participants, it also served to extend the influence of the Clinic more directly into this research. As with the previous points regarding the positive elements of navigating a closed and supervised environment, there were positive aspects of this working relationship.

First of all, the participants were immediately more at ease as they recognised the staff member and understood through her presence that this research was sanctioned by the Clinic. Secondly, by using a translator who was familiar with the subject matter and setting, the interviews went very smoothly. My translator was able to avoid sensitive phrasings or awkward methods of questioning that might have been less obvious to someone who was less aware of the condition and the social consequences therein.

However, there were also negative elements to this working relationship. The first is that her presence gave the Clinic more control over the direction of the discussion than would have otherwise been possible. Although I do not believe she exercised this power during the interviews, I do think it would have been difficult for participants to be openly critical of the Clinic as a whole. During the sessions, I did not sense tension of any kind towards the staff member and therefore I believe this was not an issue in reality. Additionally, the Institutional Review Board (IRB) for the Clinic had already checked over my interview prompts and approved them. Therefore, there would be no reason for her to interfere during the interviews themselves.

Another concern that grew out of this relationship was the potential for the translations to be inadvertently less accurate as a result of the familiarity of the subject. For example, I worried that my translator might inadvertently lead my participants towards the most common answer or away from uncomfortable themes. While I would never accuse my translator of intentionally misleading the conversation, I know from first-hand experience of prior research how easy it is to create a very different result based on a simple word substitution. Therefore, while using a translator meant my interviews went more smoothly, it also meant I had to take additional steps to ensure the translations were as accurate as possible. For example, if there was any uncertainty over the subjects brought up by my prompts, we would discuss this to add clarity. Additionally, these interviews were taped and translated by another individual before being reviewed by a Tamil speaking friend in order to ensure the translation was as accurate as possible. I am extremely grateful for the assistance these individuals gave to me and their ability to glean the clearest and most direct translation from these interviews.

The stigmatising nature of HIV status was the main determinant in choosing an urban, rather than rural setting for this research. Although Chennai is not the most international of Indian cities, it was still sufficiently diverse to allow me to move freely without attracting increased attention. This would not have been the case in a rural setting where my presence would have caused suspicion to fall onto my participants and could inadvertently lead to the revelation of their HIV-positive status. By conducting my research primarily in and around the Clinic, my presence was not disruptive to their personal lives.

The methodology described in this chapter has focused on the interactions with individuals, both patients and staff, which have informed this thesis. In order to provide a holistic view of this research, the following chapter seeks to investigate the role played by the Clinic building itself

within the illness experience of HIV-positive individuals as they arrived for tests and counselling sessions. The physical location and design of the Clinic allowed for specific interactions between individuals and created a unique social atmosphere, which will be the focus of the following chapter.

Chapter Three:

The Clinic: The Visible and the Concealed in the Here and Now

"I don't like to use concepts like rationality. Because I very much want to rely on discovering how things are actually working, how they are actually being put together by actual people."

– Dorothy Edith Smith, Sociologist[21]

"People do not 'have' diseases, which are really descriptive mechanisms created by contemporary medicine. People have stories, and the stories are narratives of their lives, their relationships, and the way they experience an illness."

– Arthur Kleinman, Anthropologist[22]

"What the sick need is teachers not treaters, health schools not hospitals, instruction not treatment, education in right living not training the sick habit. Both they and their advisors must get rid of the curing idea and the practices built upon thereon."

– Herbert M. Shelton, Naturopath[23]

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[21] Carroll, William K. 2010. "You are Here: Interview with Dorothy E. Smith." *Socialist Studies*. Vol. 6 (2) pp. 9-37.

[22] Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing and the Human Condition.* New York: Basic Books.

[23] Shelton, Herbert M. 1941. "How to Get Well." *Hygienic Review*. San Antonio, Texas: Herbert M. Shelton Publishing.

The Clinic Experience

My first day at the Clinic began with a bumpy and deafening ride through Chennai's morning traffic in one of the city's ubiquitous yellow and green auto rickshaws. After half an hour, the congested lanes of the expressway gave way to a partially paved road that wound its way through the Health Concerns Compound, passing a diabetes clinic and an Ayurvedic training facility before stopping in front of a coral coloured building. Four stories tall, the building is designed in a square around an open courtyard centre where rows of chairs have been placed to accommodate patients as they wait diligently between appointments. The schedule of the day for many will be to arrive, check in with the nurses (to have their blood pressure and weight taken), have an initial meeting with the doctor to determine if further tests are needed, and then to be seen by the counsellor before yet another wait to be seen by the doctor for a final time. This final waiting period can be extensive if further tests were needed as the results can take several hours, and possibly overnight, to come back.

As I entered the building, I passed the cashier and the pharmacy on my left before proceeding up the stairs to the administrative offices where I was greeted by the cheerful receptionist who instructed me to sit and offered chai and biscuits from her desk drawer. As a private facility, the staff members have strong relationships with several overseas organisations and work collaboratively on different research projects. Therefore, both the staff and patients were comfortable with my presence. When the head of research arrived, I was introduced quickly to the rest of the office staff before being taken on a tour of the facility.

Walking down the hallways where chairs lined the walls on both sides, I could see that these were already filled with patients waiting to be seen. Men, women and even a few children

were quietly sitting, some busy with small tasks or a newspaper while others gazed around the space. As we passed, they watched us with curiosity although no one stopped us.

Continuing the previous lightening round of introductions, I was rushed through the different parts of the building: the five doctors' offices, the counselling offices, nurses' stations and the laboratory, which spans the top floor of the building and boasts an impressive array of machinery. The building also has its own electricity generator, to ensure the patients' tests can continue despite the two-hour power cuts experienced daily in Tamil Nadu.

Returning to the administrative wing, I met with the research head again to discuss the different stages of my research and I left thinking about his advice to prepare myself mentally and emotionally for some of the experiences my participants would share. The day, although brief, had already hinted at the different layers presented in this fieldwork. It was obvious that any discussion I had with individuals, either staff or patients, in public would only touch the surface of this sensitive subject.

A Transformative Space

Within the period of liminality that this thesis examines, there is an important focus on the Clinic itself as it occupies the unique position as being the site of the diagnosis for many participants, and therefore the origins of their liminal state, while also being the location where they receive treatment and counselling which gives them the tools to come to terms with their condition. The ability to merge their condition into their daily lives, which they gain from these tools, then ends the period of liminality they were experiencing. This chapter explores these concepts with a focus on the physical space of the site while also attending to the community found within the Clinic and its ability to counter the social inefficacy felt by patients as a result of the "dynamic nominalism" found within the public perception of the HIV/AIDS (Hacking, 2002).

Central to this argument is the concept of the Clinic as a transformative space wherein a sensitive and highly stigmatised condition is normalised, which in turn allows patients a freedom they are denied in their day-to-day interactions. As emphasised by Turner, this is "the setting in which new paradigms of social and symbolic structure are put into place and established as the new orthodoxy" (Turner, 1969). Within the Clinic, the social drama of the push and pull between this new orthodoxy and the established metanarrative of HIV/AIDS, as a condition for those who do not conform to societal norms, is continuously played out as patients reiterate the social perception and staff members provide an alternative view.

Upon receiving their HIV diagnosis, individuals find themselves navigating the non-space created by their new condition. While they feel they no longer conform to the social expectations placed on them as a result of their status, they also feel uncertain of their place within the metanarrative of HIV/AIDS. This is a result of the dynamic nominalism surrounding the condition, which informs and is formed by public perception of the local epidemic. The incompatibility between their expectations of HIV sufferers and their self-image creates the distance between themselves and their families and communities which places them into the state of liminality.

This distance is inhabited and perpetuated by the metanarrative of the expected characteristics of HIV/AIDS sufferers. This public perception of the condition is based on the rumours and suspicions regarding early AIDS patients in Tamil Nadu and forms a shared understanding of how individuals with this condition will look or act. Expectations include a questionable moral character and activities such as commercial sex work or drug use. With this metanarrative swirling around them, many HIV-positive individuals choose to hide their condition from those around them, which creates a division between the way they are being perceived and the position they feel they now inhabit within society.

The main element of their liminal state is the feeling that they will not be able to maintain their position within their families and communities as a result of their condition. For example, they fear they will not be able to undertake social expectations such as getting married or having children. Therefore, the period of liminality remains until the point at which they are able to reassess those social expectations to include their condition. A large part of this process involves the knowledge and support individuals gain from the Clinic's staff and other patients, which will be discussed in further detail in later chapters. Therefore, this chapter seeks to identify the Clinic as the crossroads of this non-space existence where the practical elements of living with HIV/AIDS meet the influences of public perception and dynamic nominalism, which has been defined by Ian Hacking as the cultural categories that inform the "certain modes of identity making" (Hacking, 2002; Gibbon and Novas, 2008: 7).

Physical Placement of the Clinic

The location of the Clinic, within a medical campus and therefore surrounded by other specialised treatment facilities, allows for the facility to be hidden from the general public without being isolated. Occupying the back left corner of the campus, the Clinic is extremely private as only patients intending to attend this facility would venture so far into the campus. This allows patients to feel at ease as they do not feel they are being identified as HIV sufferers in the same way that they might be when attending a general hospital where their status can sometimes lead to heightened concerns from the staff members and other patients.

Upon entering the Clinic, patients find themselves in a large, open-air area where the pharmacy and cashier are located to the left while a nurses' station stands to the right. Directly in front of visitors there is a small walkway that leads to the waiting areas. The space is very light and busy with other patients and staff moving between appointments or filling prescriptions.

Patients know that the Clinic is a place where their HIV status is common and therefore will not be a source of shame or embarrassment and therefore they can be open with the staff members regarding their concerns. Additionally, the Clinic was designed to be able to offer patients a variety of treatment and care resources within one building in order to simplify their visits. For example, along with medical staff such as doctors and nurses, the Clinic also has counsellors and nutritionists on staff to deal with post-diagnostic concerns.

Within the illness experience of HIV-positive individuals, biomedical concerns are often secondary to the social stigma and fear surrounding their condition. As emphasised by Lock and Nguyen, knowledge of the local understanding of health and wellbeing cannot be understood outside the social, cultural, and political influences felt by patients (Lock and Nguyen, 2010: 59). To this end, Kleinman sets out a three-part discussion of the sectors within which health and wellbeing is nurtured and understood: popular, professional and folk (Kleinman, 1995: 86-87). Of these three, only the first two were evident within this medical setting.

The popular sector of the social arena of health consists of the influences of and interactions with the family and community. This is the first step for individuals who are ill as they seek advice for symptoms and treatment. The popular sector is found within all elements of the individual's understanding of their health from defining the role sick individuals have within the society and the expectations placed on that society for care to choosing healthcare practitioners, and even making decisions regarding when to seek aid within the professional or folk sectors.

On the other hand, the professional sector of the social health arena is inhabited by the Clinic's staff members. This category includes all practitioners of both biomedical and traditional health systems who work in an official capacity. Their official position within the local healthcare

system differentiates them from the folk sector, whose members are not involved with the individual's health in an official, professional sense.

Within the Clinic, the popular and professional sectors merge. In order to care for patients effectively, attention must be paid to the socio-cultural understanding of health that the patients bring with them. Within HIV/AIDS, the main point of conflict comes from the struggle between the new orthodoxy of the Clinic and the metanarrative of HIV that is deeply rooted in the public perception of the condition. As mentioned previously, this push and pull is centred on the cultural "iatrogenesis" of the local epidemic, which highlights the medical treatment and advice regarding the local epidemic received within the Clinic as directly oppositional to the socio-culturally-based beliefs about HIV/AIDS found within the general public. (Eisenberg, 1977). Defined by Kleinman as "the major obstacles to effective healthcare," this includes the socio-cultural traditions and practices that have created and sustained systematic vulnerabilities to HIV/AIDS for particular individuals (Kleinman, 1995).

The Pursuit of Privacy

The expectation of stigma and discrimination is one of the primary reasons individuals choose to frequent this Clinic. As a private institution, individuals must pay for their treatment. The cost, while reasonable for most, can skyrocket if patients need to move up to higher levels of medication. For example, there are three stages of HIV medications offered. During this research, these ranged in price from 850-3,500 rupees for the first stage, 4,000-6,000 rupees for the second stage and up to 7,000-10,000 rupees for the final third stage[24]. These costs would be a struggle for most households, especially if more than one member needed the medication. By comparison,

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[24] Using the most recent exchange rate available (via xe.com), the Indian rupee prices correspond to the following amounts in British pounds: £8.98 – £37 for the first stage of treatment, £42.29 – £63.44 for the second stage and £74 – £105.72 for the third stage.

patients also have the option of getting their treatment from one of the local government hospitals where medicine is given free of cost. However, despite the financial benefit attending the hospitals would provide, many patients still feel their privacy is more secure in the private facility.

For these patients, the Clinic offers more than biomedical care as it offers them a space to discuss their concerns and redefine their condition in the transformative nature of the space. The mental empowerment of knowing they are not alone was reported as one of the most important first steps participants had in coming to terms with their condition. Participants felt the Clinic offered them a space where they could gather important information regarding their health from the knowledge of the staff while also gaining useful insights through interactions with other HIV patients.

Staff members at the Clinic do their best to offer a place of safety to patients in order to offset the residual fears that arrive with their patients. When the Clinic was founded in 1993, the overarching vision was to prevent new infections while providing a life of dignity for people living with HIV/AIDS. As one of the first dedicated organisations for diagnosis and treatment, the Clinic became a valued option for individuals who were afraid to attend government voluntary testing centres. Dr. S explains,

> *"I am a sinner." This is the first thing HIV-positive people say. You have to get them to talk by explaining that we are all sinners and therefore they are no different to any of us. We would be so close with our patients. I think until 1996-97, we lost so many nice, good patients who we had such close relationships with. Almost family. And we've lost them. Such good drugs today. You can live like someone with hypertension. You just need to take the drugs every day.*

Lakshmi, one of the counsellors at the Clinic, echoed Dr. S's comments. She had been working at the Clinic for nearly ten years and has seen the changes in patients with the introduction

of better medications. She feels the Clinic offers a place of solace where patients can discuss their concerns without being made to feel ashamed of their condition.

> *Whenever they come here, they feel it's a safe atmosphere. They feel that they forget their problem when they come here. They spend eight to nine hours here. Sometimes even more than that. They feel that at least this one day gives them a small pleasure. And they travel such long distances; it's not like coming from a very short distance. People travel up to nine hundred kilometres in order to come here. We have a lot of patients here. That's the main thing - people don't talk to them much. Again they have the discrimination, so that's the reason they come. Once they enter here they have a smile and that gives us more encouragement to try and get them to open up. Once we go to the counsellor's room, they are so pleasant and they give us a lot of information. They build up our confidence level too.*

The Clinic has also taken steps to try and combat the burden of blame that can often fall upon women as a result of their condition. For example, both participants and Clinic staff members shared examples of women who had lived quietly within their joint households until they were diagnosed with HIV. As a result of this news, the women were suddenly accused of having brought this condition into the home through immoral or illegal behaviour. Therefore, in an instant, the women went from being seen as a member of the household to a stranger who must be removed so that the shame of inappropriate behaviour and the resulting HIV infection cannot spread to the rest of the household. This type of reaction to diagnosis is exactly the reason the Clinic has enacted a policy of only revealing test results to women if their husband also comes in for testing. As a result, the couples are forced to receive their diagnoses together, which helps to avoid the assignation of blame on the woman.

A Changing Discourse

For staff members, the relationships generated by their interactions with patients offer the opportunity to counter the metanarrative of HIV negatively influencing their patients. Their role is critical in the establishment of the new orthodoxy described by Turner. The Clinic, by operating

with the sole focus on HIV/AIDS, has therefore created a space out of the non-space established by HIV diagnosis.

The Clinic serves as a location wherein HIV-positive status is normalised and individuals can come for information, advice and support as well as biomedical treatment. In this way, the Clinic provides a platform for examining the role an organisation can play in transforming individual illness experience into a community of support, which then enables the readmission into general society experienced by participants. The establishment of this sense of "groupness" is an important step in addressing the misinformation circulating within the metanarrative of HIV as it provides individuals with examples of other patients, who do not represent to the negative characterisations that correspond with the dynamic nominalism, or cultural categories of identity, found within the local epidemic (Tutton, 2012; Hacking, 2002: 107; Gibbon and Novas, 2008: 7).

The liminal state, the role of the Clinic and the value placed on personal agency will be further discussed in the following chapters. The first chapter will address the process individuals undertake to redefine their concept of health and healthcare as they interact with the Clinic's holistic approach to health and the often stigmatising nature of public healthcare experienced within local hospitals. The next chapter will discuss the complicated nature of the illness experience for individuals who do not identify themselves as being sick and seek to answer the following questions: How does an individual navigate the stigma of having a condition that is considered shameful when they cannot disclose their status for fear of abuse? What are the potential pitfalls of accessing the sick role in this case? What are the potential benefits? How does this affect their concept of community and who is included under that umbrella? Finally, the process of how personal agency shifts from pre and post-diagnosis levels will be addressed in the final chapter as the location for the greatest impact of the liminal period.

Chapter Four:

The Medical System and the Business of (Dis)Trust

"The most important decision you will make in those first few days after learning you have HIV is choosing a doctor to take care of you. It's a decision that will impact your health as well as your quality of life for many years. Obviously it's not a decision you should take lightly."

- Mark Cichocki, HIV/AIDS Nurse Educator.[25]

"Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity."

- World Health Organization, 1948[26]

[25] Cichocki, Mark. 2009. *Living with HIV: A Patient's Guide*. Jefferson, North Carolina: McFarland and Company, Inc.

[26] World Health Organization, 1948. "Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946." Signed on 22 July, 1946 by the representatives of 61 States and entered into force on 7 April 1948. [Internet] Published online in 2003.

As noted in previous chapters, the moment of diagnosis can be seen as the origins of the liminal state as individuals are forced to comprehend their inclusion within a group previously viewed as deviant or outside of the accepted socio-cultural norms. This chapter seeks to explore the influence of this break with society by examining the changing relationship individuals have with their healthcare as they move through their diagnostic journey from isolated patients in general wards to the private, holistic approach of the Clinic. In particular, narratives of stigma within medical settings will be contrasted with the view from within the Clinic as participants wrestle with initial feelings of distrust and confusion. Within this discussion, the complicated message relating to the role of traditional medicine within the local HIV/AIDS epidemic will be examined through the example of Ayurveda.

The View from within the Exam Room

On the first floor of the Clinic, there are several exam rooms where visitors meet with the doctors on staff. These appointments focus more directly on medical issues than those with the counsellors and nutritionists. As a result, sitting in the plastic chairs lining the hallways, visitors were often more tense and silent than those waiting for other sessions. Inside, the rooms are painted a bright white and contain a desk, exam table and all of the usual equipment. One of the youngest members of staff, Dr. P, has spent his entire medical career at the Clinic where he started soon after finishing his studies. Six years ago, he had been contemplating where he would like to practice when he saw an ad in the newspaper about an opening at the Clinic and decided to apply. When asked about his desire to work with HIV/AIDS patients, he explains that he was attracted by the challenge of working with such a new condition. Although HIV/AIDS had been diagnosed in Chennai more than twenty years earlier, Dr, P explained that specialist training was still extremely rare. Within his Chennai based medical school, it was unusual to come across an HIV-

positive patient. He remembered the excitement on the wards when a case would arrive, as all of the students scrambled to see for themselves. As a result, he and his colleagues had very little knowledge about HIV/AIDS treatments upon graduation. Within the Clinic, he explained, none of the other doctors had specialised in infectious disease like he had while in training. This was due to the dearth of programs within the city, with the primary training option being a small fellowship program.

An average day at the Clinic for Dr. P begins around eight in the morning, when he does rounds within the inpatient ward to check on the status of his cases. This usually takes between an hour and an hour and a half if there are a large number of patients to see. After updating the status of these patients, he will return to his office to begin the appointments for the outpatient visitors. These include not only individuals arriving for their biannual Clinic visits, but also those involved in clinical and research trials. The Clinic tries to enrol visitors in studies as a method of lowering the cost of HIV medication. These trials are primarily focused on behaviour as researchers attempt to find ways to improve adherence rates among those receiving treatment. For example, one study that was being undertaken during my time at the Clinic involved the use of text messaging as a means of reminding individuals to take their medication every day. Within the Clinic, medications are already subsidised to help offset the costs for individuals, but for those who participate in these trials, medication is either free or further discounted, which can be extremely beneficial to those on very low incomes. These appointments are usually completed by four in the afternoon, when Dr. P returns to the inpatient ward to ensure his earlier updates to medication or other notes have been taken care of and that the patients have not had any further complications.

Among the visitors to the Clinic, Dr. P has seen a major shift in their general health over the six years he has been practicing. While those in the inpatient wards are often very ill, their

number has decreased significantly as the majority of the HIV-positive individuals he sees are very healthy. As he explained, many of the most life threatening conditions are no longer as common. Ailments such as meningitis, extrapulminary tuberculosis and pneumocystis pneumonia were formerly common among visitors but now he sees mostly issues related to drug toxicity or regimen failures. Although tuberculosis has been a constant issue during his time in the Clinic, it is no longer presenting in such severe forms. He felt the obvious cause of this change over time had been the improvements within medications as well as the policy shift that saw the CD4 threshold for treatment moved from two hundred to three hundred and fifty. Interestingly, treatment for HIV does not immediately follow diagnosis for many individuals, particularly if the virus is detected early. Instead, treatment does not begin until their CD4 count, the number of a particular type of white blood cells found within a cubic millimetre of blood, has reached a set level. By adjusting the threshold one hundred and fifty points higher, this has allowed a much larger number of people to begin treatment. As he explained, this seems like a small change but with such a big population, this has made an important difference because individuals are now able to access these medications before they begin to experience more severe ill health. This has therefore meant better responses to treatment for his patients.

Unfortunately, while the medications available to HIV patients have seen tremendous improvements over the course of the global pandemic, the same cannot be said with regard to the ability of some medical staff within the city to confirm negative stereotypes of HIV-positive patients and therefore further isolate this vulnerable population. As Dr. P explained, the standard of care within local government facilities is generally very high as these organisations are able to provide medication free of charge. While this has proven to be a useful resource for HIV-positive individuals who would otherwise struggle to provide the necessary funds for their prescriptions,

the ability of doctors to individualise care is minimalised as they are tied to strict government protocols. As a result, visitors reported their experiences within these sites as being more impersonal than their treatment at the Clinic. Additionally, Dr. P explained that stigma regarding the condition remains high even within the medical profession due to the limited training available. For example, while discussing other private care options within Chennai, Dr. P noted that these facilities often recommended their patients seek treatment elsewhere as a method of keeping their HIV cases down.

> *There is a huge stigma in the social network but at the same time even in the private hospital there is a lot of stigma. They don't like to admit too many patients with HIV. At the moment they know that someone is HIV-positive, they will refer them out. That's one thing that happens. And also with the confidence, that's something that is lacking. In the hospitals, if they know you are HIV-positive, they will just mark it on the chart in big block letters: HIV-POSITIVE. It isn't private… everybody just gets to know so there is no confidence between the doctor and the patient. So they are more than happy to go elsewhere for treatment. And another big thing is that it's not just their sake, they have their children's future to worry about too. The awareness of the different types of transmission is not very high. There is quite a lot of talk about educating people but I don't know if that will work. Because, I generally tend to find people more paranoid when you attempt to educate them. Even the little things tend to set them off. It makes it a bit worse. Either you know everything or you don't know anything. Even among professional doctors. See because what happens is even among our doctors and colleagues, what happens is then they go and when we go see them, sometimes they don't realise that I also take care of a lot of HIV-positive patients and they'll be like, "Did you know that this patient is HIV-positive?" and I just think, "Of course I do". Sometimes I think, "Oh, maybe they didn't know about my work." Because if I say anything, then they'll tell me, "These people are risky" and everything. Or that I need to stay away from them. So it's that they know so little about HIV medicine, but the time to teach them all about it is too much."*

This opinion regarding the lack of awareness and training among medical staff was echoed within the narratives participants shared of their initial experiences with HIV treatment and care. Their shock at finding the same HIV misinformation within the medical centres caused them to re-evaluate their expectations of care and their understanding of the healthcare system. As Dr. P noted above, proper medical care relies on a feeling of trust between doctors and patients. When this trust is broken, individuals can find themselves increasingly isolated as they fear further

mistreatment as a result of their HIV status. Instead of seeing hospitals and doctors as a source of knowledge and impartial treatment, they become a source of added stress and shame for participants.

Experiences of Stigma within Medical Settings

When Diya was twenty-three, she was diagnosed with HIV as a result of tests undertaken during her pregnancy with her now six-year-old son. Her experience of diagnosis was extremely traumatic as she was forced to move between three hospitals as staff refused to treat her out of fear of infection.

> *Before I delivered the baby... they had to do this testing it seems, so they have done this test and they have found that I was positive. During that time, they called my mother and they have informed her about it. My mother came to me and she started crying very bitterly, but I didn't know anything. I kept thinking, "Why she was crying... Why she was crying." I could not understand anything. I was walking since they had asked me to do walking. My mother came to me and she hugged me and she was crying. I kept asking her, "What ma? What ma?" I was walking and the doctor who did check-up for me was there and I went and asked the doctor. And then the doctor told me that I was positive and I was infected. That is all not even a single soul was next to me as soon as they came to know that I was positive. Only my mother and my sister were standing along with me. Doctor, nurse, ayah[27]. Nobody was there.*

Immediately, Diya found her doctor keeping his distance from her as she struggled to come to terms with what this diagnosis meant. He refused to stand by her bedside and instead offered answers to her questions from across the room. This meant that everyone else on the ward could hear their discussion, which magnified the emotional trauma of the diagnosis itself. Additionally, shortly after this discussion, Diya and her family were asked to leave the hospital.

> *Doctor only informed me, but that doctor also was not there next to me. That doctor was standing far away. Yes, from far the doctor was answering me. I didn't know anything about this disease. How did this disease come to me? Did I get it from my husband? I couldn't understand anything. I didn't know anything. I was not even aware how this disease will spread. When they said I was positive, I kept crying. They kept telling something and all. They said, "Even your child might be infected since your positive. Here*

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[27] In this instance, "Ayah" refers to the nursing staff available within the wards of the hospital.

we don't have that medicine. You go to the bigger hospital. Only there that medicine is available." Immediately, that night itself we took an auto and we got shifted to Egmore hospital. They never allowed me to stay there.

Diya's mental anguish at the treatment she received was compounded by the fact that she had willingly chosen to attend the hospital for a pregnancy check-up. She had trusted the doctors to help her maintain her child's health and instead, when a life threatening condition was detected, they had been sent away. When she arrived at the larger facility, her treatment was equally poor as some members of staff refused to interact with her. In this way, the medical staff were confirming her worst fears about how the diagnosis would come to impact her life and she felt suicide may be her only choice. Fortunately, the larger hospital also had counsellors on staff to assist with diagnosis who were able to calm her emotions.

Since we were staying there I went for check-up in that hospital and they did like that to me. Immediately, that night itself they shifted me in an auto. My mother, my sister and me all three of us we came to the bigger hospital. In that hospital, only the counsellors who give counselling they spoke nicely with us. Only the counsellors they spoke nicely with me. Rest of them, they didn't even bother to see me. They said go and sit in that corner. My mother gave me a piece of cloth and she asked me to lay down and she said adjust for some time. For my sake, you should be alive. I said, "No ma, I want to die. It will be disgraceful if others come to know about it. Without knowing what it is how will I survive." Counsellors came and they gave me counselling. They said, "It is nothing and it will become all right. The child will not be infected. They will give medicine to the baby as soon as it is born."

Doctors behaved very disgracefully with me and I was driven to the point where I felt I should strangle myself with that piece of cloth and die. We were disgraced to that level. I was not able to stay in that place at all. It was 5 o'clock in the morning. I said to my mother, "I don't want to stay in this place. If I am in this place, I will die ma. Please take me away from this place." From here we went to a third hospital. The doctor who provided me medicine... that doctor is good. He took care of me well.

Although Diya had ultimately had a positive experience with the final doctor that day, the same could not be said of the dermatologists she was sent to within the same hospital. She has found that the awareness of her condition and their subsequent behaviour towards her was radically different between the two offices.

Then I have gone to the skin doctor, but they will not touch and all. They are aware of my status. They gave me prescription for skin problem and all, but they will not touch and all. Whoever doctor it might be they will not touch and all. Only my sister and my mother they will touch me and they will apply ointment for me. Until now, no doctor has touched me and all.

At present it is okay. At least they are kind enough to ask me to sit. Earlier as soon as I went they used to make me sit in a corner, but now the doctor will ask me to sit next to them. Just like how you are sitting now I will sit and I will answer the questions whatever the doctor asks.

Despite the fact that Diya's experiences have improved over the last six years as she came to terms with her diagnosis, she still feels the shame and embarrassment caused by the low standard of care she received. In her opinion, doctors are among those best placed to understand the condition and therefore should offer the best treatment and care to their patients, rather than continuing to stereotype and stigmatise those who are already suffering.

Mainly it happened in the hospital only and doctors are to be blamed. You are talking about awareness - firstly provide awareness to the doctors. Firstly, let those people get the awareness. Some of them will have the desire to have a baby. For such people they can caringly handle them. They don't have to touch us or do anything to us but if they talk nicely that is sufficient. By touching the disease is not going to spread that is what you tell. By touching the disease will not spread. By hugging the disease will not spread. By kissing also the disease will not spread. We are not asking you to do all these things. They can just touch us and provide us treatment. They had put the stitches to me, but they were not even ready to touch that and see. Then what for are you a doctor. You can remain as a common man. If we have problem, then only we will go to a doctor. I didn't know that I was infected with HIV and I didn't know how I got that disease also. After they told only I came to know mostly my husband must have gone outside, so through him I must have got the disease. Then you should only take care of us because you are aware of all this information like it will not spread through these ways and it will spread only through these ways. You are aware of all these information. Then if you give us some support what is wrong about it? That is my question.

For Shruti, 38, her first experiences of the healthcare system while HIV-positive were as a result of her husband's declining health. She and her mother-in-law had taken him to their local hospital as he was experiencing paralysis along one side of his body. They were already extremely upset and concerned as he had experienced such a rapid onset of symptoms. However, instead of

finding answers and treatment, they found only confusion as they were sent from one hospital to the next. At each turn, they found increasing stigma and felt that the doctors were simply dismissing him rather than actively seeking out a treatment for his condition.

Once they came to know about the result they took my husband and put him in a corner. I had gone home with my child to collect some lunch for him. When I came to know that he was positive I was very disheartened, so I went home. My mother-in-law was in the hospital. By the time I could come back from home bringing his clothes and lunch they had shifted him to a ward that was in the corner. They asked us to immediately take him to another hospital. I was very upset. A counsellor there suggested that we first take him to a special clinic so immediately we took him there. When we took him there and they saw him, they said he is in critical condition so immediately we must take him to the hospital instead. They said, "You have to put admission for him there and get treatment there. Here, we are providing service for minor emergency problems. That is all." Immediately, we shifted him to the hospital. It was 5:30 in the evening when we reached there. Finally, they put an admission for him in the hospital. Even in that hospital, when they saw him with his limbs paralysed and all they looked at him with disgust. That was their behaviour towards him. In whatever way he would have got that disease… at least they could have showed some courtesy to him. They said, "Your limbs are paralysed and you want to stay in the first bed is it? Go to some other bed in the last."

As Shruti went on to explain, receiving proper care that includes a kind demeanour can make all the difference for patients who are suffering. Although their experience in the first hospital caused a lot of mental anguish for both her and her husband, she is grateful that they finally found a doctor who would care for him.

Yes. During that time, it was quite disheartening for me. Afterwards from that ward he was shifted to another ward. We went to a different ward. I was feeling very bad and I thought why people are like this. After that, a new doctor saw him. He was a very nice man. In that ward, he used to follow the patient regularly and he treated him well. If my husband has recovered so much, it is all because of him only.

Many of my participants found that medical staff members within other institutions or hospitals were extremely hesitant to interact directly with them or with their test kits. For example, Riya, 33, felt she was being singled out by laboratory staff when they refused to take her blood sample from her and instead suggested that she leave it at the door. Although she understood their

concerns, it was still deeply embarrassing as other patients could see that she was being treated differently.

> *I am getting tablets from a children hospital for my son. Earlier I was getting here only in the Clinic but now they have changed it and they said we have to collect the medicine from children hospital only for children. When I went there they asked us to get blood test done to find out about the CD4 count and they asked us to go down to a ward to get the testing done. When I went to that ward they didn't even touch that blood sample. They said just leave it there and go. That was a little bit hurting to me. They were taking the blood samples from others, but when they came to know that I had come from HIV ward they did not touch the blood sample. They said you just keep it there and we will take it later on. That was a bit disheartening, but in the Clinic it is not like that. They will treat us like friends. They will draw blood. When comparing both the Clinic is good.*

Aarohi's status was discovered after she had two difficult pregnancies, which left her with a series of strange symptoms. For example, she struggled to walk after her second pregnancy and found she was constantly feeling ill. Despite her symptoms, she was not offered an HIV test until she was five months into her third pregnancy. She had gone to a new hospital because her husband could no longer provide her with the funds to continue attending the private institute where she had gone for her previous deliveries. The new hospital was smaller and run by the government. When she went for her tests, they asked her to call her husband so that he could also receive testing. When their results arrived, they both had to endure pointed personal questions regarding potential extramarital activities before they were allowed to leave. After returning home, Aarohi was still shaken by the comments made by the staff members that, had she been diagnosed earlier, she should have considered an abortion.

> *During that time, I became very sick and I was not in a position to get up and walk. I was going to a private clinic for check-up and there they didn't ask me to do HIV testing. After my second delivery, I was not able to walk at all. I was very weak and I was staying at my mother's place only. My mother took care of me. After that I recovered and I was fine. When I got conceived for the third time, my husband was not giving me money as he used to give to me earlier so I went to the government hospital for check-up. That too, I went to the hospital during fifth month of my pregnancy. They said if I had gone earlier then they would have aborted the baby, but now since the baby was five months old they could not abort the baby.*

Despite her initial misgivings about the attitudes of the hospital staff members, Aarohi felt she had no other choice but to return to the same hospital when she was in labour with her child. However, the stigma continued to cause problems for her with some staff as she remained in the ward to recover from the caesarean delivery.

> *Nobody isolated me or did like that, but during my delivery time I had some problem. They didn't take care of me nicely. Doctor was not a problem. They had allotted a doctor for me and there was no problem with that doctor. Suppose if that doctor was sick and he was not in a position to come to the hospital then instead of him another doctor used to come and that doctor used to show faces and look at me disgustingly. He was like that. For a few days, I was taking treatment from him. What else to do? I had to tolerate all those things. Patients in other beds in my ward they used to ask me why is that they keep taking blood sample so frequently for testing. I lied to them telling that I had got sugar problem. What else could I tell? I didn't disclose to anybody in the hospital. Ayahs and all, oh my god, the way they used to see me it used to be so ruthless. They were aware of it. In the case sheet they would have written in detail about the patient. In every ward they will enquire and come like who is taking ART? They will come there and they will ask, "Who is taking ART?"*

> *They will tell the name and they will enquire. Suppose if ten beds are there in that ward then I will raise my hand and I will tell it is me. They will come and they will give me injection. Sometimes, they will not tell anything. They will just come and they will give injection and they will go off immediately. Some of them will look somewhat at us. I used to think I have come off here for treatment. I have to endure everything finish my treatment and go. I used to not make a big issue of it.*

> *They removed my male child by doing caesarean to me. I was not in a position to get up and walk and all. I was in the bed only. During that time, they made me suffer a lot. They used to tell, "You should have remained good. You have gone out and done mistake and all and now you come and torture us." They used to scold me like that. I said, "Whether I have done mistake or not then only my conscious knows about it, so don't talk disgracefully about me." They said, "Why is it that you get so much of anger." They scolded me like this and that.*

Aarohi 's concerns about her care continued when her son became ill a few months later. She worries now that his HIV status directly influenced the treatment he received while in the hospital.

> *When my son was down with loose motion and when we took him and admitted him in the hospital they did not take care of him properly. Yes, they didn't take care of my son*

properly. Eight days he was in the hospital and then he died. The doctor said, "Console yourself, it is good that your son died since he was HIV-positive." What else can I do.

Priya, 31, shared Aarohi's concerns regarding insufficient care as she had experienced similar difficulties while trying to secure treatment for her husband. Although he had been admitted to one of the local hospitals, there was only a general ward and therefore he was surrounded by non-HIV patients. She began to hear from these patients that her husband was in constant pain and not receiving assistance.

No. People from other wards also used to come and ask me, "What happened ma? We can hear his voice in that end. We can hear his voice near that gate and near this gate." The vendors outside the hospital they used to tell me. My husband used to shout so loudly. They used to scold him but what to do. I used to tell, "Don't shout, please." Some of them used to tell he is crying out in pain. Some of them used to tell we didn't get sleep at all. That man was shouting in his bed throughout the night. They used to talk like that and all.

When his condition worsened, the doctors suggested that he start ART medications. However, they insisted that he would need to change hospitals in order to receive this treatment, despite the fact that his original hospital was advertised as being able to care for HIV/AIDS patients.

He became very sick and then in 2005 they decided to start him on ART. Due to some problem they said they will not give him ART in that hospital. We enquired whether they will give ART in another government hospital and they agreed to give ART. Then we moved him to this new hospital. They gave ART for fifteen days and he was supposed to be in the bed there only. He was in the bed for fifteen days. Even during that time, he used to shout "Headache…Headache…." He used to shout very loudly. The doctor who was on the night duty called me and said, "Your husband will die. He is in a very critical condition. You do one thing take him away and go off, because if he dies here then we will only burn him off and we will not give his body to you."

Priya was shocked that a medical professional was advising her to take her husband out of the hospital when he needed treatment so badly and that she was being threatened with not being able to remove his body if he were to pass away. Uncertain of her options, she turned to her husband's younger brother for help, even though he was not aware of their HIV statuses.

I didn't know what to do and I didn't have anybody for support also. I didn't know anything about it. My brother-in-law helped me. My husband's last brother, he helped me. He is in Chennai only. I took him only for my support and I told him whatever the doctor told me. He said, "You are staying in a rented house and if you take your husband to the house, you will have problem. Your husband is shouting so badly. In rented house and all we cannot take him and keep him there. They will scold you. Whatever happens let it happen, we will keep him here in the hospital only and we will take care of him." I agreed and I said okay. When he was shouting like that the doctor who was going to attend patients in the upstairs ward came down to see him. He asked what problem was he having and then he wrote an injection for him. In that night, my brother-in-law took that prescription and went on his bicycle in search of that injection. He has searched in all the local hospitals but he has not found that injection. Then finally in one medical shop he has got the injection and he brought it to the hospital. The pharmacist has come to know that this injection is for HIV patient, but my brother-in-law was not aware of it. He is uneducated. He didn't know that my husband was suffering with this disease and even I had not told him about this. My brother-in-law has thought instead of buying one injection let me buy two injections since his brother was suffering with headache. He has asked the pharmacist to give another injection but that person has scolded him and he has sent him away. Even during that time, he has not understood why the pharmacist was behaving like that. Then he brought the injection and gave it to the doctor. The doctor gave that injection to my husband and only after putting that injection my husband slept nicely. Then in the morning, doctors came and they did check-up for him. After that he recovered.

Priya's experience demonstrates the difficulties HIV-positive individuals can face at the different levels within the health system. Despite her husband being admitted to a hospital ward, her brother-in-law still had to search the city for the recommended treatment and was only able to obtain it from a small shop, wherein he faced further stigma due to the nature of the treatment. This episode demonstrates the hidden nature of some of the issues individuals face. For example, it is widely reported that HIV medications are provided at government run hospitals and therefore individuals should be able to procure these prescriptions. However, as Priya found, this is not always the case and it is up to individuals to find the resources to help themselves. This experience highlights part of the process for redefining healthcare as individuals shift their expectations of care.

For Saanvi, 35, her experience was directly related to the belief of some health professionals that a mother-in-law should informed immediately about issues concerning her

daughter-in-law. As many staff members in the Clinic explained, this was a tradition among many health facilities with some going so far as to disclose to the mother-in-law before their own patient. However, this practice was abandoned when the Clinic was founded as staff realised that this was creating an environment of blame rather than care, which ultimately caused increased discrimination for the women involved. However, despite the concerns within the Clinic, this process is still found within many of the facilities within Chennai. Saanvi found that her wishes were ignored and she was looked on with suspicion when she tried to avoid this disclosure.

> *They said you are infected with AIDS. They asked me, "Did you do any mistake or did you go somewhere?" The doctor asked me like that. I told no. There is nothing like that. Then they asked me who had accompanied me. I said my mother-in-law had come along with me. They asked me to call her. I said, "Don't tell to her. She is aged and she will not be able to withstand it." They did not listen to me. They said, "Are you trying to hide it?"*

> *Then I got my mother-in-law and he spoke with her. My mother-in-law started crying and she told why did it happen like this? She said, "My son did not have this disease and he has got it after marriage only." She told it in such a way that I was responsible for the disease since he got the disease after one year of our marriage. I just remained silent. My mother-in-law spoke like that but in return I didn't tell anything. In my house, they didn't know that I was infected with HIV. When they came to know, my mother and my sisters and all said after marriage only you have become like this so just leave him and come off. I said, "I am married. What to do? Now that even I am also infected with it and my husband is also infected, so both of us will live together for some more time."*

Additionally, Priya found that she experienced similar dismissal by the medical staff as that found by Shruti and Diya earlier. After discovering her husband's status, the doctor who had been treating him immediately withdrew his care and demanded that they leave his facility.

> *When I went and gave the result to the doctor in that hospital, that doctor sent my husband away from that ward. He sent away my husband because he was infected with HIV. After he saw the result what that doctor did was he sent my husband away from that ward. Yes. He told us go away. He didn't tell us where to go and what to do and all. He said your husband is discharged, go anywhere and get treatment for him. In that hospital, there was a ward boy and he came and he told us, "Go off to a bigger hospital and there they will give good treatment to your husband." From there I took him to the closest hospital and I got him admitted there. I admitted him in there and after that for two years he was alive and then he passed away.*

The tendency for patients to feel powerless within interactions with medical staff results is one of the main reasons participants gave for their refusal to speak out against the stigma when they were experiencing it. As Saanvi explained, the doctor was seen as the only hope for treatment and therefore, even if they were being treated poorly, it was better than receiving no treatment at all.

Earlier, I used to not talk like this and all. If I was like this earlier then I would have nicely given back to that doctor. During that time, I was very scared. I thought if I spoke against them then they might not provide me treatment and all, so I spoke within limits only.

Pari, 37, also felt powerless to stop the impersonal questions and unprofessional behaviour of one of the doctors. Her experience of the drastic shift in treatment from the moment the staff came to know about her HIV status was bewildering enough on its own and then compounded by the ill treatment received from the doctor assigned to them.

For seven days, they treated nicely only. The day they came to know the status, they discharged us and they sent us off. There nobody gave us counselling and all. We went and directly met the doctor. He came and he started scolding. He asked, "Have you got married? Was it a love or an arranged marriage? Did you elope with anyone? Was it a forced marriage?" The doctor asked me these questions. I said, "No sir, mine was an arranged marriage, arranged by the elders. I am from a village. My place is here and his place is there. It was an arranged marriage fixed by elders only." When a person is infected with that disease their face and their health look different and during that time I was looking very young. When someone sees them during that stage they feel that there is no match between him and me. So, the doctor was asking me, "In your house did they force you for this marriage. Did they force you and tell to marry this person only or were you in love with this person? Did you do love marriage and run away with him?" He asked me like that and all. I said, "There is nothing like that. In my village, everyone saw him and then only they got me married to him." He spoke only that and he didn't speak anything else.

Like Pari, Prisha, 34, also found that the treatment medical professionals offered her after they came to know that she was HIV-positive was extremely hurtful and frightening. Although neither woman has had medical training, they could easily see that their treatment was not conforming to the standards usually expected in these facilities.

In government hospital, they said you will not get the disease but if their blood comes in contact with you then you will get the disease. In the beginning itself my mother got scared because she is older and she cannot understand. They explained the condition to her but she still did not understand. In our village, my family is given a lot of respect, but in the hospital they took my baby with one hand and they just handled the baby carelessly. They took my baby with just two fingers like this… They lifted my baby's hand with two fingers. My mother only saw that and she was only scolding them. That too they have used their left hand two fingers to lift the baby and see if the child was breathing or not when it was kept in the incubator. Even after wearing gloves they have lifted the baby like that. My mother came to me and she cried. She said, "Why are they doing like that and why is that they are treating the baby so carelessly. After providing treatment for everyone lastly they will come to you and give you treatment, injection and tablets and all. They touch your baby with only two fingers. What kind of a disease are you infected with? In our village, we isolated Dalits like that and treat them like that. Likewise, they are treating you here." My mother was very sad with the treatment provided to us here. After I went back to my village I told my mother in detail and made her understand about it.

As Akshara, 34, explained, the issues of stigma are often worse within private hospitals where the government protocols of care of not as strictly adhered to. She found that the staff members were nervous about touching HIV patients even when universal precautions, such as wearing appropriate protection like gloves and masks, were observed:

Yes, they have isolated me. In private hospital. If you go to private hospital and if you tell them your status, then they will not treat you at all. First they scolded me. They will not come and treat us first. First they will attend to normal deliveries and then treat normal patients and give them medicines and injection. In the same ward, everyone will be there. The doctor will attend all the other patients and finally they will come and attend us. While removing the stitches they will remove the stitches of all the normal patients first and then they will send them home and, lastly, they will come to people like me and remove the stitches and then send us home. They will wear gloves while attending them and while attending us, but they will provide treatment to those people only first. While removing the stitches for the patient who have undergone operation first they will remove the stitches of normal patients and lastly they will call us and remove the stitches. They will talk about us behind our backs, but in front of us they will not do anything. The doctors will come and they will ask how are you and all. They will wear gloves and come and they will just touch the wound and see and write prescription and give us and go off. Doctors will not do anything. Only certain nurses will do like that.

If they have to remove the stitches they will remove it with the help of forceps. Even though they are wearing gloves they will not use hands to remove the stitches. They will use forceps only to remove the stitch. For one woman, her skin was very thick so the nurse was above to use her hands to remove it. Suddenly, another sister said don't use your hands. That nurse opened the file and saw and in the file they would have mentioned about

our disease. Then that nurse said okay and she didn't use her hands. Then the nurse who was wearing the gloves she came and she removed the stitch and send the patient. They will use forceps only to clean the blood with cotton and then send them. After that incident, I don't go to government hospital at all.

The impersonal treatment experienced by participants like Akshara, as medical staff refused to touch them without the aid of unnecessary utensils, has a deep impact on the desire to attend medical facilities in the future. The next section examines the influence of these experiences and the resulting disenfranchisement within participant narratives.

Disenfranchisement with the Medical System

These early experiences of stigma continued to colour participants' interactions with the medical system and therefore many found themselves shying away from accessing treatment out of fear of further stigmatisation or discrimination. As a result, stigma is able to have a lasting impact on these participants through the disturbance of the social trust found in medical interactions. Lucy Gilson (2003) has identified relationship and behaviour problems as the most critical challenges within health systems (Gilson, 2003: 1453). The relationship found between patients and doctors can be viewed as informing a major part of the social capital of health. Social capital has been defined as "those features of social structures (such as trust, norms, and sanctions), appropriable social institutions, and information channels that facilitate collective action" (Subrumanian, Kim, and Kawachi, 2002: S23). Both this definition and Gilson's indicate the "inherently relational" nature of healthcare as the behaviours and attitudes of both the medical staff and the patients informs the overall picture of social capital (Gilson, 2003: 1453). Within the illness experiences shared by participants, this social capital is best viewed through the changing levels of social trust felt towards their interactions with medical staff. Gilson has furthered this discussion through her examination of the levels of mistrust found within vulnerable populations and in particular, those with serious health concerns. For example, political scientists have found a direct

correlation between levels of mistrust and major illnesses, such as heart disease and cancer (Gilson, 2003: S22). Although the patients facing those conditions have different reasons for their lowered levels of trust, within HIV/AIDS the reasons for mistrust are clear as participants are forced to reassess their concept of healthcare and their position within it. It is through this alteration and approach to health that the legacy of the initial, stigma-fuelled diagnostic incidents can be fully understood.

For Diya, the remnants of the initial stigma she faced while in the hospital extended into her admission when she delivered her son a few months later. Her HIV status meant that the risk of infection for her son was extremely high and therefore it was decided that she should have a caesarean procedure. However, she felt that she had not been consulted properly regarding her choices and then, in the aftermath of the surgery, the staff members were giving her a wide berth while she remained on the ward.

> *Yes, they were aware. In the hospital they gave all the reports and all. I gave all those reports in there and they saw everything and they arranged for operation (Caesarean) the next day. I had the possibilities of a normal delivery but they denied normal delivery. They said through normal delivery the baby will have chances of getting the infection due to blood contact and all, so they advised for a Caesarean operation and denied normal delivery. They performed operation for me and then they administered medicine for my baby. After that doctors were hesitant to remove my stitches. They denied touching my stitches. I cried a lot. I was in agony. I felt what life was all about. After that I never went to that hospital. Only for getting vaccination to my son I used to go there but even for that I had to carry the book along with me. And in the book details about my disease was there. I used to be scared to take that book and go for vaccination for my son. I used to be scared if they could talk something bad about my son, so I used to think twice about taking that book along with me to the hospital, but until four to five years I provided all vaccination to my son. I used to go and get the vaccination for my son and I used to come off. I used to feel it is all right that I have to accept the disgrace for the sake of my son, but my son is negative of that disease.*

Diya continues to view medical centres with distrust as a result of her initial impressions of the judgments placed on her by the hospital staff. She felt she were being viewed as less than a person, who did not need to be given the same considerations as everyone else on the ward.

Although she continues to seek out the appropriate treatment for her son as he gets older, she explained that she does not do so for her own health. This mentality was common among participants, who avoided healthcare facilities aside from receiving their medication and check-ups relating to their HIV status. As Aarohi explained, there was a distinct difference between specialised clinics and the general care facilities available within the city.

> *Yes. Sisters[28] and all were not aware of it. He gave me a form and asked me immediately to go there. Nurses asked me, "After getting enrolled for check-up here why is it that you are going to that hospital." I said, "Here the facilities are not sufficient, so I will go there and I will continue my check-up there." I didn't disclose about my HIV status. Nurses asked me why I wanted to go to that hospital after getting enrolled here for check-up. I said facilities are not sufficient here, so I want to go to that hospital. I have people there whom I know. I gave reason like that and I got shifted my check-up card from there to here. Initially, when I came to this hospital I felt somewhat… I was scared.*

> *In ART centre, nobody has scolded me. For ART itself there is a separate centre in the hospital. In that centre nobody will scold and all. How do I tell you, for delivery and all we have to be in the same ward with others and in that ward they will be problems, because when they did Caesarean to me they changed everything there. All instruments were changed. During that time, they scolded me, "For this patient look we have so much of work to do?" They didn't treat me properly. When they asked the ayah to keep pad for me she said she will not do it. After the operation was done I was not in a position to get up and change my pad. My mother was there along with me. My mother was not aware of these things. I didn't want to tell her and I hid it from my mother. That ayah was scolding me very badly. She was telling, "Why should I change her pad. I will not touch also." She was telling like that and all. My mother only did everything for me.*

Saanvi echoed Diya's sentiments within her narrative of the treatment she received post-diagnostically in the local hospitals. While she did not face direct stigma, she instead found that being able to see the doctor became increasingly difficult. This gave her the impression that HIV patients were being treated as less important than those in the rest of the hospital, who could expect prompt and courteous care.

> *I was not getting proper sleep. No, I didn't tell the doctor because there is no one to tell. I was scared, since I am changing the medicine and I am taking often. I have pain here and*

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[28] "Sisters", like "Ayahs", is a colloquial term used for nurses by many of the participants of this research. These terms were often used interchangeably during discussions and interviews.

all and I am very scared. What to do? Doctor will not be there when I go. Doctor will not be there in government hospital. For the past three months I am going but doctor is not there for all the three months. I will carry my baby and I will go and come.

In explaining their situations, Saanvi, Aarohi and Diya focused on their care after diagnosis as evidence of their lower status within the minds of the medical staff. However, as Siya demonstrated, her position as a housewife meant that her symptoms were missed despite several hospital visits. Within the illness experience of HIV, a late diagnosis can cause a plethora of consequences for the individual as they struggle to maintain their health and ability to continue their day-to-day activities. Siya felt that her doctors should have used their knowledge about health to find the cause of her suffering earlier, as she herself was unaware of the condition and her potential risk of infection.

I didn't know I had this disease. I used to go to big hospitals. Initially, we were going to small hospitals nearby our house and we used to think these doctors are not good enough and we changed ten to fifteen hospitals. Then we went to big level hospitals and got admitted there. The only things that happened was we lost all our money that is all. I didn't do testing and all. They used to give injections for fever and medicines for cold. I used to take those medicines and come home. For two days it used to be all right and then once again I used to get it back. It was like this only and then later on I started having loose motion and I became lean losing weight. I didn't know the reason why it was happening like this. The doctors didn't ask me to do this test and even I didn't know that I should do this test. I was not aware that I would be infected with this disease. When things were like this finally I got piles problem. I used to find it very difficult to go to toilet.

Two other participants, Pari, 37, and Prisha, 34, further echoed these sentiments. They too had faced late diagnosis and felt that their doctors had not had their best interests in mind despite many warning signs regarding their health. When Pari and her husband married in 1999, her husband's health was already in decline. Over the next two years, he experienced multiple bouts of tuberculosis and was prescribed the appropriate medications. However, his drinking and smoking caused his doctors to dismiss his treatment as a waste of time because his smoking was causing the medicines to be less effective than they should be. Pari felt that while her husband was

being looked down upon, she too was being ignored as a diagnosis for him would have meant

testing for her as well. Although the doctors felt pity for her as the young wife of this patient, they

did not seek out alternative reasons for his ill health until he suffered with tuberculosis for a third

time.

> *My husband used to smoke and drink. He used to not do it regularly. He used to do it rarely, but smoking he used to do regularly. Drinking he used to do rarely like when he used to meet his friends or during functions at his work place. He used to smoke anytime during 24 hours. Due to that he had second attack of TB. He took TB medicines again, so two times he took TB medicine. Once again he got an attack and he had to take TB medicine for the third time.*

> *He finished taking for the second time. When he went for the third time the doctor there said it was a waste providing him treatment. They said there are so many people who are not in a position to avail medicine and here for one person how many times should we give medicine for TB. Then they saw me and they had sympathy for me and they felt this woman is so young and so they gave medicine for my husband. Even I was begging the doctor to give medicine for my husband and I thought if they give medicine that was sufficient for me. Then the doctor told me for your sake I will give your husband medicine. In that hospital, it is because the doctors have sympathy for the women they are providing treatment for their husbands. They feel all these women are young and because these men folk do mistake these women are suffering so much sleeping on the floor and taking care of them. The doctor scolded my husband and again he gave medicine to my husband for the third time. During that time, I was not aware about the network or places like this or organisations. We used to go to the hospital, stand in the queue and collect medicine, give the notebook to them and then go off. In the village and all we had not told anybody about this. Earlier, he was taking treatment in a different hospital. Before we came to know that he was infected with HIV he was taking treatment there. I thought whatever disease it is then it is okay. We will spend money and get cured of the disease. The third time he had TB attack, he was under admission for ten days and they used to do testing and they used to provide treatment according to that. Then finally they said there is an option we will do HIV testing and see, so they did HIV testing for him and they said he was HIV-positive.*

In India, tuberculosis is the most common condition among HIV-positive individuals and

the two conditions have been identified as "converging dual epidemics" within the global medical

community (Swaminathan and Nagendran, 2008: 527). As a result, Pari felt that her husband

should have been tested for HIV earlier as it may have led to better treatments and preventative

options. The belief that doctors had missed signs and delayed diagnoses was common among

participants and had a direct impact on their mistrust of medical staff. Alongside this perceived ignorance of the condition on the part of doctors, there was another issue alluded to previously by Saanvi. This involved the lack of care experienced by many HIV-positive individuals as they found themselves ignored by the medical staff altogether. Prisha, a thirty-four-year-old married mother of one, experienced this through her husband's poor treatment.

> I*n 2007 only he became very sick and he was in the bed. During that time, a person from our community… he came and he said come along with me and I will take you. My husband said he would never come. He said, "I will not come." That person said, "You are very sick, so come along with me." He took my husband's hand and forcibly he took him to the hospital. He made him sit in the hospital from 9 o'clock in the morning to 12 o'clock in the chair. He was sitting in the same position in the chair, but the doctor didn't come. The doctor was there inside but he kept telling he is in a meeting with the sisters. They could have had meeting in the afternoon. The working hours in the hospital is between 9 o'clock to 12 o'clock and they had fixed the meeting during that time. Then how will they attend the patients. After that incident my husband stopped going to the hospital. He sat till 12 o'clock and then he said that was enough and came back home. Then he scolded me telling that is the reason I said I will not go to hospital and all. You kept asking me to go to the hospital and see now. He was shouting at me badly. Then he went and laid down in the bed. After that he never went to the hospital. Like that if the patient changes their mind and if they go to the hospital thinking of taking treatment there are no proper services.*

In Prisha's experience, she felt that the actions of the medical staff contributed to her vulnerability as a young woman because they failed to acknowledge her wishes regarding her health and the difficulties she was experiencing. This was particularly true within the arena of reproductive health, which is a common problem for Indian women because they are unable to seek out treatment without their husbands' approval.

> *When I had the baby, before my husband could come there they removed the baby by doing operation since it was serious. In case if he had come then they would have done family planning operation for me. He was not able to come during that time. It took fifteen minutes for him to come. By that time, the case was becoming critical so my mother told the doctors to proceed with operation. The doctors did operation and removed the baby and they were not able to do family planning operation. I have not done family planning operation yet. So, what I used to do was I used to take contraceptive pills. I decided even if he wears condom or he doesn't wear condom I don't want another baby, so I was taking those pills. Now, they have stopped dispensing contraceptive pills in the government hospital. In government hospital they used to give Mala-D contraceptive pills. Now, they*

have stopped dispensing it. Now, I am purchasing it from the medical shop and I am taking it. Sometimes he will wear cover and sometimes he will not wear cover[29]. If he drinks and comes home, he will not listen to my words. He will fight if I ask him to wear condom, so I used to leave him off according to his wish. During that time, I used to take contraceptive pills. Like that I am running my life without having any children.

Due to these changes within the protocols at her local hospital, Prisha felt that her ability to make these decisions was being hampered by the medical staff. This caused her mistrust in them to grow as she felt they were acting without her best interests and, indeed, making it extremely difficult for her to make her own health decisions. At this early point in the liminal state she was experiencing, she felt she had very few options. Fortunately, she had a friend who revealed her own HIV status and helped her to come to accept her condition.

I was very disheartened. I went to the level of committing suicide. I had one friend and then I came to know that even she was also infected with HIV. Her husband is no more. She gave me comfort and made me mentally strong. She said even if you know that you are infected with HIV for your son's sake you should be alive and she told me not to disclose my status to anybody

Kalpana, a forty-six-year-old widowed mother of one, agreed with Prisha's sentiments and found that she too was being side-lined by her doctors as they discussed her health without her. When her husband was diagnosed, Kalpana was found to be negative for the virus. However, instead of clarifying the methods of avoiding infection with her, the doctors discussed her situation directly with her husband. This meant that her health was entirely in his hands while she was left in the dark.

He told that it was for TB and they drew blood from me. During that time, I didn't know even for TB they will do blood test, but now only I know for TB what testing and all will be done. I gave blood test and I came off and they have done HIV testing but I was found to be negative. I had not become positive. No, they didn't tell me anything. Even during that time, they have called my husband and they have told him, "You are positive and your wife is negative, so we have to tell the truth to her." My husband has said they should not tell anything. During that time, they have told him about safe sex practice and all and they have asked him to adhere to it. They have also said your wife might be in the window

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29 "Cover" is a common term for condoms.

period or we don't know exactly what to tell. After six months again we will do testing for her and see, but until that time you have to be careful. They have advised him like that and all, but he did not do according to that and all. He didn't practice safe sex at all. He didn't use condom at all.

During that time, I didn't have a child at all. After marriage till 1993 I didn't have a child at all. In 1993 only I got conceived. My husband had recovered and he was well and he was healthy. He started going to work. After that only, I got conceived. But every six months they used to ask me to come for testing and they used to keep doing testing for me. They never told me why they were doing testing and all for me. They didn't tell me anything. They used to draw blood and then give me another date to come and they used to send me off. Like this only, it kept happening from 1990 to 1993. It happened like this for three years. Like this every six months they used to post a letter to my house telling on this date you have to come for testing. After six months once again I used to go.

Therefore, for three years, Kalpana continued to be unaware of the risks her husband's condition posed to her own health. The lack of information meant that she was equally unaware of the fact that he had ignored medical advice regarding safer sex practices, which had meant she was regularly exposed to the virus. When she became pregnant, although the doctors had serious concerns, again she was asked to wait outside while her health was discussed with her husband.

For three years I went regularly six months once to the hospital and gave blood for testing. After that when they asked me to come the next sixth month I had got conceived. During that time, I went. They used to take x-ray for me. I told them, "Madam, it is all right to take x-ray now since I am pregnant." They doctor asked me, "Are you pregnant?" And she started looking at the other doctor with confusion and then she asked me to wait outside for some time and send your husband inside. I said my husband to go in as the doctor had asked him to come in. He went inside and I don't know what they discussed inside. I don't know anything. After that I came off. During my seventh to eighth month I went off to my mother's place. I was visiting a private doctor only, so I had not gone to government hospital at all. When I went to government hospital they didn't do HIV testing for me and they didn't do anything. I went to my mother's place and I came back. Again in the ninth month only I went back to my place and there was only one week.

When she was finally made aware of her status, Kalpana was shocked that the medical staff would have assisted her husband in keeping this information from her. The trust placed in the healthcare system involves the belief that doctors and nurses are acting to improve health for their patients and when these actions are questioned, the individual feels they have been deeply

betrayed. Kalpana tried to address her concerns with the doctors who had created this situation but found that they were unwilling to accept blame. Instead, her concerns and anger were dismissed as the doctors insisted that she focus on her treatment instead.

> *I have studied until the tenth standard. I was born and brought up in a village. They used to never send me anywhere outside. After I attained age, they stopped sending me to school and they didn't allow me to go and do further studies. I was like this and I suffered so much and after that I came and joined here and after joining here and taking counselling from them I got confidence in my life that even I can achieve something in my life. After my husband died only, I went to TRC and I asked them, "All these days, my husband was taking treatment here and you never told that he was infected with HIV. After that only they told all the stories to me." How he got TB attack and he was found HIV-positive and how they found that even I was positive and my husband telling them not to disclose anything. "Without his permission we cannot tell anything, so we didn't tell you. We cannot accept that it was our fault or your fault." They spoke in their terms only. My brother only came along with me and he only scolded them, "When you knew he was positive and if you had told his wife then you could have saved her life. It is fault on your side for not disclosing the status." The doctor said, "Okay, forget it. There is no point in arguing now. She also needs treatment." During that time, no treatment was available outside. Only TRC used to provide treatment. They gave me multivitamin tablets. During that time only I asked the doctor, "How long will I be alive?" We got married in the last of 1989 and he passed away in 1996. He was alive only for six years. Now tell me how many years will I be alive?*

As indicated by these participants, the feelings of betrayal and disenfranchisement that originate through the stigma experienced within the medical system have a direct impact on their understanding of healthcare and their position within it. The mental wounds of alienation are carried forward and colour all future interactions with medical staff as participants reported increased fear and tension or avoidance. These initial experiences can be understood as forming an added layer that encourages the creation of mental barriers that mark the beginning of the liminal state for these participants. Therefore, as part of the liminal period, their definition of healthcare needs to be altered in order to compensate for their HIV diagnosis.

The following chapter explores the impact involvement with the Clinic and positive networks of support have influenced the way participants define their concept of community. In

particular, the ability of the Clinic staff members to take on roles traditionally reserved for close family members is explored in order to understand how this form of support differs from that of more traditional community members.

Chapter Five:

Familial Comforts: Redefining the Concept of Community

"The concept of community was closely tied in classical sociological literature to the idea of a spatially bound, face-to-face sphere of human relationships based upon an innate moral order. We saw in the last section that the community institutes itself in the modern world not as a face-to-face sphere of human relations, but as an imagined community demanding allegiance from people who have no concrete relations with each other. It does this by creating images of communion and oneness"

- Veena Das, Anthropologist[30]

"Like no other illness, AIDS tests our ability to put ourselves in someone else's shoes – to empathize with the plight of our fellow man. While most would agree that the AIDS orphan or the transfusion victim or the wronged wife contracted the disease through no fault of their own, it has too often been easy for some to point to the unfaithful husband or the promiscuous youth or the gay man and say, 'This is your fault. You have sinned.' I don't think that's the satisfactory response."

- Barack Obama, President of the United States[31]

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[30] Das, Veena. 1996. *Critical Events: An Anthropological Perspective on Contemporary India*. Oxford: Oxford University Press.
[31] Obama, Barack. 2006. "World AIDS Day Speech, 2006" *Global Summit on AIDS – Dec 1, 2006*. [Internet] Published Dec 1, 2006. *.*

Upon entering the research wing of the Clinic, the first person one will encounter will be Anni, who has been the main receptionist for nearly a decade. From her desk perched at the entrance of the second floor, she can often be found welcoming visitors with her trademark smile and kind nature. After several months of witnessing first-hand her cheerful and approachable demeanour, I was not surprised to discover that she often has dealings with the Clinic's patients as well. However, what came as a shock was the title of her role in that arena: matchmaker. When I asked if I could interview her about her interactions with individuals through this position, she quickly ushered me into the conference room to begin our discussion. Sitting with her, I was not entirely sure where to start as the idea of a matchmaker who catered exclusively to HIV-positive individuals was not something that had previously come up in any of my dealings with staff members or patients. Fortunately, she was very willing to share the details of a topic she clearly felt passionately about. To begin, she told me about one of her first couples: Dhruv and Nandini.

A Clinic Matchmaker

While living in New Delhi in 2005, Dhruv was worried. The pressure from his family to marry and settle down had been building since his early twenties. Now at age thirty-five, he was running out of ways to keep them at bay. As an only child, his parents and extended family, including his aunts, uncles and grandparents, were all waiting for him to take that step. Although this situation was not unusual in India, Dhruv had a bigger problem. Even though he had disclosed his HIV-positive status to his parents, the other members of his family were unaware. As a result, Dhruv was very hesitant about dating. He knew that he would ultimately need to disclose his status to any future partners and as a result, he had avoided dating altogether. Fortunately, Dhruv came across a possible solution. Through the media, Dhruv heard about a Chennai organisation that

offered a matchmaking service alongside their HIV-related treatment and care. Filled with hope, he immediately emailed his details, including a photograph, to the Clinic and waited for a response.

Meanwhile, in Chennai, Nandini had been experiencing an opposite problem than that of Dhruv. She had been attending the Clinic since her diagnosis in 1997, and had witnessed the consequences of HIV diagnosis first-hand through the deaths of her husband and only child. While caring for her child, Nandini had resisted the advice of the Clinic's counsellors as they tried to convince her of the benefits of remarrying. Their fear was that, as her siblings were living far away, she would not have proper support if she were to become ill herself. However, she was insistent that her first priority was to care for her child. Several years after her child's death, she found herself alone and began to change her mind about marriage. Unlike Dhruv's experience, Nandini's family was not supportive of her desire to remarry as they preferred that she stay single in order to focus on caring for their elderly parents. Deciding to move forward with the marriage despite their concerns, Nandini began to discuss the options with her counsellors. When she heard about the matchmaking service, she asked the counsellors to share her details and photos with potential partners. One of the matches they found for her through their system was Dhruv.

With the help of the counsellors at the Clinic, Nandini and Dhruv were able to exchange personal resumes and photographs. Soon thereafter, Dhruv travelled from New Delhi to Chennai. When he met Nandini in person, the connection was immediate and he agreed to meet with her family members. It was also agreed that his family would join them in order to meet the potential in-laws. After continuing to exchange messages and phone calls, a month after their initial meeting they agreed to marry. At the time of my interview with Anni, they had been married for seven years and were now the proud parents of two HIV-negative children. Their story was a testament to the benefits of the Clinic's involvement in social and traditional concerns.

Dhruv and Nandini's experience was one of the first marriages arranged through the Clinic and provides an example of the way HIV within India is altering the life decisions of individuals. Within India, marriage and children are integral to cultural expectations regardless of family status or background. While the Western image of the "matchmaking mama" is viewed with amusement, the combined forces of external family members in India is not to be ignored. The decisions relating to whom and when to marry are still considered family choices rather than individual decisions. Through discussions with colleagues and friends of varying ages, it was clear the pressure regarding marriage was an influence across social boundaries. Even among my more international friends, who had studied abroad and travelled extensively, it is still very difficult for them to choose their own partners as family approval is critical to a successful match.

As one of the counsellors in the Clinic explained, the process of matchmaking for their HIV-positive patients follows very specific steps. Initially, interested parties are asked to fill in a wide variety of questions, which range from their name and age to their occupation, family background, date and location of diagnosis, and their preferred language. Also included in this list is their caste, which was the only direct reference found within this fieldwork. This is included as it can assist the matchmaking process as families are often placated if this traditional category is included. Finally, a photograph is included before the file is shared with partner organisations around India in order to try and find a match. If there is interest shown, both parties are given the other's details to see if they will suit. The next steps involve meeting in person with the counsellors present for moral support and to answer any questions they might have. The final step is to introduce the two families, which often includes disclosure of their statues as they explain their meeting. Disclosure in this setting is often better received as the families are able to see that traditional social norms, such as marriage, can continue to be followed despite HIV infection.

The inclusion of HIV status into this matchmaking setting was surprising as disclosure has always been highlighted as one of the biggest issues for patients. However, as Anni went on to explain, this seems to be changing with particular steps being made within the online dating world. In India, there are two major websites that individuals use to find partners: shaadi.com and secondshaadi.com. Shaadi.com, named after the Hindi word for marriage, is designed to help single individuals find first time partners while secondshaadi.com is focused on second marriages. These sites are very similar to those found in the West, such as OKCupid and Match.com, although the clients who use these sites are more focused on getting married than dating. Additionally, in a twist that none of my colleagues or friends in Chennai found at all surprising, it is not uncommon for family members to create profiles for their single sons or daughters in order to find them a match.

As Anni noted and I found to be true when I checked these sites, there is now a space on the profile form where individuals can opt to include their HIV status. Although this was surprising in light of the stigma still present within Indian society, it was less unusual when viewed through the lens of the Clinic interactions. The counsellors often advise single patients about the benefits of marriage, as in the case of Nandini, because they know how crucial direct support within the home can be. This is particularly true in the case of acute illness but is also an important source of companionship for patients at all times. Therefore, these changes to the online forms seem to indicate acceptance on two levels.

On the one hand, individuals are accepting that these online matchmaking sites may offer a better chance of meeting either another HIV-positive individual or someone who is accepting of their condition. Additionally, the online system allows for the maintenance of a degree of privacy as individuals are able to use a pseudonym if they prefer. This allows them to test the waters while

still protecting themselves from potential exposure. On the other hand, the inclusion of HIV as an option for profiles indicates awareness on the part of the sites themselves that HIV is a growing issue within India and is reflected within the pool of unwed individuals.

While the discussion with Anni left me wondering about the emerging market for online HIV-positive profiles and the potential repercussions of such openness, I was also intrigued by the question of community that our interview had highlighted. If the Clinic's staff were stepping forward to take on roles traditionally reserved for family members, what did this indicate about the way the Clinic was being viewed? And if it was acting as a form of community, was this new definition of community supplanting the previously held family-based version within the minds of HIV-positive individuals who visited the Clinic? Or, was this concept of community acting in unison with the rest of society by way of the plural identities that had resulted from the liminal state experienced by participants?

In discussing these questions with staff members, Clinic visitors and interview participants, it became clear that the answer was more complex than merely replacing one community for the other. A main determinant of the necessity for maintaining these separate communal spheres was the negative metanarrative of the condition and the fear of the consequences of disclosure. This had the effect of deepening the self-isolation experienced at the beginning of the liminal state. As individuals reassess their concept of community, they begin to see the benefits of assuming the sick role within the arena of the Clinic, rather than within their traditional environments.

The Sick Role

However, the method used by participants in taking on this social position proved to be the key to understanding their new concept of community. In order to understand why the sick role makes up such a large portion of the redefinition experienced, it is first useful to examine what is

included in this decision. Within the established social system, individuals who are ill can expect a large degree of care from those around them as this forms one of the main components of the social contract within health (Parsons, 1951).

The concept of the sick role revolves around the changing status of individuals who are identified as ill. The new social role is undertaken when illness interrupts the social position of the individual. Within this view, although illness is seen as a deviant state within society, the sufferer can still expect the other members of that society to attend to the prescribed traditions and norms appropriate to their new status.

However, as HIV is itself viewed as the result of deviant behaviour, the illness experience for participants involves only a tenuous link to the traditional sick role. In India, the sick role can be understood as the expectation of family support, such as emotional, financial and physical elements, which are intended to ease the burden on the individual. This can include taking on greater responsibilities and duties within the household or providing additional resources.

The ability to access this social position or, alternatively, the fear and distrust that cause participants to conceal their condition as much as possible, form the basis for a new definition of community. This is due to the desire participants feel for the classic support commonly displayed for those within the sick role. When family members and friends are not trusted to offer this support, participants begin to turn to the Clinic and the community found therein with increasing frequency.

This chapter examines the benefits to participants of accepting the sick role, their reasons for avoiding this exposure and the impact the expectations of family reactions has on this decision, and the sense of community they experience within the Clinic as a result.

Assuming the sick role – Benefits of Disclosure

Avani is a thirty-eight-year-old married mother of two living in Chennai. She was diagnosed with HIV in 2005 after her husband became ill. At the time, she felt she had no choice but to disclose her status to her family members as, with her husband also HIV-positive, she might need to rely on them someday for help.

> *I have disclosed about my status to my second younger sister. I didn't disclose my status to my first younger sister, because she is somewhat difficult. I disclosed it to my second younger sister and her husband. I have disclosed my status to my last younger sister but not to her husband. I have disclosed it to my mother, because after me my mother should be the guardian for my children.*

For Avani, the need for disclosure was due to her role as a mother and the fear of what might happen to her children if something were to happen to her. Clinic staff found that this was the most common reason for disclosure among women as family concerns were often paramount to their perception of their condition.

Siya, 34, was diagnosed in 2006 when, similarly to Avani, her husband became ill. She is in the more unusual position as her family members are all aware of her HIV-positive status. She and her husband currently live in a joint family household and therefore it would have been impossible to hide their condition.

> *My mother's side everyone knows. Even my mother-in-law's side also they know. Both our house side they are aware of it. My mother-in-law's side, they will not tell anything and they have not isolated me. There is nothing like, "She is infected with this disease so let us keep her away". There is nothing like that. As usual they will behave normally with me.*

The fear of isolation is common among visitors to the Clinic as they worry their family members will not react positively to their status. However, not only did Siya and her husband find support among their families but Siya's siblings also proved to be sources of useful information about the condition.

First I told my mother only. I told my mother, "They are telling me that I am having this disease." My mother told my younger sisters and younger brothers and she started crying. She told them, "Your sister is infected with this disease. What to do now?" My sisters and brothers have exposure to the outer world, so they said to my mother, "This is not a big disease at all. If she takes medicines and all, regularly and correctly, it will become all right." They all have exposure to outer world. I was not so much aware about this disease, but they only provided me the courage to face it.

Narratives of Avoiding the Sick Role

For the vast majority of participants and visitors to the Clinic, the idea of disclosing their status in order to access the communal care reserved for those who are ill was unthinkable. Despite the expectation of care usually found in these situations, participants felt that the stigma and fear surrounding their condition would supersede the traditions of support. Therefore, they felt there were more benefits to concealing their condition, even though this often meant isolation and increased complications as they sought to avoid the suspicions of those around them.

For Diya, a twenty-nine-year-old widowed mother of a five-year-old son, avoiding the sick role for her condition has meant swearing her mother and sister to secrecy. This has included insisting they keep this secret from other family members, as the potential for the disclosure to snowball is too high.

If I tell my other sister then surely she will tell her husband. The husband will go and tell his mother. Likewise, it will spread to others also. We cannot trust anyone. During my delivery time itself my mother swore on my head telling that she will not tell my status to anyone while she is alive. She said, "If you lead a life that is enough for me. You should not commit any suicide and all. Don't think about that at all." My mother took this oath from me. Then my sister also took an oath telling that when she gets married and goes to her husband's place she would not tell to anyone about her status. Even my sister has sworn that she will not tell my status to anyone even if it means losing her life also. So, nobody is aware of my status. Till now, nobody is aware of my status. My mother will tell my other sister that I am not well due to anaemia and heart problem.

When asked about the need for this secrecy, Diya was adamant that her other family members would not react well to the news and could cause problems for herself and possibly even her mother and sister due to their acceptance of her condition.

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They feel we must have gone in a wrong way to get this disease. They feel like that only, but they are not aware HIV can spread through injection and other ways also. If somebody provides them this information, then only they will come to know. Right now the situation is they feel if they go in wrong way they will get this disease.

This fear of the reactions of extended family members was shared by Shruti, 38. Although she had disclosed her status to her immediate family, she was careful to avoid letting others know. This desire to maintain her privacy regarding her condition was complicated by her desire to share information about HIV with her family in order to try and combat the rumours that had informed their awareness about the epidemic.

I have a fear in my heart that if they come to know about my status then they would keep me off separately. My family members are all aware and they have accepted us and they are all very close with us. Those other people are all outsiders. When I was telling them about HIV they looked troubled and they saw me differently. Two or three of them appreciated me telling you have gathered so much information on that topic. I had a feeling that why should I disclose my status to them. No, let those people not come to know about my status.

Shruti has had personal experience with disclosure resulting in negative reactions. After her husband's family realised the cause of his early death, they began to keep their distance from Shruti and her fifteen-year-old daughter.

When my husband passed away, his family came for his funeral and that is all. After that they got scared. They thought their son passed away and since I was with their son then I have got the disease. They thought since the daughter-in-law was with the son, she got the disease. And since the granddaughter was with the mother she got the disease, so if we go and stay with them then we will also get the disease. They got a fear like this, so they completely left us and they went away. Now, it has been five years but they don't even make a phone call and ask about our well-being like "How are you? What are you doing?" They will not even ask about my daughter also like how she is and what is she studying. But I am mentally strong. I do my work and shoulder my responsibilities.

Although Shruti has been able to maintain her day-to-day activities and those of her daughter as a result of a strict medication routine, she still feels panicked when friends or acquaintances inquire about her health. The kneejerk reaction of fear of disclosure is isolating in itself as the individual places a mental barrier between themselves and others.

One month back, a girl asked me, "Why akka[32] you look so weak?" I said, "Nothing, I am not well." She said, "You are becoming lean day by day as though you are affected with AIDS." When I heard that I was shocked mentally. I said, "Right now I don't have. As soon as I get it I will give it to you." I said jokingly and left that topic. I felt without telling her my status she is telling so much. I feel in case if I disclose my status to my friends then they might not remain my friends any more. I have that fear. Only one girl is friendly with me and that girl only asked about my health like that because she saw me after two months.

Just as Diya and her mother point to anaemia or heart problems as the cause of her ill health, Shruti often uses an excuse of alcoholism to explain her husband's early death. This demonstrates one method of accessing the sick role that participants enact. By claiming a different, more socially acceptable condition, they are able to explain some of their symptoms while still maintaining the relationships that they fear would disappear if their real condition was known. In Shruti's case, although alcoholism is not one of these accepted ailments, it is still a useful excuse as it will not bring suspicion onto herself or her daughter.

I have told others that my husband died because he was drunkard. That is what we have told everybody about his death. In case if I disclose it was HIV outside, some of them will go away from us. My family members all know about me and when I told them they were able to understand me, and they didn't take it up seriously. Outsiders will question me how is that possible? Then what did Shruti do? Why has she got this disease? They will start talking like that, so I have not disclosed to them my status.

For Avani, a thirty-eight-year-old married mother of two, the choice to disclose has resulted in awkwardness between herself and her family members as their initial reaction to her condition made her feel very uncomfortable in their home. As a result, she keeps a distance between them as she does not feel able to look to them for support even though her brothers are all working within the medical field.

They didn't insult me. Their children and all they got scared and they ran away from that place. It is a big house. I have three brothers and in that two brothers were giving bath to their children and dressing them up. When I told like that immediately they asked the children to go to their home and they sent them away. Their houses were next to this house.

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[32] "Akka" is the Tamil word for sister. It is extremely common to use this when speaking to friends or strangers, as long as they are of the same age as you or younger.

I was staying in the eldest brother's house. The other two elder brothers they were staying in the house next to this house. Since their children were all there my brothers had come home and even I had gone there for vacation. During that time, they did like that. I felt insulted and it was quite disheartening for me. They got scared that their children might get the infection from us so they sent the children back to their houses.

After that I stopped going stay with them. Recently only they have come and inquired about me like "How are you? Are you fine? How is your health?" Now, they come and they inquire about us. They asked me, "Why is that you are not coming there?" After such an incident happened to me there I didn't feel like going there. In case if they had provided me support during that time then definitely I would have gone there more. During that time, they insulted me and I was hurt and now I don't feel like going there. Now, they will only come and meet us and they will talk nicely with us. They will ask, "How are you? How is your health? Do you have any problem?" I will just tell I am fine that is all.

The experience with her family members has had the opposite effect than intended as their difficult initial reactions have only served to convince Avani of the importance of preventing further disclosure. As mentioned previously, concerns about the welfare of children is often paramount within decisions regarding disclosure. However, in Avani's case, this concern only strengthens her resolution as she feels this is the best way to protect herself and her children from discrimination.

Why I didn't tell others is tomorrow my children's future will be affected. They will tell they are affected with this kind of disease. Tomorrow they might have problems in getting married. Their life itself will be affected, so I have not disclosed my status to anybody. We are staying in a rented house. In case if the owner comes to know about our status definitely he will increase the rent, so we don't have the opportunity to disclose about our status in our neighbourhood. Since I am working in this HIV field the people surrounding me they know about my status. The hospitals where I go for field work there the doctors and nurses are aware of it. Like this they all know about my status, but in my neighbourhood they are not aware of it.

This sentiment was echoed by Aarohi, 28. As a married mother of two daughters, ages seven and eight, she is very concerned with how her condition might negatively impact her children's futures. A particular area of concern involves their education, with fears that disclosure might result in discrimination for the girls.

In my family, nobody is aware of it. In my husband's family it is the same. Nobody is aware of it. We have not disclosed to anybody because if they come to know, they might isolate us and keep us separately. I have to look into my children's future. My future has become like this only. If they come to know outside, they will not admit my children into the school. There are so many problems.

The potential consequences of disclosure were well known to all of the participants in this research. They had seen examples of abuse and discrimination through the media and heard stories first hand from other HIV-positive individuals. This shared fear has led to a feeling of distrust or betrayal as individuals mentally isolate themselves from community members. Two of my participants, Riya and Aarohi, gave examples of HIV-related discrimination they had heard of. As Riya, 31, explains:

I have heard many of them tell about it. There has been separation between sisters itself because of this disease. Relatives and all have forsaken them and they have gone. I have heard many of them tell like that, so I don't have the desire to disclose my status to anybody. I have a thought that they might behave like that with me also. Until now, my sister and brother they have not behaved like that with me. They are married. They have not behaved badly with me, but still I am scared to disclose my status. I am scared to disclose my status hereafter to anyone. Suppose if they isolate us and keep us away then I would feel very bad, so that is the reason I don't want to disclose. They have misconception only. According to them, HIV will spread through illegal sexual contact. They have only that thought in their minds. They don't have knowledge about other ways of spreading and all. There are four to five other ways of spreading also, but they are not aware of it. They feel HIV will spread like this only. People will say, "That woman is like that. We should not talk with her." They will get a thought like that only within them, but I am aware that HIV will spread through blood transfusion and all. They are not aware and they need still more awareness on it.

Aarohi, 28, had heard similar stories in the media that had caused her to fear the consequences of disclosing her status. The potential for HIV-positive status to result in isolation or removal from the community was particularly worrisome as this would mean the individual was left without any support from those around them. Although many participants avoid the sick role through nondisclosure of their status, they are still able to benefit from the communal traditions

and experiences that are allotted to their membership within the society. If this were to be withdrawn, individuals would be left to deal with the consequences on their own.

> *When we see the stories in the newspapers, so many people are suffering due to their status. I read about one incident. When the people in the village came to know about it, they sent that family away from the village. This incident has happened in some village. The family was actually thrown out of the village. Here in Chennai, it is not as bad as this. But if they come to know, we will have issues. How will I tell them, even for a small issue people will talk disgracefully. They might kill you. If they come to know about this, they will say that is the woman who would have gone the wrong way. They will not talk about the man. They will first put the blame on the woman only. That is the reason I did not disclose my status to anybody. I feel when they come to know... I want to hide it as much as possible.*

As Aarohi went on to explain, the act of disclosing her status was not the issue. She felt that consequences of sharing her status were too much to risk as she had seen too many examples of the negative experiences of others.

> *I can boldly go and tell everyone that I have this disease. The telling is not the big issue. But it is the problems that will follow that will be too much. We will not get a house for rent. One day on television I saw a program about this. A lady had gone and she had talked about her status in a meeting. She had revealed her status to everyone in the meeting. By the time she had returned back to her home, her house owner had removed all of her belongings and left them in the road. They must have heard about the meeting. Like that, problems will happen.*

> *In that meeting, she had spoken about HIV and said that she was still leading a happy life. She and her husband said they were happy. She said that whatever has happened to them, they had to accept it and be happy. She said that they were both healthy still and so there was no reason to panic. She spoke like this in the meeting and it was on television. Later they showed on television how they were thrown out of the house. Look what happened to them!*

The feelings of betrayal expressed by participants are a reaction to the violation, in their eyes, of the social trust between themselves and their friends and family members. One of the most interesting elements of the local epidemic is the ability of the virus to alter perceptions of individuals. Instead of stopping to consider alternative routes of infection, individuals are judged immediately despite a lifetime of evidence to the contrary. This point was further emphasised by the director of the Clinic, Dr. S, who explained the necessity of policies such as those regarding

joint disclosure for married couples[33]. In her opinion, women were excessively burdened by the virus as they acted as the primary caregivers for others but then faced increased stigmatisation with regards to their own status.

I think the women are on the receiving end of everything. Because of the men, they have this condition. These poor women have no idea their husband is up to all this mischief. The women have such trust in them. But the guys go ahead and do everything. And when they get sick, the women will take care of the man, the children… all until he dies. But this poor woman is also suffering and there is very few who really take care of them. So they are at the receiving end but they give all their love and care to the family and even to their in-laws. They will keep doing everything. But then she gets blamed for everything. If the man dies, then this woman must have brought it and given it to my son. That's the general feeling in most of the families we see. So we need to sit and talk to them and tell them not to act this way. You know, so even among the educated there is a lot of blaming of the female in the families. It's everywhere. In India that is the norm.

The public perception of the condition is so unflinchingly negative that participants felt anger at how quickly opinions of them could change among those closest to them. Aarohi explains further:

My friends are not aware of it. They would not even talk with me if they did, there is no doubt about this. They will have a fear that the infection might spread to them. That is the only reason. They will have that fear. They might even get a thought like that this woman is not good. The first thought they will get is this one only. She must have done a mistake. She was with us only and without telling us, she has made a mistake. They will think like this about me only. Then they will stop talking with me. They will think even if they touch me then they might get the disease. They will behave like that.

They will tell that I have done some mistake because without doing a mistake how could I get this disease? They will tell that this disease will come only to those who go in a wrong way. They will tell like that. For example, suppose there are ten families in a colony and there is a small issue. All the ladies will join together and they will talk and talk. This will make it into a big issue. In case I disclose my status, then what would happen? First of all, I will never get a house to rent. In Chennai, this is one of the main reasons to not disclose. Everything will become a problem.

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[33] This policy was discussed in Chapter Three.

Familial Betrayal and Discrimination

At issue within the benefit of the sick role is the element of trust. The close bonds of kinship are meant to result in care for members who are in need. As a result, the destruction of that trust, as seen in negative reactions to disclosures, can be very difficult for participants to bear. Nancy Scheper-Hughes and Philippe Bourgois have highlighted the family as one of the most important representations of social institutions (Scheper-Hughes and Bourgois, 2003: 3). In this way, the betrayal experienced within the family structure forms a concentrated version of the discrimination faced by HIV-positive individuals and is particularly important within joint families in India. As indicated by the Clinic's focus on equal treatment of both husbands and wives, these issues of betrayal and disclosure are magnified in joint families wherein the wife is often placed at a disadvantage as they have joined their husband's family rather than remaining with their own. The close quarters can result in discrimination as family members rely on misinformed beliefs about the condition in their interactions with the HIV-positive individual. Priya, a thirty-one-year-old mother of two daughters, was unfortunately the victim of these potential consequences after she disclosed her status to her younger sister. Abandoned by her husband shortly after their diagnoses in 2005, Priya has been dependent on family members for support to supplement her income from outreach work. Although she lives in a joint household with her sister, this has not proven to be a benefit when it came to disclosure. While her sister has maintained her privacy by not disclosing her status further, she has made life within the home very difficult for Priya.

> *I had not disclosed to anyone except my younger sister. I had a thought in case if others come to know about it they might isolate us and keep us away. I had a fear like that and nothing else, so I didn't tell anybody. Then I disclosed it to my younger sister. Two or three years ago, my health got upset and within me I got scared whether I would die soon. My younger sister is married to my brother-in-law. The brother-in-law who helped me in the hospital to him we have given our younger sister. During that time, what I thought was suppose if something happens to me then my younger sister would take care of my children and even her husband also will think it is their brother's children and even he might take*

care. I thought like that and I told her, but that ended up in a problem. My sister's husband said her, "You should not go to your sister's house." When he came to the hospital and helped us he didn't know that his brother was infected with HIV. When I told my younger sister, she in turn told her husband and only then he came to know about it. Then he said to her, "Nobody should go to your sister's place." Even now also, they are like that only. Without her husband's knowledge my sister will come and go. My younger sister has a daughter, so she will tell me, "Don't give my daughter any food and all and don't feed her with your hands." She will still stigmatise me like that.

I trusted my younger sister who was born with me and I disclosed my status to her, but that itself ended up in a big problem. Then I disclosed to my close friend but I didn't have any problem there. Then I disclosed to my father, and after disclosing it to my father I watched whether he behaved differently with me or when I went to their house did he behave differently. There was nothing like that. My father never used to talk about that at all. He is the same as usual as before. My younger sister only is like that and is quite disheartening to me. If she comes to house in the evening if I give the soap that we are using, then she will say she doesn't want that. Suppose if it is my menses time she will not allow her daughter to sit close to me. She will ask me whether I am using pad or cloth pad. If I tell cloth pad then she will ask me how will you wash that and all. She will ask me many questions like that. She will not allow me to feed her daughter. She will ask my daughters to feed her daughter. She will do like that and all.

She knows about HIV. She knows everything. What can I say? Others talk about isolation; it is like that only. She will try to isolate me. She will not talk badly to others but she will show it in action. She will tell, "Akka, you don't feed my daughter. Ask your children to feed my daughter." During menses time, I will keep cloth pad during night-time, so she will ask me "Did you properly wash it" and "Put it away properly". She will ask her daughter not to go here and there and all because of me. She will never think if I talk like that might hurt my sister and already she is suffering with this disease. She will never think like that. Even until now she is like that only. She will hurt me very badly.

Siya, 34, has had a similar experience to that of Priya with her extended family members. Although her immediate family is aware of her and her husband's status, she has found that the acceptance of her condition does not extend beyond her household. The most hurtful experiences have been through gossip shared by her extended family. Although they will not discriminate or abuse her personally, they make her feel as though she is being examined and judged from a distance.

My husband's family will talk about us. When we go to attend a marriage, they will tell their relatives about this disease. My husband's elder brother will not talk but his wife will tell her mother's side. It is like that. To my sister-in-law's family, my sister-in-law will tell

them that I am infected with this disease. They will all join together and they will discuss among themselves and that act hurts me very much. They will not behave in a manner to hurt me but they will talk among themselves and act in front of me as though they have not told anything about me. But the way they act tells me that they know. They don't come to me and ask questions about the disease. Instead they talk about me to each other.

As far as disclosing her status beyond her family members, Siya explains that she does not see any benefit to doing so. While she might hope that disclosure would bring support and provide her neighbours with a greater understanding of the condition, in reality she feels it would only cause problems for her family. As discussed in the previous chapter, the ability to distinguish between the social self and the HIV-positive self, and therefore to present the appropriate characteristics to those around them in different settings, is a key element to the increasing level of personal agency that occurs through the process of the liminal state.

There is no necessity for me to disclose to my neighbours about my status. So why should I tell? By disclosing my status, what is going to happen? If I tell to them, and if they show me sympathy, then it would be all right. But if I disclose then they would talk disgracefully about me then why should I tell them. They would tell she must have gone a wrong way and that is how she got this disease. They will talk like that only. Will they provide any help to me? Nothing like that. Then why should I disclose to them? Without telling them, I can always lead a normal life and go about my life as usual. Why should I disclose to them?

Saanvi, 35, has experienced a similar level of stigma within the household as that which Priya described. Although her family members are not outwardly abusive or cruel to her, they are constantly reminding her of her status through their actions which only serve to isolate her within the household. Additionally, their limited understanding of HIV means that they do not see the reality of her condition, such as maintaining her health, and instead focus on the socially accepted view of HIV as a death sentence as a means of dismissing her position within the home.

At present, they are aware of it. Earlier, I didn't tell anybody. I had a fear that in case I disclosed to them my status, then they might isolate me. So I didn't tell anybody. But they came to know about it soon after because they came to the hospital with me for some injections. My elder sister came to know by seeing the doctor's notes. She went and asked the doctor at the next bed. That is how she came to know. Afterwards, the first thing they did was keep a separate plate for me. Also a separate soap and towel for me. They used to

tell me that I will only be alive for six months more. The doctors in the hospital had told like that to them. Such big tales!

Despite her experiences of isolation within the household, Saanvi refuses to look to her neighbours for support as she feels that their reactions to her disclosure would be just as negative as that of her family members.

I have not disclosed to my neighbours at all. The people residing there will start to see me differently. I would not like that. If this disease is a common disease, then we can go and tell everyone. Like diabetes and all. But AIDS means it will spread through wrong means only. Advertisement has said like that… that AIDS will spread through illegal sexual contact. So whoever sees a HIV-infected person they will see them in that sight only. I will never tell.

Although the experiences of discrimination within families shared by Priya, Siya and Saanvi have caused mental anguish and feelings of isolation, they were still able to live within the households and their family members protected their privacy by not disclosing their status to the neighbours or others outside the home. Additionally, despite the negative reactions experienced, these participants were still able to maintain their roles within their households and were accepted by their family members as they continued to fulfil their duties, such as cooking or caring for their children.

As discussed in pervious chapters, the role of women within the home is often characterised by constrained agency and economic dependency, which in turn creates an environment where women are disadvantaged. This vulnerability can then expand with the death of their husband. Widows in India have historically been given a low social status and were often victimised or shunned as a result (Chen and Dreze, 1995: 2437). Described by Mohini Giri (2002) as a "living death," widowhood was traditionally considered to be outside of the life cycle for women. In effect, this meant that widows were no longer individuals who should be included within the social structure of society and therefore, widowhood was seen as "a personal and social aberration, to be

devoutly wished away" (Giri, 2002: 19). A strict code of conduct was enforced for widows, who had to wear a coarse, white sari, which required enormous sacrifices such as living away from the main family residence and only eating "roots, flowers and fruit" (Giri, 2009: 25; Chen and Dreze, 1995: 2437).

Within the illness experience of HIV/AIDS, there is a gender-based difference within the care received by individuals as women are often responsible for their husband's care (Tarakeshwar, Nalini, et al, 2006: 408). As noted by Dr. S within her interactions with Clinic visitors, this care is not returned as many HIV-positive women find themselves responsible for their own care. As a result, it is common to find women have placed their care as secondary to those of others. When women are widowed as a result of HIV/AIDS, they often face uncertainty and insecurity, as they have spent their married lives being economically and socially dependent on their partners and in-laws (Fassin, 2007: 244; Tarakeshwar, Nalini, et al, 2006: 408). Often the blame placed on them for their husband's death results in their exclusion from family concerns or activities (Tarakeshwar, Nalini et al, 2006: 414). In 2001, a study by the Joint United Nations Programme on HIV/AIDS (UNAIDS) found a clear distinction made by parents between their son and their daughter-in-law, despite the fact that both were HIV-positive. This blame placed on women as the source of HIV infection was found to result in direct discrimination within the home. This included the denial of medical treatment, a lower quality or amount of food, and removal from the home (UNAIDS 2001: 44).

Although the status of widows has improved in recent decades, the added stigma of being HIV-positive leaves women vulnerable to mistreatment by family members who view them as a burden or a source of shame. While the strict code of behaviour for widows is no longer enforced,

women often experience a much subtler form of discrimination (Giri, 2009: 25). As two of my participants explained, common areas of concern involve the withholding of inheritance or income.

Pari is a thirty-seven-year-old mother of two, with a ten-year-old daughter and a sixteen-year-old son. After the death of her first husband, she found that his family was no longer willing to accommodate her and even refused to grant her the inheritance she had been expecting.

> *I was staying in their house only. I thought they might give me property but they didn't. They chased me off. I didn't have a child so they didn't give me property. They said that because I had this disease, what did I need for property? Nobody said anything to help me. They were all silent. They thought if she goes let her go. They thought if they talked for me then they would have to give me property so they remained silent. If they talked for me, then it would be good for me but if they didn't talk, then it would be good for them. So they remained silent.*

After discovering the extent of the family feelings against her and their desire to cut her out of any inheritance, Pari went to one of the local television stations and spoke out against their treatment of her. She explains that until that moment of betrayal, she had never held any anger towards them and had sought to live peacefully within the home. She had also never expressed anger toward her husband, despite the fact that his actions had brought the condition into their lives.

> *I told everything, like that I didn't know anything about that disease and I had not even heard of that name. I didn't know how this disease would spread and how this disease would not spread. Even in case someone thought they were infected with this disease, I didn't know how to go and find out also. After I came to know that I was infected with this disease, I didn't get anger. I didn't feel shattered and I didn't have hatred towards anyone. Until my husband's death I took care of him nicely only. After he died, I had the exact opposite experience. His family were putting the entire blame on me. I said definitely I got this disease only through my husband. Today many women are getting cheated like this in the society. So, if you come to know that if your husband is HIV-infected, then immediately you should get the property registered in your name. Even though our husband has done this, don't leave him but get the property in your name. Like that I spoke on television. After they watched that program in my house, they started talking about me. I was not staying in my house. When that program got telecasted I don't know where I was staying, because after watching that program I thought everyone will start questioning me. During that time, there was no phone also. One week later, everyone was in my in-law's house*

and they asked me about the program. I was trying to manage their reactions by telling them that I didn't speak and all. Later on I told only my mother in my house.

In my village they don't have a cable connection. In the next village, they have seen the program and they have told in my house that I had given a program. They have told in my house, "Your daughter has spoken like this on the TV." In my village, nobody knew about it. Somebody in the next village who knew us had seen the program and they have told my younger brother and he asked me. Then I told him about my disease. Then next I thought where should I go and what should I do. After talking on the television I didn't remain in that place because I thought everyone would come to know about it, so I came off.

Although Pari regretted her actions in speaking on television because it meant that she had to leave her village and her family, she still feels strongly that her message was accurate and that many other women are experiencing the same discrimination at the hands of their in-laws. She was fortunate in that she was able to leave their household after her husband's death. Since then she has not had contact with them and they have not granted her any of the inheritance she demanded.

Now I don't speak to my husband's family. I don't have any communication with them. I don't go to that area and I don't enquire about them also. Now, I have got married for the second time. I have not disclosed my status openly to everyone. My second husband's father, mother, sister, and uncle they are not aware of my HIV status. Nobody is aware of my HIV status. He has got lot of relatives. I thought if they come to know then a lot of problems might arise, so at present I have not revealed my HIV status to anyone. I will not talk to them on HIV status, but in general I will talk with them. I will not tell I am HIV-positive and all. If somebody has seen me talking about it previously somewhere I am not bothered. At present, I want to live in disguise so I am staying quiet. Disguise means I don't want this information to be known to them for some time. When they come to know on their own let them know about it. I will not go on television again to discuss this. If I go and talk on television everyone will watch the program. My husband feels it should not be known to others. I feel if others come to know about my status then that is all right for me but I will not go out to tell them. I am earning and I am living with my earning. I feel that way. With this issue I feel both of us should not have any problem, so I staying quiet.

Prisha, 34, found herself unable to make the decision regarding disclosure as her husband took the choice away from her by revealing their status himself. His behaviour caused a lot of shame for Prisha and resulted in embarrassment and further discrimination by those around her. She feels her HIV status was the cause of her mistreatment as it made her family members think less of her, as if she had no reason to live and therefore they were not obligated to treat her fairly.

My husband used to drink and he used to go and tell all our relatives about our status. He would say that he and his wife were infected with HIV. He told my relatives only. He told my grandma, auntie, uncle and all. He went to that side and told everyone that I was infected with HIV. It is a disgrace to me that they have all come to know about my status. They don't give me any respect now. Even though they all know the reason why I got this infection, tell that I am infected with HIV. They look at me with hatred. I feel they are talking about me.

While working for her uncle, Prisha found her earnings being withheld without cause. Although her uncle claimed he would pay her when he had the necessary funds, she was shocked that her inability to pay for her food or medication left him unmoved.

Recently, I was working for my uncle. I stopped going to export and instead I was working for my uncle for some time. He was not paying me salary properly. He used to give me little by little. I said, "I am not well. If you pay me properly it would be helpful for me. I am not having money even for food. Give my salary in total correctly." He said, "If you are not well what for me. If you are well or if you are not well what for me? When I get money during that time only I can give you salary. I cannot give now." When he told like that it was quite disheartening for me because a person who knew everything was talking like that. I am asking for the money what I have worked for. I am not going and asking him money just like that. I worked in that place. Since he was a relative of mine I was not in a position to talk against him, but he was talking rubbish. I was telling him, "I am not well and it is very difficult for me." He said, "If it is difficult for you what should I do. I don't have money right now. When I have money I will give you during that time." He told like that and he went away.

It has been previously posited that the sick role can vary according to the type of illness involved. For example, Elliot Freidson (1971) has drawn a distinction between legitimate illnesses and those that are considered stigmatising. Within these categories, legitimate conditions include well-known diseases such as the measles and the chicken pox. Meanwhile, stigmatising diseases include conditions that are not as accepted within society. An interesting distinction between these two categories is the timeframe of the illnesses in each group (Freidson, 1971). For example, the conditions considered legitimate are those that have a relatively short lifespan. These conditions also have widely available treatments and the individual can be expected to recover if given the

appropriate care. Meanwhile, the stigmatising category includes chronic conditions such as HIV/AIDS or mental illnesses, which are not as easily treated.

John Janzen has sought to explain this difference through a view of illness as a form of deviance (Janzen, 2002: 144). Therefore, a short period of time is considered acceptable while a prolonged state results in the deviant status becoming more pronounced. Additionally, the sick role is designed to be temporary with the individual returning to their previous position within society. As a result, chronic conditions that threaten this return are seen as problematic.

This difference between the two categories ties into the explanations given by Arthur Kleinman and Bruce Kapferer with regards to the abandonment and discrimination experienced by sufferers at the hands of their family members. Normally this would be seen as unacceptable within the bounds of the social trust, however, the ability to declassify individuals as part of the community allows for the expectations of care to be withdrawn. Kapferer (1979) has demonstrated how the process leading to this treatment can be viewed as the negation of the "normal self," which then enables society to retract the expectations of care for individuals (Kapferer 1979: 110). Meanwhile, Kleinman sees the withdrawal of support as the result of families having "run out of energy, patience and funds" (Kleinman 2009: 603).

The inability for participants to disclose their status to those around them points to a division between their social lives and their HIV-positive lives. As indicated in the previous chapter, the interactions with their family and friends inadvertently continue to confirm the negative opinion of the epidemic and therefore the expectation of negative repercussions if their status is revealed. As a result, participants place barriers between themselves and their community members as a method of concealing their condition from others. Part of the need for this distance involves the distinction between knowledge and belief found within these communities.

As highlighted by Pertti and Gretel Pelto (1997), these terms are useful in understanding how HIV/AIDS diagnosis is able to alter the communal approach to health experienced by participants (Pelto and Pelto, 1997). After diagnosis, participants found their understanding of their condition and the local epidemic increasing exponentially as they interact with the Clinic staff members and other patients. This then creates the barrier between the individual and those around them as the general awareness of the epidemic remains low, wherein the metanarrative of HIV/AIDS shared by the public can be viewed as part of a cultural belief system. In this setting, belief is defined as formed by traditional ideas that are not always confirmed by scientific fact. Therefore, the knowledge held by participants regarding their condition is at odds with the commonly accepted details shared by those around them. The beliefs held regarding health affairs are often seen as "answering instrumental and moral imperatives" and as a result, particularly within the response to HIV/AIDS, this can mean strict moral judgments placed on individuals (Young, 1976: 5). This difference between belief and knowledge then results in the isolation experienced by individuals as they feel unable to discuss their status and knowledge about the epidemic without risking negative consequences from this disclosure. Therefore, they are unable to go to their community members for support, which then creates the potential for the Clinic based community to act as an alternative option. Within this experience of community, individuals are able to find answers to their questions or receive advice about different concerns from others who share their heightened awareness of HIV and who are able to offer their support without the threat of exposure.

Therapeutic Companionship

The ability for HIV-positive individuals to interact with other members of the local epidemic has been previously highlighted as an important element of the illness experience. Vinh-

Kim Nguyen (2005) has noted the ability of these interactions to empower sufferers as it develops a system of "therapeutic companionship" (Nguyen, 2005: 127). Therapeutic companionship was one of the adaptations made by the North American homosexual community in response to the HIV/AIDS epidemic. Designed as a sort of "buddy system," this social movement within the HIV community allowed for the transition from individual suffering to group solidarity (Nguyen, 2005: 127). While for many illnesses and conditions the similarity of symptoms creates the feeling of companionship and allows individuals to bond over their shared illness experience, within HIV/AIDS there is a wide variety of subsequent conditions and opportunistic infections (Napier, 2003). As a result, the shared experience of HIV/AIDS revolves around the continued stigma and discrimination faced by individuals, which creates a shared sense of community as individuals are able to use their experiences to inform collective empowerment. In Chennai, the sense of community centred on the Clinic is strengthened further through the positive networks and support groups that form the backbone of HIV/AIDS advocacy within the city. These groups offer a safe space to discuss the lived reality of the condition and provide a platform for individuals to share their experiences with wider audiences.

For Diya, 29, her first introduction to the support group was eye opening as she began to understand the community that she had become a part of. Diagnosed in 2006, her awareness of other HIV-patients had not moved beyond the glimpses she gathered while waiting for her appointments within the Clinic. She kept to herself and focused on the interactions with the medical staff and, as a result, her understanding of the condition was entirely gleaned through these discussions. Although the counsellors provided a lot of useful information that helped her to feel more comfortable with her status, it was not until 2012 that she first attended a support group meeting. At the time of our interview, she had been attending regularly for three months and had

already begun to understand the benefits of sharing personal experiences with other like-minded

individuals. While the Clinic staff members are able to assist with social advice and medical issues,

these support groups are able to offer more direct assistance such as with financial difficulties.

> *I had asked if anybody could help my son since I was finding it very difficult to provide his education. He told me about Sumathi akka and he asked me to go and meet her. He also gave her phone number to me so I made a phone call to her. First I made a phone call to this akka. She talked nicely with me, inquiring about me. She talked very happily with me. I was not aware that even this akka also was HIV-positive just like me. I was not aware of it.*

> *Three months before I came here, I came to know her status. When I came here I was very scared. There was a girl here and that girl only did the counselling like, "How are you? Are you fine? Are you taking the medicine?" I said I am taking medicine. Initially when I came here I was very scared. I was scared if some known person might come off here and see me come here. I was very scared. When I came here they all spoke with me nicely and they asked us to introduce ourselves. Everyone introduced themselves. During that time, Sumathi also introduced herself that she was also positive. When I heard that I was shocked. Then only I came to know everyone who comes here are HIV-positive and I was a little bit relaxed. I saw everyone was mentally strong and I felt I was only a coward all these days. I felt I could have taken medicine earlier itself.*

Prisha, 34, also found the support networks through concerns about her son's education.

As her husband's moods were extremely unpredictable, he was struggling to provide the necessary

funds to support their son. She had heard about the positive networks and decided to try to see if

they could help.

> *Two counsellors gave me addresses of two or three networks and they asked me to go and get registered in these networks by giving my name and address. They said that they will provide help for my son's education every year. Yes, they are providing help. Like this the networks are there and they will provide help. With that I am managing. If possible I will go to work otherwise with whatever I get I will try to manage.*

In addition to the support for her son's education, Diya found that her involvement with

the support group not only changed her view of how she had previously dealt with her condition,

which revolved around concealment and fear of disclosure, but it also changed the way she saw

her future as an HIV-positive individual. A main element of this change was the ability to see herself as part of a community of support, rather than on her own as she had been before.

> *Definitely, I have come out. I have come out of fear. What kind of fear means that, like me, so many people are there. I was thinking I alone was down with this disease, but now I see so many people are suffering with this disease. When I see them I feel I can be one among them. Instead of dying alone I can stay with these people happily and then die. That thought I have got now. Now, suppose if this akka calls me up she will ask me, "Did you have your food? Did you take the tablets? Don't sit outside in sun? Don't sit in hot sun in the shop?" Like this she will give me advice. Earlier I didn't have anyone to make a call and talk or anyone to call and talk with me. Only my mother and my sister they used to take care of me. They used to keep telling eat…. eat…. After coming here, I have got lot of friends. Many of them who are like me get help for their food and rent and all. Help is being provided. For people like me who have newly come we need help, because until now I have not received any help.*

The ability of these support groups to provide support and opportunities for their members was echoed by Avani, 38. Like Diya, Avani found herself primarily interacting with hospital staff or those within the Clinic as she went through the process of collecting medications and having appointments. Through these meetings, she felt she had received a lot of useful information about her condition, which had helped her to understand the realities of living with HIV. However, the support group was able to offer her a new occupation as an HIV-positive health worker undertaking home visits to check on the well-being of other individuals in her position. Within this work, she has found that awareness even among HIV-positive individuals is still very low and as a result, she often needs to counsel them about the HIV-positive community and the example other individuals have set for positive living and not allowing HIV to define them.

Aarohi, 28, agreed with Avani's opinion regarding the benefits to self-esteem and the countering of depression that the support groups offered. Aarohi had spent the early years of diagnosis attending one of the local government hospitals, which had given her the first impression that the reality of living with HIV/AIDS might be very different to the expectations offered by the social metanarrative of the condition.

In the hospital, I saw hundreds of them like me coming there for check-up and I felt a bit relaxed after seeing them and it was very consoling to me. I know I have to keep myself mentally strong. When meetings are organised I have to go and I have to participate in it. Networks are there and they will call us every month to go and attend the meeting. When we go there we will get friends there. We can talk with many of them there and we can become friendly with them there. We can share our difficulties with them. It is good to go and participate in such meetings. Instead of worrying about the disease, which has infected us, it is better to take medicine and take nutritious food and we should be mentally strong. That is enough.

Akshara, 34, was able to expand upon the benefits of this support system as a method of improving individuals' opinion of their condition. The financial and emotional support combines to create a more positive outlook of the future as participants are able to share their advice regarding medication, income support, and their illness experiences.

Through trust they will ask for help and they feel with all the support and help they are getting they can lead a life. There they will even teach us how to do our own business and they will pay salary also. They will keep that money and earn more. If they are not well they will go to hospital and take treatment. Government hospitals are there and there are hospitals that will provide free services also. Through the Clinic they will provide free service also. So, infected people are living with courage now and they don't show off that they have got the disease. If they have money in their hands, they get confidence and nobody can make out that they have that disease. They look like normal people only.

Priya, 31, also highlighted the benefits of support groups that offered meetings only for women as this allowed for greater privacy. She felt that having men in the same meetings would cause her embarrassment and negatively impact her ability to take part in the discussions. Additionally, like Avani, Priya has also been able to find work through the support network, which has given her greater confidence and control over her environment now that she is able to earn a living after her husband's abandonment.

I got registered here in 2005 and after that regularly every month I used to come here for support group meeting. I will not go to other networks and all, because there gents will come, so I will not go there. It will be very embarrassing for me, so I will not go there. Here it is only for women, so I don't have any problem and it is nice to come here. I will come and participate in the meeting. Suppose, if I have any doubt I will ask them. During that time of diagnosis, I said, "My husband has abandoned me and I am struggling with my children. The income I am getting is not sufficient for us, so please get me a job."

During that time, they got me a job in a NGO in Santhome. There I worked for three years and after that the project got over. There was job vacancy here, so I came back here and joined as outreach worker.

The importance of these support groups as an option for HIV-positive individuals is best understood when the experience within hospital waiting areas is compared to these meetings. Unlike the Clinic, government hospitals provide a wide range of services rather than focusing only on HIV patients. Therefore, the waiting areas have a mix of patients attending different appointments. Kalpana, a forty-six-year-old widow with a seventeen-year-old son, found that she struggled to find other HIV-positive patients when she would ask around the hospital ward. She explained that she would see couples come in and would inquire whether they were there for HIV-related appointments but was unsuccessful as every time the answer would be no. As HIV-positive herself, she understood the instinct to conceal their condition. However, as a result, she had never met another woman who admitted to being HIV-positive until she came to the support group.

After I came to know that I had HIV infection then within my mind I had a slackness. I used to feel I am infected with HIV. I am not well.....I am not well. I got such a thought. After that only I became very sick and after coming to network and listening to counselling here then only I got a confidence that I could do everything. All these people are nice then why it will not be possible for me. The reason is within my mind I am shattered and I have become like this. When I see all these people they do all kind of work then why is it not possible for me. Then I got confidence to overcome everything. With that confidence only I started eating nicely and I started taking medicine and again I was able to do all work.

Through these positive networks and support groups, this new alternative community experienced by participants is able to extend beyond the walls of the Clinic. As a private organisation that has to charge for medications (albeit largely supplemented by the Clinic itself), many HIV-positive individuals in Chennai choose to continue to receive treatment from the government run hospitals where they can receive their prescriptions free of charge. As a result, the

support networks are able to reach these individuals who are otherwise unable to benefit from the therapeutic companionship within the local epidemic.

As demonstrated by the earlier sections relating to participants' views of the sick role and its element of disclosure to family and friends, many individuals feel unable to discuss their condition with those around them for fear that this would lead to isolation. As a result, they hide their diagnosis as much as possible, suppressing the desire for the expectations of care and support normally offered to those who are ill. This self-isolation forms the beginning of the liminal state, as described in the previous chapter. However, the involvement of the support group creates a narrative of shared suffering, wherein the reality of that suffering is examined. Through this outlet, participants felt their view of the future had been greatly improved. However, the role of the Clinic within the communal approach to illness experienced by participants should not be underestimated. The next section examines this impact through a discussion of the sick role as viewed through the Clinic's ability to offer support when compared to that of family and friends.

The Sick Role and Community within the Clinic

The complicated nature of the sick role for HIV-positive individuals is mirrored by the liminal state experienced by participants. Just as the sick role has been described as the "construction, deconstruction and reconstruction of specific social rules related to health and illness," participants found themselves undergoing a similar transition as a result of their HIV statuses (Schilling, 2002). This chapter has sought to develop the discussion of the sick role as an example of the impetus participants felt for redefining their concept of community to allow for membership in both their traditional social setting and the communal elements of the Clinic. Just as participants were found to be maintaining plural identities in the previous chapter, it is clear from their narratives contained therein that they have a similar method for acquiring social support.

When contemplating the tenuous link to the sick role experienced by participants within traditional society, the shortcomings found therein can be better understood through an examination of the expectations of this social position. As a result, the inability for family and friends to offer the expected care is seen as a result of their cultural belief system, which does not include an understanding of the realities of an HIV-positive illness experience.

Talcott Parsons (1978) has identified three essential features of the sick role within social settings (Parsons, 1978: 21; Schilling, 2002: 624). The first element involves the removal of the assumption of blame from the sick individual. This is commonly found among most conditions, as individuals are forgiven past transgressions due to their current health concerns. As highlighted by Susan Sontag (1989), an example of this can be found within the social treatment of cancer sufferers. Even in cases of lung cancer among long-term smokers, the assignment of blame is not discussed (Sontag, 1989). Among the general public, and within families, this is most often not the case for HIV-positive individuals. As demonstrated by the participants of this research, blame and the associated stigmatisation is often experienced as a result of disclosure or anticipated by those who have not yet revealed their status. In this light, the Clinic offers the most realistic option for accepting the sick role. As the staff members expect HIV-positive statuses, there is nothing for participants to hide. Additionally, assignments of blame were never discussed as the staff members sought to keep visitors focused on future concerns, such as the maintenance of health, both physical and mental, and the continuing family obligations for individuals.

The second element identified by Parsons involves the ability of sick individuals to be excused from their social obligations for the duration of their illness. This is not found within day-to-day activities for participants, and, as evidenced by the narratives of the new definitions of self-discussed previously, the opposite is more commonly experienced. Participants reported taking on

additional household duties and new occupations outside their homes as they compensated for the decreased earning capacity of their HIV-positive husbands. This is another example of how social expectations within the Clinic differ from those outside of it. While life at home may involve increasing duties and obligations, the time spent within the Clinic is focused solely on the illness experience of the individual. While in the waiting areas or moving from one appointment to another, individuals are allowed to focus on their condition and the way it is impacting their lives. This is part of the transformative nature of the Clinic arena. The act of entering this designated space is an equalising one as all visitors are treated the same despite differing occupations, backgrounds and health concerns. The only expectations placed on Clinic visitors is that they keep to their visitation schedule, which usually involves appointments twice a year.

Finally, the third aspect of the sick role described by Parsons is the necessity of "seeking help" (Parsons, 1978: 21). This action is further elaborated as seeking out "technically competent" treatment from qualified healthcare providers (Parsons, 1978: 21). This is the stage in the sick role where the involvement of the Clinic is the most obviously appropriate. As the source of biomedical interventions, the Clinic serves to fulfil this necessary stage. However, there is the added element of the counselling services found therein, which helps to support visitors as they navigate their new settings and health concerns. The inclusion of these staff members provides the necessary social support for visitors who may find interactions with doctors to be confusing as the subjects discussed are often very new to them. It has been posited that individuals tend to filter the information given by doctors through their own socio-cultural understandings of health (Strong and Davis, 1977; Schilling, 2002: 628). As a result, the counsellors are able to use these beliefs about health to further explain their condition.

Plural Communities

The narratives discussed in this chapter have been intended as an example of the reasoning behind the plural communities experienced by participants. As highlighted in the previous chapter, the ability for HIV-positive individuals to access alternative identities in response to particular settings has enabled them to accept their condition while still maintaining their social roles without revealing their status. The issue of disclosure is further implicated in the reasoning behind avoiding the sick role within their communities as participants felt uncomfortable opening themselves up to the stigmatisation they were expecting. Those who had chosen to disclose their condition to family members found that they were even discriminated against within the household as their relatives relied on outdated beliefs about the condition to inform their interactions. Examples of this included refusing to share cutlery or soap and keeping their children away from the HIV-positive individual. These betrayals of the social trust between family members was a source of emotional turmoil for the participants and provided further reasons to avoid further disclosure.

The maltreatment of participants by those closest to them also extended into their ability to earn a living to support themselves, as demonstrated by Prisha in her experience working for her uncle, the lack of respect accorded to HIV-positive individuals meant that their position was often tenuous despite their familial ties. Without the collective empowerment of the HIV-positive community, individuals are forced to navigate the complications of stigma on their own.

In this way, the community based in the Clinic is able to offer a different set of benefits to the HIV-positive individual than their traditional society can. This community represents the biosociality of the Clinic with its ability to extend the concept of shared experience into political, economic and social concerns. For example, the Clinic staff members are active in attempts to increase awareness of the condition around the city through lobbying to have HIV/AIDS included

in school curriculums and through the provision of legal support in cases of workplace discrimination. Further, as a result of the influence and support of the positive networks operating in and around the Clinic, HIV-positive individuals are able to receive further benefits such as assistance with familial concerns and occupational training and opportunities.

Within the Clinic, the adaptation of traditional family roles, such as that of the matchmaker exhibited by Anni, highlights the trust felt between the staff members and the Clinic visitors. This trust is built on a foundation of privacy, wherein the Clinic is seen as a reprieve from the suspicions and stigma of the general public. As a result, participants felt comfortable not only turning to staff members for advice but also following their recommendations regarding support groups. These positive networks are dependent on the Clinic and the approval given by staff in order to recruit new members while also acting to further the reach of the new metanarrative of HIV/AIDS as a chronic, yet manageable condition. This ability of the Clinic and its staff members to extend their sphere of influence beyond biomedical concerns in turn informs the changes seen during the liminal period as individuals replace their existing concept of community with a new definition that includes non-traditional sources of support.

Chapter Six:

Women and Society: "Doubly Burdened"

"Yet do not let us speculate too much. Let us say that social anthropology, sociology, history – all teach us to perceive how human thought moves on. Slowly does it succeed in expressing itself, through ways that seem perilous."

- Marcel Mauss, Anthropologist[34]

"Discourses about the self and identity in anthropology are almost entirely distinct; I am calling for the establishment of a closer connection between them."

- Martin Sokefeld, Anthropologist[35]

"In any given society, feminine personality comes to define itself in relation and connection to other people more than masculine personality does. Moreover, issues of dependency are handled and experienced differently by men and women. For boys and men, both individuation and dependency issues become tied up with the sense of masculinity, or masculine identity. For girls and women, by contrast, issues of femininity, or feminine identity, are not problematic in the same way. The structural situation of child rearing, reinforced by female and male role training, produces these differences, which are replicated and reproduced in the sexual sociology of adult life."

- Nancy Chodorow, Sociologist[36]

"Autonomy indicates the ability – technical, social and psychological – to obtain information and to use it as the basis for making decisions about one's private concerns and those of one's intimates."

- Tim Dyson and Mick Moore, Political Economists[37]

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[34] Mauss, M. 1985. "A Category of the Human Mind" in *The Category of the Person: Anthropology, Philosophy, History.* Edited by Michael Carrithers, Steven Collins, and Steven Lukes. Translated by W. D. Halls. Cambridge: Cambridge University Press.

[35] Sokefeld, Martin. 1999. "Debating Self, Identity and Culture in Anthropology." *Current Anthropology .*Vol. 40 (4) pp. 417-447.

[36] Chodorow, Nancy. 1974. "Family Structure and Feminine Personality." In *Woman, Culture and Society.* Edited by Michelle Zimbalist Rosaldo and Louise Lamphere. Stanford: Stanford University Press.

[37] Dyson, Tim and Mick Moore. 1983. "On Kinship Structures, Female Autonomy, and Demographic Behavior in India." *Population and Development Review.* Vol. 9 (1) pp. 35 - 60

Shock. Fear. Bewilderment. The emotions were radiating off of the young woman sitting tensely in the little plastic chair in the counselling office. The scene was common among the women who found themselves seated in Lakshmi's tiny office at the Clinic. They were here for their first visit, either to be tested for HIV or as a result of having been tested elsewhere and directed to come to the Clinic for specialised treatment. Many of them had very little awareness of what an HIV diagnosis meant outside of the snippets of information they had gleaned from the public perception of the condition. As a result, they were waiting for Lakshmi to confirm the death sentence they were expecting.

This chapter seeks to highlight the social pressures and outside forces that create increased vulnerability to the virus among young women and inform their initial panicked reaction to their diagnosis. To demonstrate these issues, this chapter is divided into two sections, pre and post diagnosis. This is to allow for an examination of the shifting nature of the illness experience and the role the liminal state plays in allowing individuals to reassess their preconceived notions about the condition and, as a result, their societal roles and community expectations. Ultimately, this chapter seeks to shift the dialogue about illness experience within HIV for these women away from the created vulnerabilities that arise out of the structural violence they experience. Instead, the focus becomes a discourse on empowerment, which is a result of experiences within the liminal state.

Preconceptions of the Self

HIV/AIDS has quickly become recognised as a disease of the social body as the global pandemic moves into its fourth decade. As a result, it is clear that individuals experience social suffering in addition to their increased health concerns. However, this thesis seeks to move away from allowing this discourse of suffering to dominate discussions of the illness experience because

it is an overly simplified view that does not match the reality of the condition for these participants. While the concept of social suffering and the theory of structural violence are useful in understanding the pre-existing pressures that create the gender-based vulnerability seen in women's lack of awareness, this approach does not acknowledge the change seen over time and the impact increased knowledge about the condition, improved access to health care and greater personal agency have on the overall illness experience.

Martin Sokefeld (1999) has introduced the concept of plural identities within individuals as a result of their actions within societies. In a given setting, individuals may identify in one way while their view of their selves changes when presented with an alternative setting (Sokefeld, 1999: 418). Within the illness experience described by participants, this is essentially what the liminal state allows individuals to do. They are able to take a step back from their expectations about society to view the different pressures, traditions and norms from an outside position without physically leaving their social setting. Therefore, they are able to build a new identity where their HIV status is not their main feature. Through having the outlet of the Clinic and a community of other HIV-positive individuals, participants were able to separate their HIV-positive selves from their public selves, who continued to interact with their other communities.

Sokefeld further highlights the important role personal agency plays in the maintenance of these plural identities as it can be viewed as the tool through which there is both "reflexive monitoring of the self and monitoring of the self's relationship with others" (Sokefeld, 1999: 430). This has proven particularly true with HIV/AIDS as individuals are often forced to navigate the difficult journey through diagnosis, including the potential trap of disclosure, alone. However, there is a crucial difference in the pre-diagnosis and post-diagnosis social selves within their forms of agency. In the pre-diagnosis setting, this takes the form of constrained agency. Determined by

family expectations, unequal power distributions within the home and gendered social pressures, the constrained agency is felt through the inability to make decisions that would positively impact the individual. For example, economic inequality within the home leaves many women without access to the financial decision making that directly impacts their day-to-day existence. The pre-diagnosis constrained agency is wrapped in social suffering wrought by the elements of structural violence that act upon the individual.

The post-diagnosis self has been empowered by the liminal state and therefore individuals return to the social fold with an improved sense of agency with regards to their personal environment. This is a result of the changes that occur while in the liminal state wherein individuals are forced to reassess the impact their diagnosis will have on their position in society, their health and their preconceived notions of the condition. Therefore, the diagnosis of HIV-positive status can be viewed as the moment where the possibility of plural identities experienced by participants begins. As they begin to make decisions regarding the protection of their privacy or adapt their household finances to include the costs of medications, participants find themselves acting with increased personal agency. This increasing personal power continues to grow as they move towards acceptance of their condition and acknowledgement of their plural identities. In particular, this involves their view of themselves from within and beyond the Clinic, with only their Clinic selves able to acknowledge their status publicly.

Narratives of Pre-Diagnosis Life

Although the diagnosis of HIV-positive status is identified by most participants as the moment their personal risk to the epidemic became clear, the groundwork of vulnerability had actually begun much earlier as they were indoctrinated into the traditional expectations and roles assigned to women by their community members. Therefore, their descriptions of their pre-

diagnosis social training and the influence of their family members is useful in understanding why women have a lower level of awareness within the local epidemic. Additionally, their narratives are useful in highlighting the constrained agency felt at the start of their diagnostic journey.

Shruti (widowed, mother of one)

Growing up as the middle child in a family of five daughters, Shruti felt she was prepared for married life as she had the example set by her parents and her two older sisters to imitate. Although her parents encouraged her independent and curious nature throughout her studies, she was taught that her husband would be the head of the household and therefore she should follow his example for how to keep the home. While she remained close to her family, after her marriage she found herself keeping the closest contact with only one of her older sisters, who helped her with some of the household expenses when her husband became ill in 2002.

> *He used to drink and he kept becoming very lean. He was nice and healthy but he just became very lean. Earlier, in Pune, he had been working in a photo studio and was in good health. Then, he was fat and tall. But then he kept having constant weight loss and he said to me that the doctors had told him he was suffering from tuberculosis and that is why he was losing weight. When he told me that the doctors had suggested he go to another hospital for a TB check-up, I thought it was nothing to worry about. My sister's mother-in-law also had TB and we knew that she had also had constant weight loss. So I didn't think his check-up was an issue. For three months I believed he had TB and that was the cause of his health problems. He never told me that he had been diagnosed with HIV. He was taking tablets but he explained that this was for his TB so I did not question him.*

Shruti found it hard to explain the extent of her shock and anger at discovering her husband's lies and that she and her daughter were also positive for the condition. Unusually, her first response was to disclose her status to her older sister. Shruti felt too overwhelmed to deal with the news on her own, particularly as she was trying to come to terms with the betrayal of her trust and the fact that her husband's actions had put her daughter's health in jeopardy.

> *Immediately, I told my sister that day. I made a phone call to her from the hospital and asked her to come to meet me. I was afraid when I told her that my daughter and I were infected with HIV. But her reaction was kind. During that time, she hugged me and my*

daughter and cried with us bitterly. She even questioned my husband for me. She told him that at least he could have told me that he had the infection so that we too could have taken medicine. He explained that before our marriage, he had done a lot of mistakes but he would not say what those mistakes were. He said that he was afraid that I would take a wrong action, such as committing suicide, if he had told me. My sister was very strong and she made us sit down and listen to her as she explained about the television adverts about HIV and that there are medicines to take that would help. She was telling all these things but I was still finding it difficult.

When I came back home and when I saw everyone, I felt as though I was seeing some strangers there. They are all next door neighbours. But that feeling had entered my mind that I am infected with HIV and my daughter is infected with HIV. I feel a kind of shyness, nervousness and fear… like they might keep us away if they come to know my status. That fear is still here within me. I have not yet had the courage to go and disclose my status to outsiders.

Avani (married, mother of two)

Avani's upbringing was very similar to that of my other participants. Her family kept her and her sisters very close to the home. This meant that at the time of her marriage she had not had very much socialisation with individuals outside of her immediate community. As a result, Avani felt both unprepared for life away from her home and excited to finally get to experience more freedom. As a result, her HIV diagnosis was difficult to come to terms with.

In my house, they have never sent me outside. Any outside work was only done by my father or mother. My mother used to say that if I wanted to go the temple or if I wanted to go to the cinema then I should wait until my marriage. After that, I can go along with my husband to all of these things. I thought that in my husband's house things would be easier as girls in our family are very restricted. After getting married, my life became like this in my own house after the HIV status. That is a great agony to me.

In 2005, Avani became aware of her HIV status through her husband's declining health, which is similar to many of the other participants. When he began to suffer with fevers and paralysis on one side of his body, Avani took him to several hospitals where they tried different tests and treatments. At first, they suspected that his years of riding a motorcycle had affected his spine and that was causing the paralysis but the tests were inconclusive. After fifteen days of

different treatments had resulted in a lack of answers and improvements, the doctors offered her husband an HIV test.

> *During that time of the test, I was not there. My mother-in-law was with him as I had gone home. When the test results came, the doctor said he would not give them to anyone except the patient's wife, not even my mother-in-law. When I saw that section of the results, it was very disheartening for me since it was from the HIV department. It was quite difficult for me to accept because he was educated. I thought how could he get this condition? During that time, I was mentally upset. Before giving the result to me they sent me to counsellors and provided advice. It was only because of that that I could tolerate that result. After giving me my husband's results, they said that I would need to do testing too. At that moment, I was very much broken. They did testing for me and said I was also HIV-positive. I was mentally shattered. Even after that, they said they would also need to do testing for my children. I thought within me, suppose if my child is also positive. Then I should not be alive. I should die. I have younger sisters and I felt that my shame should not impact their lives.*

> *After they tested my children, they finally said that they had good news for me. They said that I had to lead a life to take care of my children and they took an oath from me before giving me the results from my children's tests. They were negative and I felt more confidence. The staff made me promise to not take a wrong decision like suicide because of my condition as I was still very upset and shattered. I used to cry bitterly but I had two children to care for. I used to carry one child along with me and come to the hospital, while the other child stayed at my mother's place. At that time, she did not know the reason for the hospital visits. I only told her my husband had TB.*

Unfortunately, the HIV diagnosis caused a lot of problems in their home as Avani, her husband and her children were living in a joint household with his parents. Their positive statuses, combined with her husband's ill health and inability to work, created tension with her mother-in-law, who ultimately asked Avani to leave with the children.

> *It was difficult for us to maintain a family. During that time, my mother-in-law said that she was unable to feed everyone in the house and she sent me back to my mother's place. She said she will only take care of her son and that is all. She created a problem like this. My husband agreed with his mother so I went to my family home. During that time my children were very young so I took a job doing stitching to care for them. I was earning and caring for my children while also caring for my husband, even though he lived separately. Monthly I used to go and meet my husband and I used to buy medicine for him and give him money. I knew that if he was with me, then I could not go out to work as a person would need to be with him to care for him throughout the day. When his health improved, he finally joined me and the children at my mother's place.*

Riya (married, mother of two)

Riya had been married for only six months when her new husband became ill. Their local doctor diagnosed an infection in his blood and suggested he be taken to a specialist clinic. Riya was left on her own as he asked his friends to take him to the clinic. When he returned to their house, he explained that he had had a reaction to TB and been given tablets. In a similar case as that of Shruti, Riya's husband was actually diagnosed with HIV but did not disclose this information to her. Unlike Shruti's experience, however, Riya's husband did not disclose his condition until six years later, when Riya's health began to fail after the birth of her second child.

> *While I was breastfeeding my second child in 2005, I felt I had a lump in my breast and I became very sick and weak. During that time, my husband suggested that we go to the specialist clinic that he had attended. It was only after I arrived at the clinic that I came to know about my husband's condition. The staff there explained that he was taking ART medications and not TB tablets. The staff said that because of his condition they would need to test me and the children as well. Then they did the blood tests and found that I was positive for HIV. For my children they found that my older son was negative but the younger son was also positive for HIV.*

Riya's husband cited the fact that their marriage was a love match, rather than an arranged marriage, as the reason he did not disclose his status to her when he was diagnosed. As it was only a short time after their marriage, he was afraid that she would leave him. Riya was scared and worried about how the delay in disclosure had affected her and her youngest son.

> *I was angry. I was cross with my husband because he had betrayed me. To such an extent, I had so much trust in him but he had been doing so much without informing me of anything. If he had told me earlier, then I would have taken care of myself. When I came to know about my second son's status, there was a big quarrel in my house between us. Even if I think of getting separated from him, I cannot. For the sake of my children I am forced to stay with him. We are staying together for the sake of my elder son. If he had also been positive, then I would have taken a different decision. But he is negative, so we are staying together for his sake.*

Aarohi (married, mother of two)

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As the youngest of four children, Aarohi knew that her parents would arrange her marriage as they had for her siblings. Her parents were very pleased with the match they had found for her and she was willing to take part in the wedding. While her husband works as an ambulance driver for one of the hospitals, Aarohi remains at home to care for their two daughters. HIV infection has been an isolating experience for her as she finds it difficult to disclose her status.

> *In 2008, I was diagnosed when I had a check-up in the fifth month of my third pregnancy. Before this, I was not aware of this condition, my husband and I were diagnosed at the same time after the doctor who treated me told me to bring him for testing. My husband used to be a lorry driver and without my knowledge he had made a mistake while out of the city. He told me that one of his friends had taken him and he accepted that he had gone a wrong way to cause this. I wanted to go to my parents and say to them that only they have got me into this situation. Look what has happened now! But then, later on, I thought that they are elderly now and if I tell them like this, what will happen? Instead, I thought I should let my difficulties go and I should keep this from them. At least this way they will be happy thinking their daughter is leading a normal, happy life.*

For Aarohi, her diagnosis caused a period of deep depression wherein she found herself fixating on her condition and the unfair nature of her infection. In her mind, all she could think about was the fact that she had done nothing wrong, made no 'mistake', and yet she now found herself labelled as yet another victim of the epidemic. Aarohi struggled to accept the identity of HIV-positive. While discussing her status with the doctor, she was further upset by his comment that, as a child growing up in a village, there would have been little chance of her gaining awareness of this condition prior to her diagnosis. In her doctor's opinion, this was due to the lower levels of education found among young women in the village settings and also the tradition of being married at younger ages. This discussion sent Aarohi further into her depression and she found herself unable to control her emotions. Instead, she spent days crying alone. After a few weeks, she found her sadness turning to fear as she began to contemplate what her status would mean for herself and her family.

There are so many people suffering due to HIV. I read about one incident in the newspaper where, when the people in the village came to know about the status, they sent that family away from their village. Here in Chennai it is not as bad as that, but if they come to know it will be very difficult. How could I tell anyone? Even for a small issue they will talk about you disgracefully and could even kill you. If they come to know about my HIV status, then they will say that I have gone the wrong way because I am a woman. They will not talk anything about the man. They will first put the blame on the woman only. That is the reason I didn't disclose my status to anybody. I want to hide it to the most possible extent that I can.

As indicated by this interview passage, Aarohi felt that her gender would mean a greater instance of stigma and discrimination. Therefore, she had been doubly burdened by the lower social status experienced by women. First, her level of awareness was directly tied to her female identity through the traditions of village life wherein she was not taught about the dangers of HIV and instead socialised to focus on family and household wellbeing. Secondly, her female status again became problematic post-diagnostically as she feared the question of blame would be placed on her shoulders despite her husband being the source of infection.

Priya (separated, mother of two)

Priya had a similar experience to Aarohi's as she also grew up in a village setting. Her family members were directly involved in her life as they made decisions regarding her well-being, her actions and ultimately who she would marry.

I was married to my mother's uncle's son. He was not her own brother but a cousin brother. Initially, he was in Andhra. During that time, I didn't know much about him. Then he came and married me since I was his sister's daughter. When he would first come to see me, I didn't know anything. I was brought up like that by my mother. I used to go to school and from there I used to come back to my house. It was like that. I studied only until the eighth standard and after that they didn't send me to school. So I was not aware of these things like HIV. Then my mother told me to marry my maternal uncle and I agreed to marry him. When we came to Chennai from my village, he struggled to find good work. He would disappear for long periods and I would have to go to my mother's place. He used to drink a lot and cause fights. Once he threw me out of the house and would not allow me to enter to collect things for the children. He disgraced me.

Despite her husband's abuse, Priya did not feel she was in a position to leave the household as this would cause tension with her family members. Her husband was distantly related and therefore a member of the family as well. As a result, Priya feared she would not find support within the other households and therefore would be unable to care for her children. Therefore, she felt she had to stay with him and try to make the best out of the situation. However, her husband made life very difficult and refused to allow her to make any decisions regarding the household finances.

> *When I would try to question why he was drinking so much, he used to say that he could do what he wanted because it was his money that he had earned. In the beginning, he had agreed to marry me without dowry. During that time, my father was very sick. My mother told him that they were not in a position to give anything for the marriage and so if he wanted to marry me, then he would have to accept that. During that time, he agreed and said that he will marry me with nothing. The reason for that was that when he was a young man, my grandparents have taken care of him nicely and been very affectionate to him. So as a token of gratitude to them, he has come from Andhra to marry me. The marriage was very simple, even my mother did not give me anything. She gave me sarees that she was wearing and utensils from within the house, nothing new. They didn't give jewels and all, just simple anklets and earrings. That is all. After getting married, he started taunting me about this. That they didn't give me anything for the marriage.*

Of additional concern was the impression her husband's actions were giving to her neighbours. As he would come and go from the house at strange hours, Priya began to fear that the neighbours would think she was not the married woman she claimed to be. This had the effect of further isolating her from potential sources of support, which meant that her self-confidence and personal agency were further constrained.

> *He would only come to the house at night. Like a thief. I don't know the reason for it. He used to come home only during midnight or early hours. In a family house, if a male comes and goes like this, they would all act suspiciously of me. I used to tell them that it was my husband but I don't know whether they trusted my words or not. I used to fight with my husband about this because it was disgracing me. But he just left to Andhra again. When he returned, he was very sick. He had wounds on his legs, cavities where I could put my finger. Very deep. It was in both legs below his knees. He also used to have lots of fevers so we knew he was very sick.*

Social Personhood

The pre-diagnosis backgrounds of these participants has focused the discussion of illness experience onto several issues which relate to women's place within their families and societies. This section will examine how identity and the concept of one's self is determined within the confines of societal expectations and norms, while also addressing the social structure that creates the vulnerabilities that women experience.

In 2007, Rehanan Ghadially provided a useful summary of the gender-based violence and social consequences women face in India, such as dowry deaths, custodial rape, female feticide, and eve teasing (Ghadially, 2007: 15). Historically women have faced greater social isolation and control than their male counterparts, which has in turn resulted in unequal sex ratios and difficulties in accessing healthcare, particularly in the case of reproductive health. This has left women vulnerable to higher levels of infant and maternal mortality and allowed for abuse through untrained sterilisation practitioners (Ghadially, 2007: 15). While gender-based violence and socially-created vulnerabilities, as indicated through the narratives of these participants, are widely considered to be issues for all areas in India, there is a marked difference between the different regions.

As indicated by previous studies into India's regional differences, there is a distinction to be made between the north and south of the country (Ghadially, 2007). Within this division, there is a particularly wide variation between the northwest and the southeast, where Tamil Nadu is located. The northwest was found to have the lowest female autonomy and most unfavourable demographic performance while the southeast demonstrated the opposite with high levels of female autonomy and more favourable demographic data (Dyson and Moore, 1983: 35). The difference between these areas has resulted in southern women's relatively improved social

position and positively impacted the different markers for social studies. These include a later age at first marriage, lower ratios of female to male infants and lower child mortality, lower overall fertility and marital fertility, and relatively low sex ratios (Dyson and Moore, 1983: 42).

Some of the main differences for women in the southern states involve the approach to marriage. Women within the southern kinship system are more likely to marry 'known' persons, such as distant family members or neighbours (Dyson and Moore, 1983: 45). As a result, they are less likely to move far from their natal homes after marriage, which allows for a greater sense of confidence through continued interactions with their families. Additionally, within this kinship system, women's sexuality and movements are not as severely controlled as their northern counterparts and therefore they are able to experience a greater level of individuality and freedom. However, despite these benefits, southern women are not entirely free of the social bonds that impact their pre-diagnosis awareness as their position within the family remains subservient through economic and social pressures.

For the participants of this research, the majority identified themselves as housewives prior to their diagnosis. They could be found living either in joint families with their husband's relatives or, more rarely, on their own with their husband and children. This setting is not unusual in India, despite the reports that the growing middle class is causing a shift away from these traditional household arrangements. For the purposes of this research, the terminology of households followed the example set by the participants. For example, the women in interviews used the term "joint family" although this does not correspond to the set definition given in previous studies.

Caldwell, Reddy and Caldwell defined the varying types of family household in their 1984 essay where they distinguished between nuclear, stem, joint and joint-stem families. The nuclear family was defined as a married couple living alone with only their children while the stem family

indicated two married couples of different generations sharing a household. By contrast, the joint family was defined as a household that contained married siblings and the joint-stem family was classified as the "classic full pyramid" indicating the presence of family members from multiple generations and varying marital statuses (Caldwell, Reddy and Caldwell, 1984: 218). For example, this could include grandparents, married and single siblings and their children. Within discussions with participants, the terms nuclear or joint-stem were never used with individuals instead referring to nuclear families as 'living separately' while other households were simply referred to as joint families. Although the role of the family in modern Indian society, particularly in the urban centres, has become less intrusive than it has been in the past, it continues to be an important influence within the formation of identity among participants (Cohen, 2002).

Defining the Self

In these settings, the definition of the self-described by participants is closely tied to the expectations and designations derived from interactions with family members. Banerjee's (2002) article on women's role within contemporary India highlights the tie between a woman's position in society and her sexuality, which is seen as something that needs to be controlled (Banerjee, 2002: 61). In particular, women are socialised from a young age to undertake household related tasks and therefore are unprepared for the labour market, which in turn places a greater value on young men who are seen as being more mobile and less encumbered with family obligations than young women looking for work (Banerjee, 2002: 65). Therefore, when the expectation of a household-based future, focused on marriage and children, is challenged by HIV diagnosis, it causes the liminal state that women find themselves in. A crucial element in this state involves the changing levels of personal agency felt by participants.

Bandura has defined personal agency as the belief that one's actions can alter the course of one's environment. Indeed, "unless people believe they can produce desired effects by their actions they have little incentive to act or to persevere in the face of difficulties" (Bandura, 2008). In the pre-diagnostic setting, women find they have very limited personal agency, which can be considered to be constrained agency. They are able to make lower level decisions in their daily activities but are unable to make more important choices regarding healthcare due to their place within the household. Dependent economically and socially, women are often left with fewer choices in order to improve their health. This gendered difference extends within HIV to create particular vulnerabilities. On the one hand, women are more biologically vulnerable to the virus with an HIV-negative woman being at least twice as likely to contract HIV from an HIV-positive man than a man would be if the roles were reversed (Mukherjee, 2007: 117). On the other hand, women are socially vulnerable as their constrained agency does not allow for the influence necessary to undertake the advice in awareness campaigns. For example, within households, a married woman could not request condom use without having suspicion fall over her motives. Within the Clinic, women continually reported that their wishes were not respected when they requested abstinence or condom use.

While southern India's comparably higher level of female freedom and autonomy results in better access to health services and more involvement in family planning than their northern counterparts, this is still relative when considered within the illness experiences of participants. In many cases, the level of healthcare access and reproductive control is largely dependent on economic concerns within the household. Within their positions as housewives, participants found they had little ability to affect the way finances were distributed within the household. This was complicated in the case of joint families as the participants found they had even less say in these

decisions. These economic concerns are linked to reproductive health choices as women are not able to act on desires for condom use as they are unable to use the household funds to purchase them.

Pre-Diagnosis Awareness of HIV/AIDS

The narratives of illness experience, as described in the following section by the participants of this research, indicate the obstacles many women in India face as they struggle to understand the repercussions of their diagnosis. Pre-diagnosis awareness is often very low and, as a result of the misinformation spread about the condition, many women are unaware of their potential risk. Additionally, gender-based difficulties in gathering information are indicated as many women receive their limited awareness via those around them, which is indicative of the socially constrained level of personal agency regarding their health decisions.

In 2006, as a young, married housewife, Diya's awareness of the growing HIV epidemic in Tamil Nadu was extremely limited. She remembered that there used to be notices on the television, which featured a man explaining that although he has HIV, he is able to live a happy life. However, she did not feel that she gained any awareness or information from these notices. Instead, the television ads only helped her to view the condition as something that only affected other people. In particular, this was seen as a disease for those who had 'done a mistake' or 'gone a wrong way'. Recalling an instance when she had been watching television with her mother, Diya explained that when the advertisement had come on the screen, her mother's first reaction was to ask, "If you have HIV go and die, why is it that you come on television?" Although the memory is painful for Diya now, she remembers laughing at the time and gossiping about what mistake the man might have done to result in this disease. She knew enough about HIV to know that sexual activity could spread the infection but she is adamant that she believed only 'illegal' or 'wrong'

sexual activity could be the cause. As a result, her first reaction to receiving her diagnosis was shame as she understood that to have tested positive meant that her husband had engaged in these actions.

Diya received her diagnosis in 2006 while in hospital to deliver her son. Although she had been to the hospital for the different tests during her pregnancy, she had not been given tests for HIV/AIDS. Looking back, she realised that the doctor should have given her these tests when she came for her check-up but is unsure why this step was skipped in her case. In Tamil Nadu, pregnant women are given HIV tests during their check-ups in order to help prevent the spread of the infection to the foetus. As a result, many women are diagnosed before their husbands, which can cause extreme distress and fear, particularly if they live with their husband's family in joint households as they know they can be blamed for bringing this condition into the family.

Like Diya, many of my other participants explained that their pre-diagnosis awareness of the HIV epidemic had revolved around the concept of "illegal sexual contact." The term 'illegal' is telling as it does not actually refer to legal consequences but rather to socially understood misbehaviour, wherein the consequences are also socially constructed. For example, Aarohi, a 33-year-old mother of two, vaguely remembered hearing about HIV while still in school in her village. She recalled that the teachers used to display posters on the boards, which referred to the condition as being a direct result of this 'illegal sexual behaviour'. When asked to define this term, she explained that sexual contact before marriage was seen as the main cause of infection and therefore marriage was seen as negating any possible risk. Additionally, women were often the target of the posters, which seemed to imply that infection was easily avoided if you were a woman as long as you did not have sexual contact outside of your marriage. As a result, her own diagnosis came as shock. By the time she was diagnosed in 2008, she had also come to know that infection could be

caused by untested blood transfusion or even drug use. As a housewife with two children to look after, she never considered herself at risk of infection as it was quite easy to look at the three causes she was aware of and identify herself as not being at risk.

For my participants, their knowledge, or lack thereof, regarding the local epidemic was gleaned primarily from those around them rather than from the official discourse on the subject. This is a common theme for my participants as, since they did not have any formal means of gaining information about the condition, they relied upon hearsay and rumours, which were easier to access. Most often, this involves their family members, which then also causes the mental anguish and fear found after diagnosis as they know how they will be judged.

Additionally, the mentality that infection meant an early death was common to all of my participants and demonstrates the level of information available to the general public as rumours spread about the epidemic. However, this level of misinformation was further aided by confusion regarding unfamiliar terms, such as HIV and AIDS. In particular, the term AIDS was often used as a catch all for the epidemic. This meant that individuals were being wrongly informed of their diagnosis. Although there was uncertainty about what HIV might mean, it was well known that AIDS meant death. Saanvi, 35, explains:

> *AIDS means within a short span I thought I would die. I thought I would become very sick. When they told me I was infected with HIV, the first thing that came to my mind is that I should die instead of living. HIV meant AIDS in my mind, I thought they were the same thing. During that time, people said AIDS only. I didn't know about HIV's difference.*

This confusion was echoed by another participant, Kalpana, 46. As she explained, her awareness of the epidemic came from posters in her school. However, the posters referred only to AIDS and featured a skeleton with the message that AIDS was a life threatening disease. Therefore, in her mind, AIDS was the condition to fear and HIV was not something she had any awareness of.

As Shruti, 38, explains, the moment of diagnosis is the point at which a barrier comes up between the individual and the rest of society, wherein they feel they no longer have a place as they are now members of a group looked at with disdain and judgment.

> *When we tell them we have HIV, the first thing that comes to their mind is that it is a disease related to illegal sexual contact. Until now, that fear is there in their mind. Suppose, if I tell others that I am infected with HIV then they will think 'Shruti has gone to someone and she has done a mistake and that is the reason Shruti has got this disease.' They will think like that only. They will not think HIV can be transmitted through injection or from a mother to a child due to breastfeeding. All this information they don't know. To my knowledge, many of them are not aware of it that HIV will spread through four ways. They are all aware of only one way. In their mind-set, all that they know is that if a woman and a man have illegal sexual contact, this disease will come.*

Socially Constructed Vulnerabilities

This awareness of the public perception of the epidemic, and the expectations of the characteristics of sufferers, combines with the internal confusion felt by the participants within this research. With the news of their diagnosis, their futures look bleak as they are relying on the misinformation and rumours they have heard for years in order to understand their condition. However, as their knowledge increases with visits to doctors, counsellors and nutritionists within the Clinic, they find themselves building a barrier between themselves and their family and communities. They feel their condition means they are ineligible for the social positions they had once expected, such as getting married or having children, and are unable to express their concerns as they fear disclosure could cause negative consequences such as isolation or abuse. Therefore, they find themselves within a period of liminality.

As highlighted in previous chapters, liminality is defined by Turner as a period wherein the individual is structurally invisible. Further clarified as a 'structurally indefinable transition-being', the liminal person finds themselves outside of the norms set by society. As Turner explains, this period is inherently complex as the individual, or liminal persona, finds themselves outside

the realm of socially classified positions while at the same time being a classification in themselves as they are recognised as being outside and therefore unacceptable within social norms (Turner, 1969: 95; Turner, 1987: 6). As demonstrated by the experiences of these participants, the rumours and misinformation that flourished during the perceived silence within the official discourse continues to negatively impact HIV-positive individuals.

This element of the illness experience for HIV-positive women is useful in offering a practical example of Ian Hackings' concept of the 'making up of people" (Hacking, 2002: 100). With a condition such as HIV, the public perception of the illness is the overriding message individuals have when they receive their diagnosis. Highlighted by Hacking (2002) as "dynamic nominalism," this involves the ability of socio-cultural concepts relating to illness to inform the identity of sufferers (Hacking, 2002). As a result, it is widely understood that HIV-infected individuals will share certain features that are considered detrimental within society, such as a questionable moral character and proclivity to undertake inappropriate or abnormal behaviour. The fear for individuals involves the ability for this perception of the condition to override their own personalities and become the defining element of their selves for those around them. In this way, public perception has the ability to 'make up people' even though the reality of the condition is often very different. The confusing nature of this situation, wherein one meets the criteria of this persona through medical diagnosis but without the social criteria applied to it, creates the liminal state that individuals find themselves in, which is part of the overarching social suffering found within the illness experience of the condition.

Social suffering was defined by Kleinman, Das and Lock in 1997 as resulting "from what political, economic and institutional power does to people and, reciprocally, from how these forms of power themselves influence response to social problems" (Kleinman, Das and Lock, 1997: ix).

Also referred to as macrostructural forces, these outside influences have been shown to directly impact not only public awareness of conditions but also, as evidenced by the narratives of the participants in this research, social forces have had a very large role in their conception of their condition (Kleinman, 1986; Das, 1993: 140; Scarry, 1985; Good and Good, 1988; Chuengsatiansup, 2001). Public perception and the official response have led to a fracturing of their selves as they try to navigate the post-diagnostic landscape wherein they find themselves belonging to multiple, conflicting categories.

As noted by Markus and Kitayama, the conception of individuality within many Asian cultures insists on the importance of recognising society's interconnected nature (Markus and Kitayama, 1991). Therefore, the emphasis for individuals is to fit into the prescribed society in order to maintain the traditions of community and family (Markus and Kitayama, 1991). This version of the self is constructed through the various tasks and expectations placed onto the individual by those around them. Therefore, all members of the society are aware of the implications for acting outside of the given norms. Societies that follow this strict organisation are reliant on the structure being adhered to and continued, resulting in an imperative interdependence among the members of the society. Therefore, when the concept of the self is directly informed by constructs such as this, the "self becomes most meaningful and complete when it is cased in the appropriate social relationship" (Markus and Kitayama 1991: 227). Within the illness experience of HIV, this communal agreement of expectations regarding individuals causes the beginning of the liminal state as individuals realise their positive status now makes them abnormal within the prescribed social organisation.

Post-Diagnosis Narratives of the Self

The participants of this research have further highlighted in the above sections the complex role assigned to women by public perception of this local epidemic. On the one hand, women are seen as part of the problem as "illegal contact" is designated as the primary route of infection. In joint families, even where the woman has no position outside of the household, women are often blamed as the carrier of the infection and treated poorly as a result. On the other hand, young women are most likely to be unaware of their risk of infection, as a result of having less education and contact outside of the home than their male counterparts. Therefore, women's role within the local epidemic varies according to public perception and the actual experience found within the Clinic. For the public, women with HIV are seen as having 'gone a wrong way', either through commercial sex work or drug use. This places them outside of social norms and they are labelled as deserving of their condition.

However, this contrasts firmly with the view from within the Clinic where women are seen as being vulnerable to infection through the actions of others, such as their husbands, and as a result of their limited personal agency with regards to health decisions. Additionally, women are often found to be more likely to adhere to their medication and therefore have better health outcomes. As one of the doctors in the Clinic explained, the socialisation women receive throughout their childhoods, which was indicated by Banerjee (2002), focuses primarily on household duties. As a result, women feel their social responsibilities, such as caring for parents or children, much more strongly than men (Banerjee 2002: 61). While this was originally a detriment to their ability to act on personal agency with regards to their health, post-diagnostically it creates the impetus to adapt to their condition in a shorter amount of time. They are more likely

to be concerned about how their illness will impact those around them and therefore they take the necessary steps to maintain their health for as long as they can.

Additionally, increased personal agency was often the result of the changing position post-diagnostic women held within their households. Although often a result of either abandonment, illness or the death of their spouse, the majority of participants had moved into the role of provider within their households as a result of HIV diagnosis. The ability to control the family finances meant an increased ability to make decisions to benefit their health and day-to-day activities. In this setting, HIV diagnosis becomes the catalyst for shifting from the socially constrained agency felt previously into a higher level of personal agency.

The participants of this research therefore echo the Clinic's position as a transformative space as they undergo a transformation within their liminal state. Upon entering the liminal state, the women felt confused and isolated by their condition as they fell back onto their awareness of the public perception of the condition. This informed their low expectations of how they would be viewed upon disclosing their status. During this period of transformation, however, they have found themselves taking on more personal agency in their decisions as they moved into different household roles, gained greater insight into their condition and began to view society from their liminal state.

Shruti (*widowed mother of one*)

As Shruti explains, many elements of her life post-diagnosis remain the same as they were before receiving her diagnosis. In this way, the only element that has changed is the need to take her daily medicine in order to maintain her health.

> *Right now, I don't have anything. As I was before when I was normal I am now. I am keeping well. When I came to know that my daughter and I were infected with HIV, mentally I was upset. After that, my daughter and I started taking medicine and now we don't have any problem. We are normal only.*

However, her HIV status is never far from her mind as she continues to see the public stigma relating to the condition. While she knows that her own status must be protected in order to avoid negative repercussions, she has been influenced by the activism within the Clinic to try and improve the public awareness as much as possible. For example, she has started talking to others about HIV/AIDS in casual atmospheres in order to help spread correct information rather than the misunderstandings or rumours more commonly discussed.

> *In the women's association, we have meetings where everyone will choose a topic and they will speak on it. So I once chose the topic of HIV and I spoke on it. This group is run through my older sister's house, where they meet. I am not a part of this group but I was visiting my sister so I joined them for the meeting. When I was speaking on HIV everybody there looked at me very troubled and they saw me differently. They thought why I am I talking about this. I said I have read like this in a book and explained what I knew about the subject. Whatever knowledge I had about HIV will now spread through them. Fifteen of them were sitting there and although everyone looked at me somewhat strange, they listened. Afterwards, their actions towards me were normal. I said I had read all these things in a book and in the newspaper. I did not tell them of my own status, only that I wanted to discuss this topic.*

As she explains, in the narrative sections below, Shruti feels actions like hers are the best way to improve awareness directly among the general public. When individuals can relate a face to the information, they are more likely to retain it.

> *For the public to understand about HIV we need to talk more about it, like how it will spread not only through sexual contact but also through injection. If we use needles that are not sterilised it can cause HIV to spread. Chances are that HIV can spread from mother to child through breastfeeding or from husbands to wives. We can tell all these things but most people lack the knowledge to accept this information. We have to tell them in ways that they can understand better. All that they know is that HIV will spread through male and female having illegal sexual contact. This is the only concept which they have understood. Since I am taking tablets and since I am attending meetings, I have so much more knowledge of HIV. General population and all, they don't know much. Deep in their mind, they have the thought that HIV will spread through a male and female having illegal sexual contact. They only know this. Apart from that they don't know about injection and all.*

Additionally, Shruti raises important points about the health possibilities of HIV-positive individuals, which are currently unknown by the public because they do not see the reality of living with the condition. Instead, the official discourse focuses on the worst case scenario for individuals.

> *I want to tell that HIV is not a disease to get scared of and all. Suppose if we have cancer or diabetes or blood pressure, then we will have fear of our food. We will cut down on sugar and salt. HIV is not like that. There is no problem at all with it. We don't have to get scared thinking about that, we can eat nicely. We can eat sugar, we can make whatever sweet we want and we can eat it. People who have blood pressure problems or diabetes or cancer… they will die of some complication. We cannot tell that people with HIV will die soon. If we take the medication, have a good diet and if we keep our mind stress-free and tension-free, then completely we can forget the thought that we are infected with HIV. We will not have the thought that we are infected with this disease. I am like that only. I keep doing my work. My daughter is like this as well; I am teaching her to think this way. So she is also free of those thoughts. What I want to tell the general population is that they should not get scared and feel HIV is a problem.*

Avani (married mother of two)

Looking back at that time in her life, Avani cannot help but feel an earlier diagnosis would have greatly benefited her family. However, the fear of HIV was so strong that individuals did not even want to think of having their own tests.

> *During that time, they only tested him for TB. When he was positive for that, they tested me as well but I was free of TB. At present, if a person is found positive for TB, they immediately will have testing done for HIV. But in 2005, this was not the case. If they had done HIV testing and suppose if they had found out he was positive right away, then his health would not have deteriorated so much. When he was still healthy we could have come to know his status. Instead, we focused on the TB and he was taking medication for this.*

Similarly to Shruti, Ayani sees the primary impediment to improving the public's perception of HIV/AIDS as being the lack of awareness about the actual reality of living with the condition. Instead of seeing the healthy lives HIV-positive individuals are experiencing, the mainstream view of the epidemic still focuses on the characteristics seen in the early years such as extreme ill health and death.

At present, I don't have the fear that I used to have. They used to put the picture of a skeleton on television and on posters, and I used to think if this disease comes to someone, then they will look like that. That used to always be in my mind but not now. I am not affected doing my day-to-day activities, nothing like that. Whatever work I was doing before, I am still doing now. Even though I have tiredness in my body, I will overcome it and I will do all of my work. If I stop my work, then there is nobody else to do my work in my home. So, all my routine work I do myself.

Avani and her immediate family now live in a separate home without either her mother or her mother-in-law. Avani felt that her presence in her family home could negatively affect her younger sisters as their neighbours do not know about her status. If her status was disclosed, her sisters might experience stigma as well as a result. She has since taken on the occupation of an HIV/AIDS field worker. This means that she undertakes home visits to HIV-positive individuals when possible and also works to increase understanding of the epidemic through awareness campaigns. As a result, she has a clear view of the uphill battle attempts to increase awareness struggle against.

Fieldwork means I will go and visit HIV infected people in their house. In the mornings, I will go for hospital visits. In the hospital they will give me the addresses of patients who have not come for their appointments or collected their medication. The fieldworkers then go to their homes to give them counselling and to motivate them to come to their appointments. I also go to the TB centre and visit with people there. If we find new HIV cases, then we encourage them through counselling to attend the correct appointments.

Through her interactions with the Clinic, and the positive networks and support groups contained therein, Ayani has experienced personal benefits such as her new occupation. Therefore, she now sees living by example as a duty to individuals who are recently diagnosed.

All I want is for people in the next generation to be benefited through this work. They should not go a wrong way or be confused. If you provide information through the serials on television, then you reach a lot of people and they will get more awareness. When we give out slips of paper, the number who read them is very low. They will take the slip from us and then they will just throw it away as they go. If it is in the form of a serial, then you will be distracted by the message of the show and you will pay attention.

Riya (*married mother of two*)

The love marriage between Riya and her husband seems to have created a different atmosphere than that experienced by the other participants after their diagnosis. Although her husband kept his status from her, Riya finds that he has been supportive of her health since her diagnosis. While her husband continues to work in an office to support the family, Riya stays at home caring for her children and her mother-in-law. When there is tension, her husband is quick to defend her from any accusations regarding her HIV status.

> *Now, suppose if there is a quarrel with my mother-in-law in the house. She will say that it is because of me that my husband has become infected with HIV. That our marriage was the day his life changed negatively. However, when she is talking like this my husband will intervene and tell her that the mistake was on his side and that she should not talk to me this way.*

As a result of their diagnoses, Riya feels she and her husband experience more equal power distributions within their relationship. Her husband knows that the decision to remain a family was Riya's to make and therefore he has accorded her a greater level of respect within the household, which he also demands from other family members.

Aarohi (*married mother of two*)

As a young woman growing up in her village, Aarohi had found her life strictly controlled by those around her as her parents dictated how she should behave, where she could go and what she was expected to accomplish in life. In her post-diagnostic life, Aarohi now finds herself with a greater sense of independence and, as a result, now sees the involvement of her family members as a burden rather than a benefit.

> *They will ask me but I have told them that I am anaemic. Mainly my mother will ask me. My father will sometimes also ask me about my health. If I go to my village, my brother's wife will ask me. She will say that since I have been taking the medication for so long that we should go and have another check-up. It is difficult to take my medication when I am visiting them. Here I am alone. I will eat on time and take the medicine regularly. If I go to my village, I cannot expect food and all to be on time. My own house is different. I have got married and I have come out of my family house. Now, my brother and his wife are there so when I go to visit I am a guest. I cannot take my medicine in front of them because*

they will question why I must do it every morning and evening. So I have to lie to them about my anaemia. I am running my days by lying like this to them.

Additionally, her diagnosis is now seen in a much more positive light than when she was first diagnosed. Far from her days of depression, Aarohi is now extremely thankful that she received her test results when she did.

I have two girls and I have to care for them. When I was diagnosed, the doctor said to me that if the tests had been done later I would have died within one year. I thanked god for that. I have consoled myself that I need to care for my daughters.

Aarohi's narrative of her illness experience is a useful example for the benefits of approaching HIV/AIDS in this manner. Her feelings about her condition and her opinion of the influence of others has altered greatly in the four years since her diagnosis. During that time, she was able to reassess not only her condition but also her acceptance of the public discourse on the local epidemic and therefore has emerged from her liminal state into a position of greater independence with drastically improved personal agency regarding her health.

Priya (*separated mother of two*)

For Priya, 31, her diagnosis with HIV ultimately proved to be more of a life-altering event than she had first suspected. Not only was she forced to confront the realities of her condition but she would also find herself doing so alone. Her transition from married woman to separated wife was extremely abrupt and as a result, she had to find the internal strength to be a single parent while also coming to terms with her HIV status.

I don't have a husband. My husband abandoned me. He abandoned me seven years back. At present, I am staying with my two children in a separate house. With only my income to support us. When he left, I was working as a cook. He told me he was going to collect ART medication and after that he never returned home. I searched for him for three months. When he left us and went, I searched for those three months but we could not find him. Then I thought, he has decided not to stay with us and he has left us so why should we keep on searching for him. I have two girl children and I have to look after their futures. I should provide them good education and I should bring them up nicely. So from then on I stopped searching for him.

Priya is currently working within the positive network making nutritious packs for HIV-positive children, which are then distributed by other members of the network. This is a role that she would not have had without her own positive status and has allowed her to not only support her family but also to try and lead by example in order to improve the lives of other HIV-positive individuals. Although she maintains strict privacy with her own status, she is able to discuss the epidemic more freely with the public as a result of her occupation. Additionally, while her husband had been completely in control of the household finances before their diagnoses, Priya is now the only breadwinner and therefore is able to dictate how funds are allocated.

The Transformations of the Liminal State

As indicated in the work of Victor Turner, the liminal state is intended to be temporary, with individuals able to take the steps that allow for their reabsorption into society. Within the narratives expressed by the participants of this research, this final step can be viewed as their acceptance of their condition and the acknowledgement that the impact this can have on their day-to-day existence is entirely up to them. The liminal state experienced within the illness experience has differed from Turner's original definition as it was primarily directed by the individual, rather than society. For example, the initial separation from society experienced upon receiving their HIV diagnosis was internal to the individual. As they struggled to come to terms with their condition, they were still maintaining their social positions as wife, mother, daughter, etc. Therefore, the liminal state can be viewed as the beginning of the plural identities described by Sokefeld as individuals began to see their social selves as separate from their HIV-positive selves as the later remains unknown to the former.

This division between the social self and the HIV-positive self follows the discussions around a public versus a private dimension within individuals, which has been previously

investigated in varied settings. The private-public dimension can be viewed as the result when the self is seen as a composite, wherein "the constituents of which vary in the public and private modes" (Cohen, 2002: 2). As demonstrated by Lienhardt (1985) and Hsu (1985), this innate division within the self allows for the adaptation needed to merge into different settings without the self being replaced or destroyed (Lienhardt, 1985; Hsu, 1985). Instead, individuals are able to bring the elements of their identities that are most appropriate to the forefront while concealing the other areas. However, as highlighted previously by Sokefeld, the ability to recognise the need for these plural identities and to maintain them involves a strong sense of personal agency, which is found among participants only in the later stages of their diagnostic journey.

An example of how increased personal agency can impact all areas of post-diagnosis life can be found within the concept of "going a wrong way." This phrase was found in nearly every interaction I had with interview participants, staff members, or visitors to the Clinic. However, its meaning changed depending on whether it was being discussed in a pre- or post-diagnosis context.

For example, "going a wrong way," when considered pre-diagnostically, was meant as undertaking behaviour seen as immoral or incorrect according to social standards. This could include engaging in sexual activity outside marriage, injecting drug use or through homosexual behaviour. This phrase was often used alongside discussions of "illegal" behaviour or "mistakes," demonstrating the serious social consequences for those involved as these activities were widely understood to be going against the prescribed traditions and expectations of the given society.

The importance of maintaining these social boundaries of behaviour ties back to the description of society given by Markus and Kitayama (1991), wherein the members of the society are seen as tightly interdependent (Markus and Kitayama, 1991). If the standards and norms of the society were not respected, then the social structure would falter.

Post-diagnostically, the definition of "going a wrong way" shifts away from actions that harm the society to those that harm the individual. For example, the most common description given by participants of "going a wrong way" involved suicide. Additionally, there is a gender-specific component as suicide was primarily discussed with women whereas men were often counselled against using drug or alcohol abuse as a means of coping with their diagnosis.

Within these narratives of post-diagnosis life, there are several areas wherein the new definition of the self has taken place for these participants. These include emotional and economic changes while also including alterations in social position as a result of these changes. While the narratives of pre-diagnosis life had painted a picture of the participants as being socially vulnerable to HIV diagnosis as a result of the actions of others, their post-diagnosis discussions delve into the renewed senses of personal agency as they are able to actively control their immediate environment.

These post-diagnosis changes in their socially visible selves were made possible through the ability of the Clinic to present a safe space wherein HIV can be acknowledged. For example, all of the participants of this research had successfully maintained their pre-diagnosis positions within society, albeit with some interesting changes. For example, many of the participants had become the main breadwinner of their families, which in turn had allowed them greater economic freedom in addition to the increased confidence this position brings.

Additionally, the Clinic also acts as a source of self-confidence as participants receive counselling over their ability to maintain their privacy regarding their HIV status. As a result of their interactions with the arena of the Clinic, within which they are able to discuss their questions and concerns, participants felt they were better able to acknowledge their condition while still remaining in their pre-diagnosis settings. Therefore, the Clinic not only provides the tools

necessary to come to terms with HIV, but also acts as the site of the primary benefits of these tools

by providing a community of HIV-positive individuals.

Conclusion

In Sickness and in Health

"It took me quite a long time to develop a voice, and now that I have it, I am not going to be silent."

- Madeleine Albright, Former United States Secretary of State.[38]

"There is no tool for development more effective than the empowerment of women."

- Kofi Annan, Former Secretary General of the United Nations[39]

"Another world is not only possible, she is on her way. On a quiet day, I can hear her breathing."

- Arundhati Roy, Author[40]

[38] Schnall, Marianne. 2010. "Madeleine Albright: An Exclusive Interview." *The Huffington Post.* [Internet] Published June 15, 2010. Updated Nov 17, 2011.

[39] UN News Centre, 2005. "Empowering women the most effective development tool, Annan says." [Internet] Published February 28, 2005. Updated February 28, 2005.

[40] Roy, Arundhati. 2003. "Confronting Empire." *World Social Forum in Porto Allegre.* 28 January 2003.

This thesis attempts to chart the diagnostic journey experienced by HIV-positive women in Chennai and has focused in particular on their illness experience throughout the process of coming to terms with their condition. The thesis has identified the complex influence the overwhelmingly negative public perception of the local epidemic has had on the women involved and the actions undertaken by the Clinic in order to support them through this difficult period. What has emerged from this research is an awareness of the transformative nature of the liminal space experienced by individuals after receiving their diagnosis and the ability of this process to create a greater sense of personal agency within participants. Therefore, this thesis ultimately seeks to begin a dialogue around the topic of HIV/AIDS among women wherein the potential for empowerment is recognised and examined.

The interviews and participant observations that took place within the Clinic were designed to gain a greater understanding of the illness experience of HIV in its entirety. As a result, these discussions ranged from the early days of the epidemic until the present, with particular attention paid to the reality of the condition as explained by interview participants. This thesis sought to understand how an HIV-positive diagnosis alters the social expectations held by participants while also seeking a greater awareness of the epidemic's public perception and the impact this had on individuals. Through an examination of socially constructed vulnerability, the ability for participants to overcome these early issues and the stigma they faced as a result of their condition was investigated in order to identify their resulting alterations to the concepts of self, community and health. These changes were then highlighted within a greater discussion regarding personal agency, the role of the Clinic as a transformative space and the ability of Clinic staff to assist with the transition experienced within the liminal state created by diagnosis.

This thesis was designed around three main areas of concern that were addressed across the six chapters. The first area involved the position of women within their family and society as traditional schemas and culturally-based stigmas relating to health were examined. The second element under investigation revolved around the role family members have within the illness experience of participants and the ways in which this involvement is altered by their condition itself. Through this discussion the concept of community and the ways in which individuals adapt their social environment to accept their HIV status were also brought into play. Finally, the third area of concern explored the impact the actions of Clinic staff members have had within the process of redefinition experienced by individuals while navigating the liminal state created by their diagnosis. While the chapters within this thesis were organised to follow the chronology of the illness experience, from diagnosis to the methods of resolving the liminal state, these themes can also be examined through the divisions of the past, present and future of the local epidemic. These categories are intended to clarify the points raised within this thesis while also charting the progress of the proposed discourse of liminality and empowerment defined by this research.

Past: Structural Violence and Vulnerable Communities

The Introduction served to set the scene for the following chapters as it examined the history of HIV/AIDS within India and Tamil Nadu. The local epidemic was contrasted against the global pandemic in order to highlight some of the culturally specific issues facing HIV-positive individuals in India. Within this discussion the timeline of the official response to the epidemic was included as a means of demonstrating the silence that initially surrounded this condition. Additionally, this chapter was intended to begin the examination of the ability for stigma and discrimination to permeate the socio-cultural landscape as it extended into the public perception of the condition. The lasting impact this delay has had was later discussed in detail through the

following chapters as they each sought to identify the methods individuals undertook in order to cope with the lingering social influence of misinformation and rumours.

Chapter One sought to highlight the theory of liminality and its use within the study of HIV/AIDS. In particular, this theory was highlighted in order to demonstrate the flexible nature of this concept and the ways in which it can be applied to the illness experience of HIV-positive women. This theory was discussed in relation to the concepts of structural violence, social suffering and the development of the concept of the self. Therefore, Chapter One was intended as an introduction to the history of liminality and it's use as an overarching theme within this thesis while also highlighting some of the gender-based obstacles women face both prior to and after their HIV diagnosis. This chapter was also intended as the starting point for a discussion regarding the changes experienced by participants as they moved through the liminal state as a result of their diagnoses.

Chapter Two continued the focus on these created vulnerabilities through an examination of the methodological concerns inherent within research into this sensitive topic. In particular, the different steps and approvals needed prior to beginning fieldwork were discussed. These included the necessity of obtaining ethics approval both within the UK and within India, the involvement of translators and the structure of interviews and participant observation. The description of the ethics approval process was included to demonstrate the sensitive nature of this research, as the primary concern for both the approval boards in the UK and India was the maintenance of participant privacy. This was intended to limit any potential consequences individuals may face as a result of taking part in this study. The involvement of translators was discussed alongside this issue because it was crucial that interview participants understood the questions posed to them and were comfortable with the language being used. For example, the need to ensure sensitivity was

demonstrated during these interviews meant that native speakers were necessary. Finally, Chapter Two included a description of the format of this research, such as the nature of interview questions and the settings used for participant observation.

Present: Empowerment within a Transformative Space

Chapter Three of the thesis set out to introduce the Clinic as a transformative space wherein HIV/AIDS is normalised. The focus of this chapter was intended to examine the role the Clinic and its staff members play within the diagnostic journey for individuals as they provide medical treatment and other social and personal advice. The Clinic was further defined as providing the support individuals needed to navigate the liminal space. This period of liminality was identified as having originated at the point of diagnosis and continuing as the participants began to reassess their previous expectations relating to their position within society, community care, and treatment within medical facilities. The liminal state then ends when these reassessments have been completed as the following chapters detailed.

Chapter Four focused on the medical side of the Clinic and the necessity for individuals to reconsider their expectations of healthcare during the diagnostic journey. Within this discussion, the experiences of stigma faced by participants within other medical facilities were presented in order to demonstrate the difficulties Clinic staff face when attempting to provide treatment to visitors. These instances of discrimination were also used to highlight the difficulty many HIV-positive individuals have in receiving proper care due to the fears of infection. This chapter therefore was able to chart the reassessment that takes place for participants as they reconsider their view of healthcare, which moves from the expectation of impartial and appropriate care to avoidance as they fear further abuse or embarrassment. These narratives were intended to further the discussion regarding the transformative nature of the Clinic as staff members were then charged

with rebuilding the trust that had been betrayed by these earlier experiences with treatment options. Therefore, the concept of healthcare held by participants was seen as having undergone several changes as individuals were not only forced to consider their health with the inclusion of a chronic illness but also as they were asked to alter their view of the medical system and the expectations of care found therein.

Chapter Five explored the divisions participants felt between themselves and their family members as they were uncomfortable or unable to access the traditional provisions of care normally allocated to individuals who are ill. The stigmatising nature of HIV/AIDS meant that participants expected negative responses to the disclosure of their status, such as isolation or abuse, and therefore they were unable to openly acknowledge their condition. This chapter focused on the sick role in order to demonstrate the barrier participants found between themselves and others. While the first half of the chapter used the illness experience of participants to demonstrate the obstacles they found between themselves and the traditional expectations of care within the sick role, the second half investigated the influence of the Clinic and its ability to create a secondary community for HIV-positive individuals. Therefore, participants were able to transfer their expectations relating to the sick role to their experiences within the Clinic, thereby continuing the separation of their selves and their HIV-positive selves.

Chapter Six sought to understand the socio-culturally-created vulnerabilities facing women within southern India and the influence these issues have with regard to risk of HIV infection. This chapter identified the differing levels of personal agency experienced by the participants from their pre-diagnosis awareness to their present post-diagnosis settings. The first half of this chapter focused on the social traditions and influences that had created an environment of vulnerability wherein the participants were unaware of the epidemic growing around them. The second half of

the chapter identified the changes within personal agency experienced as a result of their diagnosis, as individuals took on new positions within their families and were able to make health-related decisions for themselves.

This shift in agency informed the transition from social suffering to empowerment that this thesis sought to attend to. Social suffering was defined both as the socio-cultural elements that had contributed to the lack of awareness among women regarding the local epidemic prior to diagnosis and the stigma and discrimination experienced after diagnosis. Using the definition of this suffering offered by Kleinman, Das and Lock (1997), this chapter sought to identify the elements of structural violence that were present within the narratives of illness experience before moving on to the second half of the chapter, wherein these narratives shifted to describe the changing environment individuals found themselves in. In particular, the issue of defining the self was examined in order to provide evidence of the transition participants experienced from identifying themselves through the framework provided by family and community to reassessing their position within society against the backdrop of their HIV status.

Within this discussion of the self, the concept of plural identities was put forward as evidence of the increasing levels of personal agency displayed in the illness experience narratives. Martin Sokefeld's (1999) discussion of this plurality within the self was used to explain the ability of participants to maintain their positions within society while also accessing the care and treatment required by their condition. The plural identities found within their explanations could be divided into their self and their HIV-positive self. As noted by Sokefeld, the cultivation of these alternative selves requires a much higher level of personal agency than had been exhibited in the pre-diagnosis narratives. Therefore, this chapter sought to identify the areas within the day-to-day activities of participants that had created the environment for these plural identities. Life changes

such as widowhood or abandonment were seen as providing the impetus for participants to take on occupations outside of their homes that in turn provided an alternative to the economic dependency they had previously experienced. Additionally, the decision to live within their own homes, as opposed to the joint family settings seen previously, was highlighted as offering participants more control over their household decisions, which included their ability to access healthcare. The creation of plural identities found within the illness experience of these participants was further examined as this method of coping with diagnosis was seen through the framework of the liminal state, wherein it presented the final process of reabsorption into society. Individuals found their newfound ability to reassess their expectations of and position within their communities and society meant they were able to remove the mental barriers that had informed the origins of their liminal state.

The concept of plurality as a method for coping with the liminal state created by HIV diagnosis had been introduced regarding the Clinic itself and the role of the medical system in Chapters Four and Five. Chapter Five focused on the importance of community support and the ability of the Clinic staff members to take on the levels of care usually found within family settings while Chapter Four discussed the reassessments undertaken within the realm of healthcare as participants found HIV-related stigma extending into medical settings.

The view of the Clinic as acting beyond the medical concerns of participants and taking on roles traditionally reserved for family members was used as a bridge to connect the the medial approach to HIV as a holistic health concern in Chapter Four and the social and cultural concerns found within the discussion of the self in Chapter Six. As participants began to engage with their plural identities the arena of the Clinic began to provide assistance that moved beyond the medical interventions of the staff. Chapter Five highlighted the extent of this support through the example

of Clinic based matchmaking. The option of turning to this new, alternative version of community was crucial in changing the course of the liminal state as without this outlet for support individuals would remain within their isolated position. As a result, the Clinic was put forward as both the cause, through its association with the early diagnostic process, and the resolution of this liminal state, by providing the advice and tools that participants use to cope with their diagnosis.

As demonstrated in Chapter Four, traditional forms of treatment were commonly considered by participants and other individuals involved in this research as a complimentary element to biomedical approaches. Individuals reported feeling that the two medical systems were responsible for different ailments and therefore could continue to co-exist within society. However, due to concerns relating to drug toxicities and other potential problems, the staff members within the Clinic insisted that traditional treatments be avoided when allopathic medications were prescribed. While this strict approach meant that Clinic visitors were forced to alter their concept of healthcare, the Clinic had also incorporated some of the principles of traditional medicine in order to provide a more holistic treatment option for individuals. For example, while counselling services have become more common in the bigger hospitals, the Clinic is committed to providing a one stop option for individuals wherein they can receive medical advice, emotional support, and solutions to other issues including nutritional concerns and legal worries. Therefore, just as Ayurveda and other traditional forms of medicine seek to treat the whole body rather than only the illness, the Clinic has created an environment where the community of HIV-positive individuals found within the Clinic and the associated positive networks and support groups serve to provide the elements that are lacking in the outside society.

Holistic Health

On days when I would sit with Lakshmi in her tiny office and observe her counselling sessions, I was often able to discuss beliefs regarding Ayurveda directly with Clinic visitors. My questions regarding their use of traditional medicines were often greeted with blank stares as their answer was always "of course." For these visitors, the concept of a life without traditional medicine in some form was unthinkable and therefore my questions seemed absurd. The examples given were always unrelated to their current condition, and instead represented either simple solutions to common problems or efforts at preventative treatment.

For example, a middle aged man responded to my question by immediately rolling up his sleeve. He proceeded to show me a circular scar that he insisted acted as a deterrent to tetanus. The process had included a pipe being heated up and then the end was pressed into the skin of his forearm. It was unclear what the connection between this mark and tetanus was, but his belief in its power was unshakeable.

Lakshmi's response to this was to shrug and explain that she sees evidence of traditional care quite often and, depending on the patient's health status, she will intervene only occasionally. While patients are encouraged to focus on their allopathic medications, there is more leniency within this protocol than the initial impression would make it seem. I found a similar sentiment within Dr. P's exam room, as he indicated a willingness to work with the individual to find the balance they felt most comfortable with. As he explained, HIV infection does not mean that individuals must immediately begin medication. Instead, as noted in the previous sections, antiretroviral treatments are only started once the individual's CD4 count reaches a certain threshold. Therefore, he acknowledges the need to recognise the health beliefs that are present within individuals and to make the Clinic a place of cooperation.

So no, we don't usually interest them in taking these Ayurvedic medication but when they come in with a very good CD4 count, we discuss it with them. They say that they have heard that this works or that works. So just to make the patient happy, we discuss them. I mean, they shouldn't feel that we aren't listening to them or adhering to what their needs are so in those cases, what we do is we tell them to try these options out and do whatever they want to with the homeopathy. But then, if their CD4 count drops and they actually need to start actively fighting the virus, we insist that they just stick to the antiretroviral medications and not try anything with it.

This spirit of cooperation furthers the concept of the Clinic as a transformative space, wherein individuals are made to feel that their opinions and decisions regarding their health are important and personal. This is in direct opposition to the experience found within other medical facilities, where participants had felt overlooked or dismissed by staff members who made it clear that moral judgment and the fear of infection trumped the expectation of care.

For visitors to the Clinic, the slightly confusing message regarding Ayurveda creates an environment where they are forced to reconsider their expectations of the interplay between traditional and allopathic care. During counselling sessions, several individuals explained that the main source of confusion could be found within the treatment of side effects. It could be very frustrating to find a method of improving the illness experience of their condition through the treatment of these side effects only to be told that they must stop as it could negatively impact the medication that had caused the problem in the first place. For many, the concept of healthcare as improving one's health while making them feel sick was in opposition with their expectations regarding the treatment received from medical facilities. Therefore, in having to alter their understanding of health to include a chronic illness, even when symptoms were not present as discussed in Chapter Three, visitors to the Clinic had to also redefine their concept of healthcare to include much more rigid divisions between homeopathic and allopathic care.

However, despite the overall message of avoiding Ayurvedic treatments when allopathic medicine was already present found within the Clinic, the overall structure of Clinic life has direct

ties to the messages of this traditional approach. For example, when compared to the other medical facilities in the city, the organisation of the Clinic and its multifaceted approach to individual care mirrors the principles of traditional medicine. This holistic approach acknowledges the importance of including not only physical healthcare but also mental health and social care as staff members have recognised the need to support their patients emotionally as they struggle with their difficult diagnosis. Additionally, the inclusion of nutritionists can be seen as having direct parallels with Ayurveda, wherein the ingestion of particular foods are used in the treatment of many ailments (Sakar 1982). Although, in the case of the Clinic's nutritional section, the advice relating to food is meant to benefit of the effectiveness of medications by providing a healthy basis within the individual. The approach provided by the Clinic is then more easily understood by visitors as they are able to recognise familiar elements while coming to terms with their condition and their new understanding of health and healthcare.

Future: Moving Forward

During my final observations with the Clinic staff members I asked several of them to give me their thoughts on where the local HIV/AIDS epidemic would be in ten years. Their responses ranged from hopeful that a cure would be discovered within that time to practical as they considered the implications of an aging HIV-positive population. Through these discussions it was interesting to see how their position within the Clinic coloured their expectations for the future.

For example, Lakshmi, the counsellor I spent the most time with within the Clinic, was adamant that life for HIV-positive individuals would only continue to improve through continued counselling and changes in the public perception of the condition.

> *Prevalence rate has already come down. It's going to be less so. Everybody knows the subject and everyone is careful. I don't think it's going to rise. That's what I feel and hope! I mean, once upon a time, people would stay away from someone who has Tuberculosis, but it's not like that now, everyone has accepted Tuberculosis. So there is that. And this is*

not an infectious disease! If they understand the subject better, people really accept it now. No one is bothered. They just want a partner and a happy life. That's the end they want. My experience has been very challenging. I need to learn a lot. I've learned so much but still I learn. And it's so nice working here and it's interesting. I used to compare my old past experience with this now but I can see the patients when they come to approach you… I always think the counselling plays such a major role here. People develop lots of questions and they keep asking you.

The socio-cultural focus demonstrated by Lakshmi was countered by the practical concerns presented by Dr. P, who wondered what the future might hold for his patients as they began to trade their HIV symptoms for those characteristic of the natural aging process. While he shared Lakshmi's hope for a cure, he worried that the current procedures and allocations for the epidemic may prove inadequate in the face of these new challenges.

I'd be happy if the prevalence and the incidence rates lowered… but, I don't know. It's a long way away. Ten years is a long way. If you ask me in ten years, I'd still want ten years to think. Because most of the population is young and they're going to be… Because of ART medicines, they're going to be living longer. A lot longer and I think we need to equip ourselves to take care of these patients properly because whatever we have is not really equipped. So we started this program where we started giving free antiretroviral therapy and covering everybody with this therapy. But what they're going to be having is problems because of old age and things so it's just not enough if you go on just HIV medication unless you integrate everybody into the system. So they need to work on integrating everybody into this system because it's time. We probably would see a lot of things improving.

When I approached the Clinic's director with my query I was not surprised to find that her response formed a perfect combination of the issues highlighted by Lakshmi and Dr. P. With nearly thirty years of experience within HIV/AIDS issues, Dr. S has been an important force behind the scenes of the epidemic as she sought to improve patient rights, illness experiences, and general awareness of the condition. As she recalled the immense changes she has seen among the visitors to the Clinic, such as more stable health and better long term outcomes, she agreed with Lakshmi's assessment of the epidemic as steadily coming under more control.

I think, all over India, HIV has become plateaued out. In Tamil Nadu, it's really coming down. Incidence, prevalence, everything is coming down. And if there is more education

for people living with HIV and they have a lot of advocacy that fight to get drugs and good counselling and adherence… I'm sure we will be able to conquer this. But these aren't the only issues. What is worse and still there is the stigma for this disease. So we need to get rid of the stigma. You tell someone that you have diabetes and they'll say, "Oh so sad!" Or even cancer. "Oh so sad." You tell someone you have HIV and they'll say, "Oh my god, you must be a terrible person!" Immediately that judgment is there. And I don't know if that will ever go because it all started with finding it in sex workers. I always think if we had first detected it in a baby, will it have the same stigma? I don't know. If there was a cure, I'd stay home! (Laughs) But the thing is, we've moved from only treating HIV into treating other infectious diseases. Like now we work with Dengue Fever or other illnesses. We've moved on to Hepatitis B, Hepatitis C. So we are moving into other fields. Like nutrition. So that even when we find a cure, the Clinic will still be on its feet.

Dr. S continued by explaining that she does not agree with the view of HIV/AIDS as a harbinger of purely negative consequences. Although she continues to fight to improve the illness experience of HIV-positive individuals, she also maintained that the global pandemic has had a positive influence within the medical community.

I think the final thought I have is that HIV has done a lot of good plus bad. Bad in all of the topics that we've talked about before, but the good things… All our blood is so much safer now. Earlier they used to just take from a donor and give it to a recipient. Now it is being tested for hepatitis, for HIV. They're looking for malaria. They're looking for all these things before they give the blood. Why? Because we got HIV. Otherwise they didn't. They just gave the blood. Hepatitis B was there even before HIV, but they were not serious about it. So blood has become safer. Earlier it used to be ten percent of our HIV cases were due to transfusion. Today it's less than one percent. So you can see how safe blood has become. The second thing is universal precautions. People wear gloves. You would have seen my picture doing the test without gloves. Nobody wore gloves for anything. People didn't boil syringes properly, now disposable syringes have come in because of HIV. And they are getting disposed of properly. Before it wasn't there. Universal precautions even in surgery theatres. You know all the sterilisation is because of HIV. And then there are lots of things we've learned about gender in HIV. Especially about women. Because of HIV we went into the field and we saw how much violence women are facing. So we have unearthed so many things we didn't think of as medical people. Because of HIV, we went into the community. Before our work was in the hospital or the laboratory. Because of this we had to go out and see and I think it did a lot of good things also.

The view that HIV diagnosis could be seen as having an empowering impact on some individuals was largely introduced through the discussions I had with Clinic staff members regarding the illness experience of their female patients. As noted by Dr. S above, the introduction

of HIV/AIDS has resulted in many improvements to general health practices. Through the last three decades, studies have focused on social and cultural issues that would have remained under the radar of public interest if HIV had not burst onto the world stage. These include investigations into structural violence, stigma, domestic violence and other socio-economic concerns. Within the illness experiences shared in this thesis, the common themes of alienation, liminality, and finally acceptance have demonstrated the need to examine the epidemic from the viewpoint of those most directly involved.

Indeed, this approach can be viewed as having been directly influenced by the holistic methods of the Clinic. On several instances Lakshmi referred to the process of rebuilding trust and encouraging individuals to positively acknowledge their condition as "giving their humanity back." This expression struck me as being a useful phrase for considering the liminal state introduced at the beginning of the illness experience.

The liminal state places individuals in a position of structural invisibility as they are removed from their social positions as a result of either illness or behaviour (Turner, 1987). Within HIV/AIDS this separation experienced by participants comes as a result of the mental barriers they place between themselves and those closest to them. This division results in their alienation and isolation because they see their HIV status as impeding their ability to maintain the traditions and norms of their society. The condition itself is seen as resulting from deviant behaviour and therefore individuals do not believe their positive status will be accepted. Instead there are expectations of discrimination and abuse, which has forced participants to avoid disclosure as much as possible. However, the liminal state was defined by Turner as being a temporary state of existence for individuals (Turner 1987). Therefore, the process of adapting their concepts of self, community, and health to incorporate their condition and experiences within the Clinic provides

the blueprint for leaving the liminal state. Their acceptance of plural identities and new definitions of community and healthcare that allow for the inclusion of their HIV status marks the end of the period of liminality for participants.

Rebuilding Trust through Treatment

For individuals who have had negative experiences at other healthcare facilities, their first visit to the Clinic can be very nerve-wracking. These earlier instances of stigma have altered their perception of their position within the healthcare system and, as a result, their expectations regarding their care have been greatly diminished. For the Clinic staff members, these interactions are equally worrisome as they know they will need to begin the process of reintegrating patients into the healthcare system. The primary issue involves the need to re-establish trust between patient and doctor. This trust goes both ways as individuals need to be reassured that they are given the appropriate attention and care while the medical staff are seeking confidence that their directions will be followed in order to benefit the patient.

As one of the counsellors explained, at issue is the ability of the Clinic staff to convince visitors that they are not being judged for their condition. Lakshmi went on to indicate that although they do not use terms like "liminal state," the counsellors are all aware that diagnosis and experiences of stigma contribute to feelings of isolation and alienation, as individuals are uncertain about how to incorporate their HIV status into their identity. They have seen too many instances of individuals, and women in particular, being victimised as a result of their condition. Over the years, they have found the counselling service to be equally important when compared to their ability to treat the virus. In their eyes, they are giving their visitors the tools needed to come to terms with their condition in their own way.

As Dr. P had indicated at the start of Chapter Four, one of the biggest benefits of attending the Clinic is the ability to receive personalised treatment and care. Not only does this involve a greater level of flexibility for the medical staff in terms of prescribing different types of medication, but it also allows visitors to build relationships with the rest of the staff members. Through these interactions, they are able to receive advice on a wide variety of subjects, which in turn further redefines healthcare as they begin to alter their expectations to include an approach that incorporates their general well-being. Finally, the changes found here within the concept of health and healthcare can be viewed as providing some of the final steps within the period of liminality experienced by individuals. As they are able to reassess their expectations and positions within this medical arena, they are negating one of the primary causes of their liminal state, which were the feelings of isolation and dismissal that resulted from their initial treatment and care.

From Social Suffering to Empowerment

This thesis sought to place this research among the previous work of researchers such as Cecilia Van Hollen in order to provide an alternative view of the illness experience of HIV-positive women in Chennai, India. Through an examination of this experience from diagnosis to acceptance, this thesis focused on the growing personal agency participants reported as they came to terms with their new health and social situation.

While culturally-created gendered vulnerabilities informed their initial risk and understanding of their diagnosis, the influence of the Clinic and the transition period of liminality lead to a greater sense of agency and new definitions of self, community and health among participants. In this way, this thesis used the theory of liminality as an overarching theme to understand the changes experienced by participants, with the moment of diagnosis marking the beginning of the liminal period. During this period, individuals began to move away from the

socially-constructed ideas of self and community to focus their attention inwards to their new reality.

This also represented a break from more traditional definitions of community as participants created plural identities in order to receive social support on their own terms. This allowed for the separation of their HIV-positive identity from their public persona as they were able to gain specific support for their health-related concerns through their involvement with the Clinic while maintaining their privacy and therefore avoiding bringing HIV into their other relationships.

Suggestions for Future Research

In focusing attention on the illness experience of HIV-positive women in an Indian urban centre, this thesis initially sought to highlight the gender-based difficulties and obstacles to health facing this vulnerable population. In doing so, it has uncovered a complex network of coping strategies as participants faced ongoing stigma and socio-cultural limitations while coming to terms with their serious health concerns. While this thesis has attempted to contribute to the ongoing dialogue regarding social suffering, the realities of illness experiences, and issues of personal agency and empowerment, it also presents a very geographically and gender-specific view of the local epidemic within India. As such, this thesis can be viewed as the starting point for future research that seeks to expand upon the ideas shared herein. For example, this could include further examination of the condition through the perspective of HIV-positive women in other Indian settings. In particular, a comparative study involving participants from states representing both higher and lower incidence rates could provide a useful understanding of the epidemic within India. While the public awareness within Tamil Nadu was seen within this thesis as negatively contributing to the illness experience through the influence of stigma, it would be interesting to

compare this with areas of lower awareness rates in order to assess the impact this has on HIV-positive individuals locally.

In addition, this study focused entirely on the experiences of women and therefore the discourse on potential empowerment as a result of HIV-diagnosis would be further informed through a comparison with the illness experience of their male counterparts. For example, just as there have been gendered differences within the methods of infection, adherence to treatment, and care offered by family members, the inadvertent benefits enjoyed by the participants in this research may also prove to be gender-specific. Finally, future research could also expand upon the research contained within this thesis through an investigation into the illness experiences outside of urban centres, such as within the rural areas of Tamil Nadu. The information gathered therein could then be contrasted with the results from this urban setting in order to form a more complete picture of the illness experience of HIV/AIDS among women in this southern Indian state.

Bibliography

Adelman, R. C. and L. M. Verbrugge. 2000. Death Makes News: The Social Impact of

Disease on Newspaper Coverage. *Journal of Health and Social Behaviour.* 41 (3) 347-

367.

Aggleton, Peter and Hilary Homans. 1988. *Social Aspects of AIDS*. Philadelphia: The

Falmer Press.

Ahern, Laura M. 2001. "Language and Agency" in *Annual Review of Anthropology.* Vol. 30 (1)

109 – 137

Ali, Syed. 2002. "Collective and Elective Ethnicity: Caste Among Urban Muslims in India."

Sociological Forum. Vol. 17 (4) 593-620.

Amin, Avni. 2004. *Risk, Mortality, and Blame: A Critical Analysis of Government and U.S. Donor*

Responses to HIV Infections Among Sex Workers in India. Takoma Park, MD: Centre for

Health and Gender Equality.

Auge, Marc. 2009 *Non-Places: Introduction to an Anthropology of Supermodernity*.

London: Verso Books.

AVERT, 2010. *History of HIV and AIDS.* [Internet] Updated September 13, 2010.

www.avert.gov

Bailey, Ajay, and Inge Hutter. 2006. "Cultural Heuristics in risk assessment of HIV/AIDS." *Culture, Health & Sexuality*. Vol. 8 (5) 465-477.

Balmori, Helena Hofbauer, 2003. Gender and Budgets: Overview Report. *BRIDGE Development– Gender.* Brighton: Institute of Development Studies.

Bandura, A. 2008. "An agentic perspective on positive psychology." *Positive Psychology: Exploring the best in people.* Vol. 1. Ed by Shane Lopez. Westport CT: Praeger Publishers/Greenwood Publishing Group.

Banerjee, Nirmala. 2002. "Between the Devil and the Deep Sea: Shrinking Options for Women in Contemporary India." *The Violence of Development: The Politics of Identity, Gender and Social Inequalities in India.* London, UK: Zen Books Ltd.

Berger, Peter and Frank Heidemann. *The Modern Anthropology of India: Ethnography, Themes and Theory.* London: Routledge

Berreman, Gerald D. 1960. "Caste in India and the United States." *American Journal of Sociology.* Vol. 66 (2) 120-127.

Beteille, Andre. 1992. "Caste and Family in Representations of Indian Society." *Anthropology Today,* Vol. 8 (1) 13-18.

Beteille, Andre. 1992. *The Backward Classes in Contemporary India.* Oxford: Oxford University
    Press.

Bhardwaj, S. M. 1980. "Medical Pluralism and Homeopathy: A Geographic Perspective."
    Social Science and Medicine. Vol. 148, 209 – 216.

Bhat, Ramesh. 2004. *Treating HIV/AIDS patients in India with antiretroviral therapy: a*
    management challenge. Ahmedabad: Indian Institute of Management.

Bhattacharya, Rinki. 2004. Behind Closed Doors: Domestic Violence in India. New Delhi: Sage
    Publications, LTD.

Biehl, Joao. 2007a. *Will to Live: AIDS Therapies and the Politics of Survival.* Berkeley:
    University of California Press.

Biehl, Joao. 2007b. "Pharmaceuticalization: AIDS Treatment and Global Health Politics."
    Anthropological Quarterly. Vol. 80 (4) 1083 – 1126.

Biehl, Joao and Amy Moran-Thomas. 2009. "Symptom: Subjectivities, Social Ills,
    Technologies." *Annual Review of Anthropology*. Vol. 38, 267 – 288.

Bolton, Ralph. 1995. "Rethinking Anthropology: The Study of AIDS." In *Culture and Sexual Risk.* Ed. by Han ten Brummelhuis and Gilbert Herdt. The Netherlands: Gordon and Breach Science Publishers SA.

Bulmer, Martin. 1984. *The Chicago School of Sociology: Institutionalization, Diversity, and the Rise of Sociological Research.* Chicago: University of Chicago Press.

Caldwell, John C., P.H. Reddy and Pat Caldwell, 1984. "The Determinants of Family Structure in Rural South India." *Journal of Marriage and Family.* Vol. 46 (1) 215-229.

Carroll, William K. 2010. "You are Here: Interview with Dorothy E. Smith." *Socialist Studies.* Vol. 6 (2) 9 – 37.

Cichocki, Mark. 2009. *Living with HIV: A Patient's Guide*. Jefferson, North Carolina: McFarland and Company, Inc.

Chandra, Prabha S., et al. 2006. "Quality of life in HIV subtype C infection among asymptomatic subjects and its association with CD4 counts and viral loads - A study from South India." *Quality of Life Research*. Vol. 15 (10) 1597 - 1605.

Chen, Marty and Jean Dreze. 1995. "Recent Research on Widows in India: Workshop and Conference Report." *Economic and Political Weekly*. Vol 30 (39) 2435 - 2450

Chodorow, Nancy. 1974. "Family Structure and Feminine Personality." In *Woman, Culture and Society.* Edited by Michelle Zimbalist Rosaldo and Louise Lamphere. Stanford: Stanford University Press.

--------------------. 2001. "Family Structure and Feminine Personality." *Feminism in the Study of Religion.* Edited by Darlene M. Juschka. New York: Continuum.

Chuengsatiansup, Komatra. 2001. "Marginality, Suffering and Community: The Politics of Collective Experience and Empowerment in Thailand." in *Remaking a World: Violence, Social Suffering and Recovery.* Ed. By Veena Das and Arthur Kleinman. University of California Press.

Cohen, Jon. 2004. "HIV/AIDS: India's Many Epidemics." *Science, New Series.* Vol. 304 (5670) 504-509.

Daniel, Valentine. 1984. *Fluid Signs: Being a Person the Tamil Way.* Berkeley: University of California Press.

Das, Veena. 1990. "Our Work to Cry, Your Work to Listen." In *Mirrors of Violence: Communities, Riots and Survivors in South Asia*. Ed by Veena Das. Delhi: Oxford University Press.

------------. 1993. "Moral Orientations to Suffering: Legitimation, Power and Healing." In *Health and Social Change in International Perspecitve.* Ed by L.C. Chen et al. Cambridge: Harvard University Press.

------------, 1996. *Critical Events: An Anthropological Perspective on Contemporary India.* Oxford: Oxford University Press.

Datta, Bishakha and Geetanjali Misra. 2000. "Advocacy for Sexual and Reproductive Health: The Challenge of India." *Reproductive Health Matters.* Vol. 8 (16) 24 - 34.

Desai, Sapna. 2005. "HIV and Domestic Violence: Intersections in the Lives of Married Women in India." *Health and Human Rights*. Vol. 8 (2) 140 - 168.

Dietrich, Ursula, Janak K. Maniar and Helga Rübsamen-Waigmann. 1995. "The   epidemiology of HIV in India." *Trends in Microbiology*. Vol. 3 (1) pp. 17 – 22

Dirks, Nicholas, B. 2001. *Castes of Mind: Colonialism and the making of modern India.* Princeton, New Jersey: Princeton University Press.

Dumont, Louis. 1970. *Homo Hierarchicus: The Caste System and Its Implications.* Chicago: The University of Chicago Press.

Dworkin, Shari L. 2005. "Who Is Epidemiologically Fathomable in the HIV/AIDS Epidemic? Gender, Sexuality and Intersectionality in Public Health." *Culture, Health and Sexuality.* Vol. 7 (6) 615 - 623

Dyson, Tim. 2003. "HIV/AIDS and Urbanization." *Population and Development Review.* Vol. 29 (3) 427 - 442.

Dyson, Tim and Mick Moore. 1983. "On Kinship Strucutre, Female Autonomy and Demographic Behavior in India." *Population and Development Review*. Vol. 9 (1) 35 - 60.

Eaton, David. 2008. "Ambivalent Inquiry: Dilemmas of AIDS in the Republic of Congo." In *Postcolonial Disorders*. Ed. Mary-Jo DelVecchio Good, Sandra Teresa Hyde, Sarah Pinto and Byron J. Good. Berkeley: University of California Press.

Ecks, Stefan. 2005. "Pharmaceutical Citizenship: Antidepressant Marketing and the Promise of Demarginalization in India." *Anthropology and Medicine.* Vol. 12 (3) 239 - 254.

Eisenberg, Leon. 1977. "Disease and Illness: Distinctions Between Professional and Popular Ideas of Sickness." *Culture, Medicine and Psychiatry*. Vol. 1 (1) 9 - 23.

Estroff, Susan. 1993. "Identity, Disability, and Schizophrenia: The Problem with Chronicity." In *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life.* Ed. by Shirley Lindenbaum and Margaret Lock. Berkeley: University of California Press.

Evans-Pritchard, E.E. 1971. *Anthropology and History: A Lecture.* Manchester: Manchester University Press.

Farmer, Paul, 2001. *Infections and Inequalities: The Modern Plagues.* University of California Press.

---------------, 2004. "An Anthropology of Structural Violence". *Current Anthropology*. Vol. 45 (3) 305 - 325

Farmer, P. and A. Kleinman, 1989. "AIDS as Human Suffering". *Daedalus,* 118 (2) 135 - 160.

Farmer, P., et al. 2006. "Structural Violence and Clinical Medicine". *PLoS Med.* Vol. 3 (1)

Fassin, Didier. 2007. *When Bodies Remember: Experiences and Politics of AIDS in South Africa.* California Series in Public Anthropology.

Fee, E. and D. M. Fox, 1989. The Contemporary Historiography of AIDS. *Journal of Social History,* 23 (2), 303 - 314.

Fox, D. M., 1986. AIDS and the American Health Polity: The History and Prospects of a Crisis of

      Authority. *The Milbank Quarterly,* 64 (1), pp. 7-33.

Foucault, Michel. 1990. [1976] "Method." *The History of Sexuality*. Vol. 1, 92-102

Frankel, Stephen. 1986. *The Huli Response to Illness*. Cambridge: Cambridge University

      Press

Freidson, Elliot. 1971. *Professions of Medicine.*. New York: Dodd, Mead.

Fujiki, Norio, Masakatu Sudo and Darryl Macer. 2001. *Bioethics and the Impact of*

      Genomics in the 21st Century: Pharmacogenomics, DNA Polymorphism and Medical

      Genetics Services. Proceedings of the Seventh International Bioethics Seminar in Fukui:

      Tsukuba Science City Japan: Eubios Ethics Institute.

Gaitonde, Vishwas R. 2001. A Thief in the night: Understanding AIDS. Chennai: East West

      Books.

Galtung, Johan and Tord Höivik. 1971. *Journal of Peace Research.* Vol. 8, No. 1 (1971), 73 - 76

Garner, Alex. 2012. "Out about HIV" *The Huffington Post*. [Internet] Published September

      13, 2012. Updated February 2, 2016.

Ghadially, Rehana. 2007. *Urban Women in Contemporary India: A Reader*. Ed by

    Rehana Ghadially. New Delhi: Sage Publications, India Pvt Ltd.

Ghosh, Jayati. 2002. "A Geographical Perspective on HIV/AIDS in India." *Geographical*

    Review. Vol. 92 (1) 114 - 126.

Gibbon, Sahra and C. Novas. 2008. *Biosocialities, Genetics and the Social Sciences:*

    Making Biologies and Identities. London: Routledge.

Gilson, Lucy. 2003. "Trust and the development of health care as a social institution." *Social*

    Science and Medicine. Vol 56 (7) 1453 - 1468

Giri, V. Mohini. 2002. *Living Death: Trauma of Widowhood in India.* New Delhi: Gyan

    Publishing House.

Gochman, David S. 1988. "Health Behavior: Plural Perspectives." in *Health Behavior:*

    Emerging Research Perspectives. New York: Plenum Press.

Godwin, Peter. *The Looming Epidemic: The Impact of HIV&AIDS in India.* New Delhi: Mosaic

    Books.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity* New Jersey: Prentice-Hall.

Good, Byron J. 1977. The Heart of What's the Matter: The Semantics of Illness in Iran. *Culture, Medicine and Psychiatry*. Vol. 1 (1) 25 - 58.

Good, Mary-Jo, and Byron Good. 1988. "Ritual, the State and the Transformation of Emotional Discourse in Iranian Society." *Culture, medicine and Psychiatry*. Vol. 12 (1) 43 - 63.

Gupta, Dipankar. 2005. "Caste and Politics: Identity Over System." *Annual Review of Anthropology*. Vol. 34, 409 - 427.

Gray, Anne. 2003. *Research Practice for Cultural Studies.* London: SAGE Publications   LTD.

Hacking, Ian. 2002. "Making Up People." in *Historical Ontology.* Cambridge: Harvard University Press.

Halmshaw, Caroline and Kate Hawkins. 2004. "Capitalizing on Global HIV/AIDS Funding: The Challenge for Civil Society and Government." *Reproductive Health Matters*. Vol. 12 (24) 35 - 41.

Harper, Edward B. 1964. "Ritual Pollution as an Instigator of Caste and Religion." *Journal of Asian Studies.* Vol. 23, 151 - 197.

Hastrup, Kirsten and Peter Hervik. *Social Experience and Anthropological Knowledge.*

Hsu, F.L.K. 1985. "The self in cross-cultural perspective." In *Culture and Self: Asian and Western Perspectives.* Ed by A. Marsella, G. DeVos and F.L.K Hsu. London: Tavistock.

Hymes, Kenneth B., et al. 1981. Kaposi's Sarcoma in Homosexual Men – A Report of Eight Cases. *The Lancet.* Vol. 318 (8247) 598-600.

Inhorn, Marcia and Frank van Balen. 2002. *Infertility Around the Globe: New Thinking on Childlessness, Gender, and New Reproductive Terminologies.* Berkley: University of California Press.

Janzen, John M. 2002. *The Social Fabric of Health: An Introduction to Medical Anthropology.* New York: McGraw-Hill.

Jeffrey, Roger. 1988. *The Politics of Health in India.* Berkeley: University of California Press.

Kakar, Sudhir. 1982. *Shamans, Mystics and Doctors: A Psychological Inquiry into India and Its Healing Traditions.* New York: Alfred A Knopf, Inc.

Kapferer, Bruce. 1979. "Mind, Self, and Other in Demonic Illness: The Negation and Reconstruction of Self." *American Ethnologist*. Vol. 6 (1) 110 - 133.

Kassebaum, Gene. G, and Barbara O. Baumann. 1965. "Dimensions of the Sick Role in Chronic Illness." *Journal of Health and Human Behavior*. Vol. 6 (1) 16 - 27.

Kimberly, Judy A., Julianne M. Serovich, Kathryn Greene. 1995. "Disclosure of HIV-Positive Status: Five Women's Stories." *Family Relations,* Vol. 44 (3) 316 - 322.

Kleinman, Arthur, Veena Das and Margaret Lock. 1997. *Social Suffering*. University of California Press.

Kleinman, Arthur, Leon Eisenberg, and Byron J. Good. 1978. "Culture, Illness and Care." *Annals of Internal Medicine* Vol. 88: 251 - 258.

Kleinman, Arthur. 1980. "Culture, Health Care Systems, and Clinical Reality." In *Patients and Healers in the Context of Culture*. University of California Press.

Kleinman, Arthur. 1986. *Social Origins of Distress and Disease: Depression, Neurasthenia, and Pain in Modern China.* New Haven: Yale University Press.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing and the Human Conditon.* New York: Basic Books.

Kleinman, Arthur. 1995 *Writing at the Margin: Discourse Between Anthropology and Medicine.* Berkeley: University of California Press.

Kolenda, Pauline M. 1968. "Region, Caste, and Family Structure: A comparative study of the Indian "Joint" Family." Structure and Change in Indian Society. Ed. By Milton B. Singer, Bernard S. Cohn.

Kuller, L.H. and L. A. Kingsley, 1986. The Epidemic of AIDS: A Failure of Public Health Policy. *The Milbank Quarterly,* 64 (1), 56 - 78

Kumarasamy, N., Suniti Solomon, Timothy P. Flanigan, R. Hemalatha, S. P. Thyagarajan, and Kenneth H. Mayer. 2003. "Natural History of Human Immunodeficiency Virus Disease in Southern India." *Clinical Infectious Diseases.* Vol. 36 (1) 79-85.

Lad, Vasant. *Ayurveda: The Science of Self Healing*. Twin Lakes, WI: Lotus Press.

Lefebvre, Henri. 1990 [1971]. *Everyday Life in the Modern World.* New York: Harper and Row

Lieberman, Evan S. 2009. *Boundaries of Contagion: How Ethnic Politics Have Shaped Government Responses to AIDS.*

Lienhardt, R.G. 1985. "Self: public, private. Some African representations." In *The Category of the Person: Anthropology, Philosophy, History.* Ed by M. Carrithers, et   al. Cambridge: Cambridge University Press.

Link, Bruce G. and Jo C. Phelan. 2001. "Conceptualizing Stigma." *Annual Review of Sociology*. Vol. 27, 363 - 385.

Lock, Margaret and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine.* New Jersey: Wiley-Blackwell.

MacNaughton, Gillian. 2004. *Women's Human Rights Related to Health-Care Services in the Context of HIV/AIDS.* Health and Human Rights Working Paper Series No. 5. London: Interights.

Majumdar, Basanti. 2004. "An Exploration of Socioeconomic, Spiritual, and Family Support Among HIV-Positive Women in India." *Journal of Human Ecology.* Vol. 17 (4) 313 – 314.

Markus, Hazel Rose and Shinobu Kitayama, 1991. "Culture and the Self: Implications for Cognition, Emotion and Motivation." Psychological Review, Vol 98 (2) 224 - 253.

Mauss, Marcel. 1985 [1938]. "A Category of the human mind: the notion of the person; the notion of the self." In *The category of the Person: Anthropology, philosophy, history*. Ed. By

Michael Carrithers, Steven Collins, Steven Lukes. Translated by   W.D.   Halls.

Cambridge: Cambridge University Press.

McHugh, E. 1998. "Situating Persons: Honor and Identity in Nepal." In *Selves in Time and Place:*

Identities, Experience and History in Nepal. Ed. by D. Skinner, A. Pach   III,   and   D.

Holland. New York: Rowman and Littlefield.

Minocha, Aneeta A. 1980. "Medial Pluralism and Health Services in India." *Social Science*

and Medicine. Vol. 148, pp. 217 – 223.

Mitra, Pramit, Vibhuti Hate, and Teresita Schaffer. 2007. "India: Fitting HIV/AIDS into a

Public Health Strategy." *Center for Strategic and International Studies.*

Morris, Brian. 1994. *Anthropology of the Self: The Individual in Cultural Perspective.*

London: Pluto Press.

Mukherjee, Joia S. 2007. "Structural Violence, Poverty and the AIDS Pandemic." *Society*

for International Development. Vol 50 (2) 115 -121

NACO, 2014. "Assessment of Prevention of Parent to Child Transmission of HIV (PPTCT)

Services. Implementation in the States of Andhra Pradesh Telangana, Karnataka and Tamil

Nadu." *NACO.GOV.IN* Published October 17, 2014. Accessed March 1, 2015.

NACO, 2017. "Annual Report". NACO.GOV.IN Published April 7, 2017. Accessed October 15, 2017.

Nabokov, Isabelle. 2000. *Religion against the Self: An Ethnography of Tamil Rituals*. Oxford: Oxford University Press.

Nath, Lalit M. "The Epidemic in India: An Overview." *The Looming Epidemic: The Impact of HIV&AIDS in India.* Ed by Peter Godwin. New Delhi: Mosaic Books.

Napier, A. David. 2003. *The Age of Immunology: Conceiving a Future in an Alienating World.* Chicago: The University of Chicago Press.

Napier, A. David, et al. 2014. "The Lancet Commission: Culture and Health." *The Lancet.* Published online October 29, 2014.

Nguyen, Vinh-Kim, 2005. "Antiretroviral, Globalism, Biopolitics and Therapeutic Citizenships." In *Global Assemblages: technology, politics, and ethics as anthropological problems.* Ed. by Aihwa Ong. Malden, MA: Blackwell Publishing Ltd.

Obama, Barack. 2006. "World AIDS Day Speech, 2006" *Global Summit on AIDS – Dec 1, 2006.* [Internet] Published Dec 1, 2006.

O'Reilly, Karen. 2005. *Ethnographic Methods*. New York: Routledge.

Pallikadavath, Saseendran and R. William Stones. 2003. "Women's Reproductive Health Security and HIV/AIDS in India." *Economic and Political Weekly*. Vol. 38 (39) 4173 - 4181.

Parsons, Talcott. 1951. "Illness and the Role of the Physician." *Personality in Nature, Society and Culture.* Ed by C. Kluckhohn and H.A. Maray. New York: Knopf.

---------------, 1978. *Action Theory and the Human Condition*. New York: Free Press.

Pelto, Pertti and Gretel H. Pelto. 1997. "Studying Knowledge, Culture and Behavior in Applied Medical Anthropology." *Medical Anthropology Quarterly*.

PEPFAR, 2011. www.pepfar.gov

Pisani, Elizabeth. 2000. "AIDS into the 21st Century: Some Critical Considerations." *Reproductive Health Matters*. Vol. 8 (15) 63 - 76

Prus, Robert. 1996. *Symbolic Interaction and Ethnographic Research: Intersubjectivity and the Study of Human Lived Experience.* Albany: State University of New York Press.

Rabinow, Paul. 1996. *Making PCR: A Story of Biotechnology*. Chicago: The University of Chicago Press.

Radley, Alan. 1994. *Making Sense of Illness: The Social Psychology of Health and Disease*. London: Sage Publications.

Reddy, Gayatri. 2005. *With Respect to Sex: Negotiating Hijra Identity in South Asia*. Chicago: Chicago University Press.

Reynolds Whyte, S. 2009. "Health Identities and Subjectivities: The Ethnographic Challenge." *Medical Anthropology Quarterly*. Vol. 23 (1) 6 - 15.

Rodrigues, Jeanette J., et al. 1995. "Risk factors for HIV infection in people attending clinics for sexually transmitted diseases in India." *British Medical Journal.* Vol. 311 (7000) 283 - 286.

Roy, Arundhati. 2003. "Confronting Empire." *World Social Forum in Porto Allegre..* 28 January 2003.

Sanghavi, Prachi, Kavi Bhalla, and Veena Das. 2001. "Fire-related deaths in India in 2001: A retrospective analysis of data." *Lancet*. Vol. 373 (9671) 1282 - 1288.

Scarry, Elaine. 1985. *The Body in Pain: The Making and Unmaking of the World.* New

York: Oxford University Press.

Scheper-Hughes, Nancy and Philippe Bourgois. 2003. "Introduction: Making Sense of Violence." In *Violence in War and Peace: An Anthology*. Ed by Nancy Scheper-Hughes and Philippe Bourgois. Oxford: Blackwell Publishing.

Schilling, Chris. 2002. "Culture, the 'Sick Role' and the Consumption of Health." *The British Journal of Sociology*. Vol. 53 (4) 621 - 638

Schnall, Marianne. 2010. "Madeleine Albright: An Exclusive Interview." *The Huffington Post*. [Internet] Published June 15, 2010. Updated November 17, 2011.

Sharma, Ursula. 1999. *Caste*. Philadelphia: Open University Press.

Shelton, Herbert M. 1941. "How to Get Well." *Hygienic Review*. San Antonio, Texas: Herbert M. Shelton Publishing.

Singh, Ekta. 2005. *Caste System in India: A Historical Perspective*. New Delhi: Kalpaz Publications.

Sokefeld, Martin. 1999. "Debating Self, Identity and Culture in Anthropology." *Current Anthropology*. Vol. 40 (4) 417 - 448.

Sontag, Susan, 1989. *AIDS and its Metaphors*. London: The Penguin Press.

------------------, 1990. *Illness as Metaphor and AIDS and its Metaphors.* New York: Farrar, Straus and Giroux.

Srinivas, M. N. 1957. "Caste in Modern India." *The Journal of Asian Studies*. Vol. 16 (4) 529 - 548.

Srinivas, M. N. 1962. "Varna and Caste." In *Caste in Modern India*. Bombay: Asia Publishing House

Steinbrook, Robert. 2007. "HIV in India – A Complex Epidemic." *The New England Journal of Medicine.* Vol. 356. 1089 - 1093.

Strathern, Marilyn. 1999. "The Ethnographic Effect." *Property, Substance and Effect.* London: Athlone Press.

Strauss, Anselm. 2009. *Mirrors and Masks: The Search for Identity*. New Brunswick: Transaction Publishers.

Strong, P. and A Davis. 1977. "Roles, Role Formats and Medical Encounters." *Sociological Review* Vol 25 (4) 755 - 800

Subramanian, S.V., Daniel J. Kim and Ichiro Kawachi. "Social Trust and Self-Rated Health in US Communities: A Multilevel Analysis." *Journal of Urban Health: Bulletin of the New York Academy of Medicine* Vol. 79 (4) S21 - S35

Swaminathan, S. and G. Nagendran. 2008. "HIV and Tuberculosis in India." *Journal of Biosciences.* Vol 33 (4) 527 - 37.

Turner, Victor W. 1957. *Schism and Continuity in African Society: A Study of Ndembu Village Life*. New York: Humanities Press, Inc.

--------------. 1964. "Betwixt and Between: The Liminal Period in Rites de Passage." *The Proceedings of the American Ethnological Society*. Symposium on New Approaches to the Study of Religion. 4 - 20.

----------------. 1967. "Betwixt and Between: The Liminal Period in Rites of Passage" in *The Forest of Symbols: Aspects of Ndembu Ritual.* New York: Cornell University Press.

---------------. 1969. *The Ritual Process: Structure and Anti-Structure (Foundations on Human Behavior).* Piscataway, New Jersey: Aldine Transactions.

----------------. 1977. "Variations on a Theme of Liminality." *Secular Ritual.* Ed by Sally Moore and Barbara Myerhoff. Amsterdam: Van Gorcum.

---------------. 1987. "Betwixt and Between: The Liminal Period in Rites of Passage" in *Betwixt and Between: Patterns of Masculine and Feminine Initiation*. Edited by Louise Carus Mahdi, Steven Foster, and Meredith Little. Chicago: Open Court Publishing.

Turner, V. and E. L. B. Turner. 1978. *Image and Pilgrimage in Christian Culture.* Columbia: Columbia University Press.

Tutton, Richard. 2012. "Patient Advocacy, Biosociality and other Identity Practices." Paper presented to ESRC Genomics Network Annual Conference, British Library, London: 23 April 2012.

UNAIDS, 2001. "India: HIV and AIDS-related Discrimination, Stigmatization, and Denial." *UNAIDS Best Practice Collection*. Geneva, Switzerland: UNAIDS.

UNAIDS, 2015. "Technical Report: India HIV Estimates – 2012" *UNAIDS.ORG* Accessed December, 2014.

UN News Centre, 2005. "Empowering women the most effective development tool, Annan says." [Internet] Published February 28, 2005. Updated February 28, 2005.

United Nations Office of the Secretary-General. 2004. "Stronger leaders needed at every level in fight against HIV/AIDS says Secretary-General in address to Bangkok conference." [Internet] Published July 12, 2004.

Van Hollen, Cecilia.. 2007. "Navigating HIV, Pregnancy and Childbearing in South India: Pragmatics and Constraints in Women's Decision Making". *Medical Anthropology – Cross-Cultural Studies in Health and Illness.* Vol. 26 (1) 7 - 52

Van Hollen, Cecilia. 2013. *Birth in the Age of AIDS: Women, Reproduction and HIV/AIDS in India.* Stanford, California: Stanford University Press.

Warner, Lloyd W. 1959. *The Living and the Dead: A Study of the Symbolic Life of Americans.* New Haven, CT: Yale University Press.

Willams, Raymond. 1958. *Culture and Society, 1780-1950.* London: Chatto and Windus.

Williams, Raymond. 1978. *Politics and Letters*. London: Verso.

Williams, Raymond. 1981. *The Sociology of Culture*. Chicago: University of Chicago Press.

World Health Organisation, 1948. "Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June, 1946." Signed on 22 July, 1946 by the representatives of 61 States and entered into force on 7 April 1948. [Internet] Published online in 2003. www.who.org

Ybema, Sierk, et al. 2009. "Articulating Identities". *Human Relations*. Vol. 62 (3) 299 – 322

Young, Allan. 1976. "Some Implications of Medical Beliefs and Practices for Social Anthropology." *American Anthropologist.* Vol. 78 (1) 5 - 24.

Appendix A

UCL DEPARTMENT OF ANTHROPOLOGY
FACULTY OF SOCIAL AND HISTORICAL SCIENCES
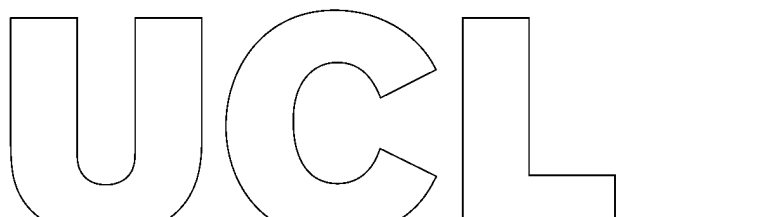
Participant Information Form
HIV/AIDS in India: Individual, Community, Health System.
Researcher: Caitlin O'Grady (UCL)

My name is Caitlin O'Grady and I am conducting doctoral research at University College London. I am interested in learning more about your experience of living with HIV in India including what has been most important to you and problems or obstacles within treatment. The general aim of my research is to document your views and experiences of how HIV/AIDS is approached and understood within Chennai.

What will involvement in this study entail?
If you agree to participate, my study will involve an interview in which I will ask several general questions. Please note that some of the questions will relate to your personal history and will span the period of pre-diagnosis to the present day. However, these are very basic questions and the main information gathered will be up to your discretion. I am interested in what you choose to share with me and there is not one particular answer I am looking for. You do not have to answer any questions that make you feel uncomfortable and you are free to say so at any given point. Interviews will last approximately an hour, but may run longer if there is more you would like to discuss.

Do I have to take part in all aspects of the research?
Participation, while extremely appreciated, is completely voluntary. You may include as much or as little information in discussions as you feel comfortable. Again, you may decide to end the interview at any stage. At no time will there be pressure to continue if you wish to stop.

How will my information be used?
All discussions will remain confidential and will only be used for this particular study. The data will be collected and stored in accordance with the Data Protection Act 1998 – this is the part of British law protecting anyone's personal information. The names of participants will not be included as each individual will be assigned a pseudonym for the purposes of this research.

How will participation be beneficial to me?
This research is being undertaken with the hopes of drawing attention to important issues facing individuals living with HIV/AIDS as identified by the individuals themselves. Participants will be reimbursed 250 rupees for their participation.

What is the next step?
Please find attached a sample consent form. I will bring a copy to our interview for you to sign. Again, personal information will not be included in the research and you will instead be assigned a pseudonym. For questions relating to your rights, please contact YRGCARE Chairperson, Dr. Jayakar Paul (044-23633320) or Co-Chairperson, Dr. V. Kumaraswami (044-26646207).

Thank you and best wishes,
Caitlin O'Grady (Caitlin.O'Grady.09@ucl.ac.uk)
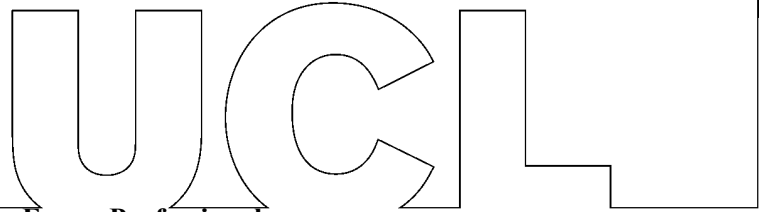
Participant Information Form: Professional
HIV/AIDS in India: Individual, Community, Health System.
Researcher: Caitlin O'Grady (UCL)

My name is Caitlin O'Grady and I am conducting doctoral research at University College London. I am interested in learning more about what you view as important about the HIV/AIDS epidemic within India, with particular regard to policy and programming decisions. The general aim of my research is to document your views and experiences of how HIV/AIDS is approached and understood within Chennai

What will involvement in this study entail?
If you agree to participate, my study will involve an interview in which I will ask several general questions. Please note that some of the questions will relate to your professional history and will span the period from 1985 to the present. However, these are very basic questions and the main information gathered will be up to your discretion. I am interested in what you choose to share with me and there is not one particular answer I am looking for. You do not have to answer any questions that make you feel uncomfortable and you are free to say so at any given point. Interviews will last approximately an hour, but may run longer if there is more you would like to discuss.

Do I have to take part in all aspects of the research?
Participation, while extremely appreciated, is at the individual's discretion. You may include as much or as little information in discussions as you feel comfortable. Again, you may decide to end the interview at any stage. At no time will there be pressure to continue if you wish to stop.

How will my information be used?
All discussions will remain confidential and will only be used for this particular study. The data will be collected and stored in accordance with the Data Protection Act 1998 – this is the part of British law protecting anyone's personal information. The names of participants will not be included as each individual will be assigned a pseudonym for the purposes of this research.

How will participation be beneficial to me?
This research is being undertaken with the hopes of drawing attention to important issues facing individuals within the local epidemic as identified by the individuals themselves. Participants will be reimbursed 250 rupees for their participation.

What is the next step?
Please find attached a sample consent form. I will bring a copy to our interview for you to sign. Again, personal information will not be included in the research and you will instead be assigned a pseudonym. For questions relating to your rights, please contact YRGCARE Chairperson, Dr. Jayakar Paul (044-23633320) or Co-Chairperson, Dr. V. Kumaraswami (044-26646207).

Thank you and best wishes,
Caitlin O'Grady (Caitlin.O'Grady.09@ucl.ac.uk)

Appendix B
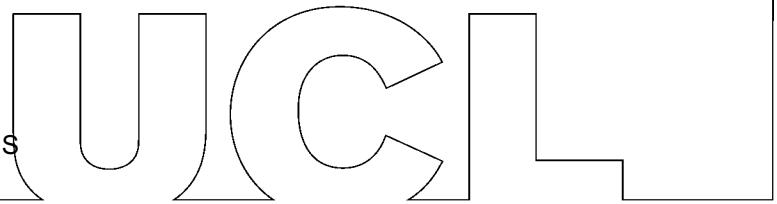
Informed Consent Form for Interviews and Focus Groups

HIV/AIDS in India: Individual, Community, Health System.
Researcher: Caitlin O'Grady (UCL)

Name:……………………………………………………………………....

Please tick the relevant boxes:

RESEARCH PARTICIPANT CONSENT	YES	NO
I have been given a participation information sheet, which I have read and understand.		
I understand that participation is voluntary and I can withdraw from the research at any time.		
I am aware of and consent to the tape recording of my discussion with the researcher.		
I consent to the information shared for the purposes of this study being used in a university doctoral thesis and/or for publication in a research journal and future work by this researcher. I understand I will be assigned a pseudonym.		
I give consent that I would like to participate in this research.		

Signature of Participant: …………………………………………………..
Date: ……………………………..

Signature of Researcher: ………………………………………………….
Date: ……………………………..

Signature of Witness: ....
Date: ....

Appendix C

Research Questionnaire
Interviews with HIV-positive individuals and individuals working with HIV/AIDS issues.

Sample Starter Questions for HIV-positive Individuals:

Q1.　　Could you please give your age and occupation?

Q2.　　How long have you been HIV-positive?

Q3.　　What were the circumstances that led to your diagnosis? Did you have any symptoms?

Q4.　　What was your understanding of HIV/AIDS prior to your diagnosis?

Q5.　　Where did your knowledge of HIV/AIDS come from? School? Television? Radio?

Friends?

Q6.　　In what ways has your HIV status affected your daily routine?

Q7.　　Have you disclosed your status to others? What were their reactions to the news?

Q8.　　Has your HIV status impacted your family relationships? Or your interactions with

friends?

Q9.　　What is your religious background? Has this impacted your understanding of HIV?

Q10.　　Have you experienced instances of stigma or discrimination based on your HIV status?

Q11.　　In your opinion, what is the public perception of HIV/AIDS?

Q12.　　Where does public knowledge of HIV/AIDS come from?

Q13.　　Are you aware of any incorrect rumours about HIV? Or public misconceptions?

Q14.　　In your opinion, how could public understanding of HIV/AIDS be improved?

Q15.　　Can you suggest anyone who might be willing to take part in this research? Family

members? Friends? Other HIV-positive individuals?

Q16.　　Is it possible to meet with you again as a follow up to this interview?

Sample Starter Questions for Professional Individuals in the HIV/AIDS Field:

Q1. Could you please give your name and occupation?

Q2. How long have you been working in this field?

Q3. Have you worked in any other areas of HIV/AIDS?

Q4. Please describe the interaction of your occupation and HIV/AIDS.

Q5. Could you please share your impression of the current local epidemic?

Q6. In your professional opinion, what is the public understanding of HIV/AIDS?

Q7. Where does the public get this information?

Q8. What, in your opinion, has been the best method for sharing information with the public?

Q9. Does stigma towards HIV-positive individuals still exist? Can you give examples?

Q10. In your professional opinion, who is at the greatest risk of HIV infection in Chennai? Why?

Q11. In your professional opinion, what needs to be done to slow the local epidemic?

Q12. How can this be accomplished?

Q13. Do your co-workers or other members of your occupation share your opinions? Do they differ?

Q14. Can you suggest anyone who might be willing to take part in this research?

Q15. Would it be possible to meet with you again as a follow up to this interview?