

An Exploration of HIV Related Stigma within the Context of Kerala, India

by

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## Abstract

**Purpose** To understand through explorations of the experiences of HIV positive individuals whether these individuals experience stigma in relation to HIV/AIDS and how it has impacted their lives and that of their families.

**Design** Qualitative study used ethnographic techniques (interviews, questionnaires, informal conversations, observation, field notes) to collect data over a four-month period.

**Setting** Data was collected from nine districts in the northern, central, and southern regions of the state of Kerala, India.

**Participants** Shared their perspectives on HIV related stigma (n=49 total). Of the 38 participants interviewed, 12 were HIV positives, 19 were HIV positives who also worked or volunteered with HIV positive networks (known as positive speakers), 2 were caregivers of HIV positives, and 5 were key informants involved with community organizations providing services to HIV positives. Informal conversations with 11 unaffected were also utilized.

**Findings** were organized into four themes. (1) Anti-stigma/prevention strategies such as positive living and positive speaking offered positive speakers unique challenges and opportunities as they were called upon to be the face and voice of HIV (2) Contrary to expectations that formal education which also included awareness about HIV could increase one's knowledge and subsequently dispel ignorance and stigma, the findings pointed out how knowledge itself is a resource that allowed stigma to unfold along existing social hierarchies. (3) Unconscious prejudices about physical appearances

influenced perceptions of HIV risk, and a stigmatized identity waxed and waned with a change in physical appearance as the HIV positive oscillated between illness and health.

(4) “Immoral behaviour” as the cause of HIV infection entered into family/caregiver decisions regarding the use of family resources for the treatment and care of the HIV positive member. Gender and social class also impinged on family decisions in numerous ways.

**Conclusions** This research project has highlighted the need to develop a more nuanced understanding of HIV related stigma that extends beyond the current conceptualization of stigma as “ignorance” or lack of awareness about modes of HIV transmission.

Refining current understandings of HIV related stigma could guide research, policy, and practice.

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*For my husband, Sabu, daughter, Cecily and Baby on the way*

## Chapter I: Introduction

UNAIDS estimates that there are approximately 2.5 million HIV/AIDS infections in India (UNAIDS, 2006). Despite the controversy surrounding published statistics on the prevalence rate, India continues to be in a category of overall low prevalence countries with an adult prevalence rate of less than 1% (UNAIDS, 2009). However, the sheer size of India's ever expanding population has made it the epicenter of the HIV epidemic in South-East Asia (Bharat, Aggleton, & Tyrer, 2001). Kerala, where this study is conducted, is located at the southwest tip of India. With a population of over 30 million people, Kerala is one of the states in India with the lowest prevalence rates (Elamon, 2005; Xavier, 2004). However, surrounded by high prevalence states such as Karnataka and Tamil Nadu, Kerala faces a unique challenge in maintaining its low prevalence status (Elamon, 2005). The presence of a large number of trucking communities, inward migration from the surrounding states due to unemployment, and the highly mobile nature of the general population especially to high HIV prevalent sites such as Mumbai for better employment prospects contribute to Kerala's higher risk (Elamon, 2005; Xavier, 2004).

A former director of the WHO global program on AIDS, the late Jonathan Mann identified three phases of the HIV/AIDS epidemic: "the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination and denial" (Parker & Aggelton, 2002). After this statement was made in 1987, international efforts have largely focused on finding a cure for HIV/AIDS or preventing the transmission of HIV from high-risk groups, such as commercial sex workers or injection drug users (IDU) to the general population (Parker & Aggelton, 2002). However, the "epidemic of stigma, discrimination and denial" received less attention and thus remains less understood.

The purpose of this research was to understand through explorations of the experiences of HIV positive individuals whether these individuals experience stigma in relation to HIV/AIDS and how it has impacted their lives and that of their families. In chapter II, I explore the literature on stigma, and related terms – prejudice and discrimination. Chapter III provides a background of the state of Kerala, India where this study is conducted. Chapter IV describes the research methods and procedures. The study findings are presented in chapter V. Chapter VI discusses the relationship of the findings in relation to the research questions and the available literature. Directions for future research, policy, and practice are also discussed. Chapter VI ends with the limitations of the study and a brief conclusion section.

## Chapter II: Literature Review

### Defining Stigma

On the topic of stigma, the Joint United Nations Programme on HIV/AIDS (UNAIDS) frequently refers to the need to fight stigma, but this remains a challenging task especially because there is no consensus on the definition of stigma (Castro & Farmer, 2005). The stigma research tradition stems from the seminal works of sociologist Goffman, *Stigma: Notes on the Management of Spoiled Identity* (1963). Stigma research has traditionally focused on studying people with unusual conditions, such as facial disfigurement, mental illness, short stature, HIV/AIDS, and so on (Stuber, Meyer, & Link, 2008). Most studies on HIV/AIDS-related stigma refer to Goffman's definition of stigma. He describes stigma as an "attribute that is deeply discrediting" and as one that reduces the affected person "from a whole and usual person to a tainted, discounted one"(Goffman, 1963). After four decades of Goffman's classic work on stigma, the ever-widening range of this phenomenon has produced a massive body of literature that does not use a common definition or coherent theory of disease stigma (Deacon, Stephney, & Prosalendis, 2005).

Stigma has been cited as undermining public health efforts to combat HIV/AIDS in several ways. Stigma inhibits preventive behaviors , delays diagnosis, negatively influences care-seeking behaviors, quality of care received, and the perception and treatment of people living with AIDS (Gerbert, Macquire, Bleeker, Coates, & McPhee, 1991; Herek & Glunt, 1988; Herek, 1990; Macintyre, Brown, & Sosler, 2001; Malcolm et al., 1998; Muyinda, Selley, Pickering, & Barton, 1997). The failure of governments to protect the rights of people living with AIDS, logistic and economic barriers that hinder

global access to antiretroviral drugs and high quality care, social inequalities that initiate and perpetuate structural discrimination, as well as individual perceptions and attitudes have been cited as possible causes and consequences of stigma (Castro & Farmer, 2005; Parker & Aggelton, 2002). Some authors have even argued that stigma may slow down the transmission of AIDS from high-risk groups to the general population (Kurzban & Leary, 2001; Reidpath & Chan, 2006). Although the debate on the definition, relevance, cause, measurement and approaches to address HIV/AIDS stigma are ongoing, there is considerable agreement that the issue needs to be addressed from a wider variety of contexts in order to obtain a comprehensive picture of stigma (Brown, Macintyre, & Trujillo, 2003; Nyblade, 2006; Parker & Aggelton, 2002).

While social psychology contributed to a substantial portion of the work on stigma, research on stigma is multidisciplinary and includes contributions by psychologists, sociologists, anthropologists, political scientists, and social geographers (Link & Phelan, 2001). Because the concept of stigma has been applied to an enormous array of circumstances, and investigators have approached stigma from different theoretical orientations and disciplinary perspectives, there is a wealth of information on what needs to be included in the stigma concept (Link & Phelan, 2001). Although some researchers argue a conflation of definitions has hampered our understanding of what stigma is and how it can be tackled (Deacon et al., 2005), it seems that the variation in definitions of stigma is likely to continue and may even be necessary given the complexity of the phenomenon and its application (Link & Phelan, 2001). My intention is not to identify any one conceptualization as epistemologically or morally superior to any other, but to sift through these varied understandings of stigma and draw on them

from time to time to understand the multitude of experiences that are attributed to HIV/AIDS. Within this context, the effort is not to view various conceptualizations to be in conflict with each other but to see them as alternate visions stemming from different frames of reference. In the following section, I will discuss why bridging the disparate yet similar traditions of stigma and prejudice research is considered important. I will also explore various theories in an effort to deepen the understanding of HIV related stigma.

### **Bridging Stigma and Prejudice Research Traditions**

The Health & Society Scholars Working Group in 2006, that convened scholars across the social and health sciences, recommended bridging the traditions of stigma and prejudice research to deepen our understanding of stigma and the health implications of stigma, and prejudice (Stuber et al., 2008). Prejudice research tradition stems from social psychologist Allport's foundational works on *The Nature of Prejudice* (1954). Allport defines prejudice as “ an aversive or hostile attitude toward a person who belongs to a group, simply because he belongs to that group, and is therefore presumed to have the objectionable qualities ascribed to the group” (p. 7 as cited in Dovidio, Glick, & Budman, 2005). Scholars interested in prejudice focus on far more ordinary yet profound implications of gender, age, race, and class divisions (Stuber et al., 2008). The large body of research that came five decades after Allport reinforce many of his conclusions and speculations, but also point out some of the limitations in his thinking (Dovidio et al., 2005). Even though stigma and prejudice have less conceptual differences, the bulk of the literature on stigma and prejudice are organized around a single disciplinary

perspective, either stigma or prejudice, but rarely do they focus on both (Stuber et al., 2008).

While stigma and prejudice evolved along different evolutionary tracks bridging these two traditions is considered an important endeavour (Deacon et al., 2005; Stuber et al., 2008; Phelan, Link, & Dovidio, 2008). The first reason is because stigma and prejudice have much in common and distinctions that arose were out of differences in emphasis and focus. Thus, a greater collaboration between these two traditions can enhance existing models (Stuber et al., 2008). Work in the stigma tradition has been primarily concerned with norm enforcement and disease avoidance while social processes driven by exploitation and domination have been the primary focus of the prejudice tradition (Phelan et al., 2008). However, the social processes involved in enacting and maintaining stigma and prejudice are similar in that both involve categorization, labeling, stereotyping, negative emotions, interactional discomfort, social rejection and other forms of discrimination, status loss and harmful effects on life chances of targets (Phelan et al., 2008). An area that could benefit from the integration of these two research traditions is how psychosocial stress has been conceptualized in the lives of marginalized groups (Stuber et al., 2008). There is a vast body of literature on the psychological impact of prejudice and discrimination primarily from the perspective of the perpetrator where a non-marginalized person treats a marginalized person unfairly (Stuber et al., 2008). On the other hand, stigma researchers conceptualize stigma mainly from the perspective of the target rather than the perpetrator (Phelan et al., 2008). Stigma research refers to two types of psychosocial stress: anticipated stigma, and internalized (self) stigma (Stuber et al., 2008). Sometimes stigma is referred to as a stressor because

it involves the anticipation of negative treatment. For example, attempts to protect one's self-esteem through concealment and the vigilance required to maintain one's HIV positive statuses hidden are themselves described as emotionally exhausting experiences (Alonzo & Reynolds, 1995). Stigma has also been described as a stressor when individuals direct negative societal attitudes towards the self or the so-called internalization of stigma. Internalized stigma or self-stigma is focused on understanding how much stigma perceived and experienced have led to a negative self-image (Nyblade, 2006). Unlike stigma research, understanding internalized forms of oppression has not been the major focus of the prejudice research tradition (Stuber et al., 2008). Although there is greater collaboration between stigma and prejudice research traditions in the recent decade, some scholars argue a focus on internalized oppression to the exclusion of interpersonal and structural forms of oppression, and exploitation and dominance to the exclusion of internalizing or vigilance behaviour have limited our understanding of the health impacts of stigma, prejudice, and discrimination (Stuber et al., 2008).

Another area of cooperation is the intersection of multiple sources of stigma and prejudice where typically research is focused on one area and not the others (Stuber et al., 2008). HIV stigma often exists on top of pre-existing prejudices based on gender, class, age, socio-economic status and sexuality. Therefore, it has been called a layered stigma (Campbell, Nair, Maimane, & Nicholson, 2007; Nyblade, 2006). Consequently, each individual within a family and the family as a whole unit may experience stigma differently. For example, researchers focus on gender discrimination or HIV related stigma but rarely do they focus on the social reality that disadvantaged groups experience stigma for more than one reason. Also, unlike what is suggested by most



studies HIV status might bestow protection on some groups more than others and in the process unfairly stigmatize other groups. Therefore, studies that focus on the impact of multiple identities are needed. This could shed light on how the intersections of multiple disadvantaged/ advantaged statuses impact health (Stuber et al., 2008).

A third reason why an integration of stigma and prejudice research is necessary pertains to innovations by prejudice researchers into the areas of unconscious forms of prejudice (Dovidio et al., 2008). Studies into unconscious forms of prejudice have reinforced Allport's findings that people may be unaware of the source of their prejudice and even unconscious that their prejudices influence their behaviour in significant ways (Dovidio et al., 2008). This body of work has obvious implications for stigma researchers since unconscious (or unintentional) forms of bias can exist even in the absence of overt forms of violence and exclusion as it becomes more and more socially inappropriate to frown upon conditions such as HIV/AIDS publicly. This suggests that stigma and prejudice can exist in qualitatively different forms such as subtle control and exploitation, which are easily overlooked but nevertheless disadvantages groups without any apparent antipathy (Dovidio et al., 2008). For example, research on race and gender based divisions in the US over the past 50 years suggest that overt forms of race prejudice and sexism were declining as the public embraced principles of equality and integration but benevolent forms of prejudice continue to impede disadvantaged groups' socio-economic progress (Dovidio et al., 2008).

In general, stigma and prejudice are believed to impact health through the following pathways. The positive impacts documented are few and far between with the bulk of the literature emphasizing the adverse impacts on health. First, numerous studies

from different parts of the world on HIV/AIDS have documented the health harming consequences of stress processes activated (anticipated and internalized stigma) through interactions between marginalized and non-marginalized groups (for example studies from India: D'cruz, 2004; Tarakeshwar et al., 2006). In addition to family and community settings, discrimination and mistreatment in health care institutions, educational settings, and employment sector were also found to have negative health implications ranging from constricted social networks, low self-esteem, income loss, unemployment, and compromised quality of life (Elamon, 2005; Parker & Aggleton, 2002). However, responses of people toward disadvantaged groups are not consistently negative whether the disadvantage is due to a particular disease status or group membership. For example, HIV positive status evoked mixed reactions at both the individual and family level, and attitudes toward disadvantaged races (blacks) often involved a desire to be fair and egalitarian despite negative affective responses (Bharat et al., 2001; Dovidio et al., 2005). Likewise, marginalized groups do not experience stigma consistently. Also, as a social construction the processes and expression of stigma are highly situation specific and context dependent (Levin & Van Laar, 2006). For example, despite financial burden and emotional distress a study among 50 HIV positives in Chennai, India found both male and female participants to be high in positive self-concept and resilience (Tarakeshwar et al., 2006). The second pathway through which stigma and prejudice impact health is that since people are not always aware of the source of their prejudices or even that their biases affect their behaviour unconsciously, discrimination can occur automatically or spontaneously and health disadvantages experienced by a marginalized group can exist outside a model where someone

intentionally does something unfair to someone else (Stuber et al., 2008). For instance, there are numerous examples of how institutional practices, legislations, policies, and other socio-cultural processes disadvantage HIV positives because they are denied access to health and life resources (Elamon, 2005; Parker & Aggleton, 2002). Third, both stigma and prejudice researchers point out that impaired social interactions between marginalized and non-marginalized groups can occur as a result of internalized forms of oppression and avoidance (Stuber et al., 2008). Understanding the linkages between stigma and prejudice has important implications for public health practice. Research into this area could shed light on innovative approaches and points of intervention to reduce the impact of stigma and prejudice.

### **Stigma and Prejudice: A Theoretical Overview**

The problem of HIV related stigma in India has been raised in related research on barriers to testing, treatment, care and adherence, quality of life, and social responses to HIV/AIDS (Bharat et al., 2001; Elamon, 2005; Parker & Aggleton, 2002). It is important to understand HIV related stigma within the context of broader social, political, and cultural environment and address it as one among the many factors that disadvantage groups. In the following sections, the evolution of the terms stigma, prejudice, and discrimination are explored further in an effort to deepen understanding of HIV related stigma.

Although Goffman advised that we needed a “ language of relationships, and not attributes” (1963, p. 3) and Allport’s classic weaved historical, economic, sociological, and psychological perspectives into coherent themes, much of traditional stigma and

prejudice studies viewed processes and consequences of stigma and prejudice mostly in individualistic terms (Dovidio et al., 2005). Therefore, there was a tendency to view stigmatizing as a character flaw and the experience of being stigmatized as a crushing blow severe enough to distort one's personality (Dovidio et al., 2005; Heatherton, Kleck, Hebl, & Hull, 2003). Drawing on traditional psychological understanding of stigma, awareness programs regarded stigma partly or wholly as a problem of individual ignorance (Deacon et al., 2005). Hence, these programs focused on dispelling ignorance by giving people facts about HIV/AIDS so as to increase the public's tolerance of HIV positives (Deacon et al., 2005). But, social-psychological views of stigma and prejudice have been dramatically transformed during the past half-century (Dovidio et al., 2005; Heatherton et al., 2003). Current views on stigma and prejudice no longer regard stereotyping as abnormal, pathological behaviours but as normal (if undesired) cognitive processes (Heatherton et al., 2003). Similarly, the experience of being targeted results in a set of psychological predicaments rather than deep-seated, consistently negative, even pathological consequences (Heatherton et al., 2003). Thus, currently stigma and prejudice are regarded as highly situation specific, context dependent, non-pathological, complex social processes (Levin & Van Laar, 2006) although this understanding is reflected poorly in most awareness programs (Yang & Kleinman, 2008).

### **Social control models.**

In order to emphasize stigma as a complex social process and explain why educational interventions to reduce ignorance and increase tolerance had not completely succeeded in eliminating stigma, some researchers have developed alternate

conceptualizations of stigma. Instead of the traditional emphasis on internal oppression, stigma is understood as a complex social process linked to competition for power and control that is tied to existing social mechanisms of dominance and inequality (Link & Phelan, 2001; Parker & Aggeleton, 2002). These approaches advocate for exploring issues of power, dominance, history, and the functions of stigma in producing and perpetuating social inequalities; and provide a better explanation to understand the persistent nature of stigma within a variety of contexts. For example, (People Living with HIV/AIDS (PLHA) could stigmatize each other based on existing social hierarchies among themselves and family members or peer groups may experience stigma differently based on power differentials due to their gender or age. However, some limitations have been pointed out. Deacon and colleagues (2005) argue that social control models focus too much attention on the broad picture at the expense of ignoring what stigma means for micro-level interactions. Secondly, the emphasis on power and control alone appears insufficient to explain how existing social inequalities foster stigma or how stigma perpetuates existing inequalities within the context of HIV/AIDS. Social control and psychological theories suggest it is fear arising from concerns of self-preservation and/or dominance that drive stigma and prejudice. However, rather than fearing social exclusion if PLHA choose to hide their HIV positive status from their families out of love and respect for their loved ones because they do not want to hurt them, how does that fit into a power-control model? In the spirit of cooperation, harmony, and group solidarity, if PLHA accept their restrictions or even self-impose them and their actions are culturally interpreted, praised, and supported as actions of great power and love by their in-group, are they being stigmatized? In other words, if

self-sacrifice is viewed as “power” are they being exploited? Surprisingly, the vast literature on stigma, and prejudice mentions little about love, respect, or any other emotional resources. Also, the tendency is to view power and love as polar opposites. Thus, in the absence of love, power leads to exploitation and dominance. This conceptualization is echoed in US civil rights leader Martin Luther King’s statement: “Power without love is reckless and abusive, and love without power is sentimental and anaemic.” The role of love in inter-group relations finds sparse mention in the prejudice research literature. It is argued that in a world vexed by uncertainty, rather than risk stiff resistance and repercussions, dominants may choose to befriend, love, or reason with their subordinates on whose cooperation they depend to maintain their privileged status (Dovidio et al., 2005). Dominant groups define the needs and interests of the subordinates, society as a whole, and claim to act on the “best interests” of everyone. Those who comply are rewarded with praise, social inclusion, admiration, and love, and those who lapse into socially inappropriate behaviours are excluded, ridiculed, humiliated, and stigmatized (Dovidio et al., 2005). What is implied is not a consistently malicious attempt to subjugate, but rather an unconscious, learned response that has evolved over time as groups with varying degrees of power pursued their mutually opposed mutually contingent goals (Dovidio et al., 2005). Consequently, cultural values and institutional contexts may be defined and redefined to establish and maintain existing social structures. Another limitation of social control models is how discrimination has been included in the definitions of stigma. For example, in one of the social control models, Link and Phelan (2001) propose stigma to exist when the components of labelling, stereotyping, separation, status loss, and discrimination

converge in an asymmetrical power situation that allows these components to unfold. But, Deacon and colleagues (2005) argue if people were to internalize stigma or anticipate being stigmatized or discriminated they may still experience the negative impacts of stigma (being labelled, stereotyped, separated, and fearing a loss of status) without actually being discriminated. The question raised is what does discrimination actually mean? Does it only include the clearly apparent forms of discrimination such as violence and exclusion or does it also include more subtle forms of discrimination? Apparently emanating from the prejudice research tradition the term “discrimination” can be explained by how prejudice has been understood in prejudice research. Contemporary prejudice researchers argue that Allport’s definition of prejudice as “an antipathy based upon a faulty and inflexible generalization” was the fundamental blind spot that had gone undetected for decades (Dovidio et al., 2005). Allport’s emphasis on antipathy directed the field towards an understanding of prejudice as something that resulted in violence and exclusion at the expense of ignoring other forms of prejudice that included subtle control and exploitation or discrimination that resulted from unconscious prejudices (Dovidio et al., 2005). For example, Allport overlooked “the ordinariness of gender prejudice” or benevolent paternalism (Dovidio et al., 2005). Recognizing the limitations of Allport’s original conception of prejudice has profound implications for stigma research as well since both traditions are heavily influenced by each other.

### **Differentiating stigma, prejudice and discrimination.**

Although some studies clearly explain what is included in the term “stigma” and differentiate stigma and discrimination much of the work on stigma does not do so (Deacon et al., 2005). For example, Nyblade (2006) defines discrimination as the “actual stigma experienced” or “enacted stigma”, but others define stigma as “ any negative thoughts, feelings or actions towards people living with HIV/AIDS ” (Campbell et al., 2007). Link and Phelan (2001) use the term discrimination to refer to both internalized forms of oppression (self stigma, vigilance behaviour, avoidance etc), and structural forms of oppression stemming from unfair institutional practices, policies, and socio-cultural processes. In an effort to distinguish stigma, prejudice and discrimination Deacon and colleagues (2005) define stigma and prejudice as “ideologies”, what people say as “expressed stigma”, and what people do as “discrimination”. However, the conflation of definitions is rarely viewed as problematic probably because the major concern with stigma has been that it causes discrimination of some sort – whether they are internal oppressions, or overt expressions that included violence and exclusion (Deacon et al., 2005). Consequently, a wide array of barriers that prevented HIV positives’ access to health and positive life outcomes were categorized as HIV/AIDS stigma. Over the decades, stigma has come to mean anything that people say or do to undermine public health intervention efforts or that restricts PLHA’s access to employment, education, health and reasonable quality of life (Deacon et al., 2005). Using the same term “HIV related stigma” to refer to an entire range of barriers that deals with HIV/AIDS without addressing how multiple identities impact health does not help with understanding what causes these different barriers or developing interventions



to address them. Also, negative beliefs about or actions toward PLHA may be associated with a number of factors such as over inflated perception of risk, individual characteristics or behaviour unrelated to HIV status, circumstance of a household unconnected to HIV/AIDS (e.g., poverty, unemployment, addictions), or other identities that person or in-group has that are unconnected to HIV/AIDS.

### **The instrumental – symbolic framework of stigma.**

Herek and Capitano (1998) provide a useful model to understand why not all PLHA experience the same kind of stigma and why individual experience of stigma varies with the context. A conceptualization of stigma that is based on its functional aspects is Herek and Capitano's (1998) classification of stigma as instrumental and symbolic stigma. Instrumental stigma refers to stigma that arises out of the concern for self-preservation especially because HIV/AIDS is an incurable, debilitating disease that not only infects but also drains one's resources. Moral or symbolic stigma stems from value-based ideology that condemns immoral sexual behaviour. The instrumental-symbolic framework is particularly important for HIV/AIDS because the co-joint effects of symbolic (links HIV/AIDS to promiscuity) and instrumental (disease related factors such as contagiousness, treatability, and severity) stigma has made it even more stigmatizing than other diseases such as cancer or hepatitis (Deacon et al., 2005). Although it may be difficult to disentangle instrumental and symbolic stigma in any particular situation Herek (2002) suggests that since instrumental stigma is based on over-inflated perceptions of risk or resource constraints, it carries less social baggage and can be more easily shifted than symbolic stigma that is based on moral judgements. Tied

to existing forms of social inequalities (for example, gender or class divisions) and power relationships symbolic stigma is more entrenched and therefore more difficult to shift. Currently, a lack of understanding about scientifically identified ways of HIV transmission is usually termed stigma or “ignorance”, and the understanding of HIV/AIDS based on current biomedical information is termed “knowledge” (Deacon et al., 2005). Arguably, a test of instrumental stigma tied to over-inflated perceptions of risk (or the so-called stigma of “ignorance”) is whether it can be reduced through the provision of information materials about the routes of HIV transmission. But, despite the provision of biomedical information people may still perceive themselves to be at risk because of a lack of trust in the source of information and its provider, dislike of how the message was conveyed or how it made them feel, provision of general information rather than the specifics tailored to clarify how HIV is *not* transmitted, a preference for alternate medical models, fear of being stigmatized for claiming to possess knowledge or even talking about a taboo topic (Deacon et al., 2005; Herek, 2002). Thus, for information to grow into knowledge it must be perceived as credible by target audiences. A lack of trust has been associated with misperceptions of HIV transmission and greater willingness to stigmatize PLHA (Deacon et al., 2005). Also, couched in biomedical knowledge that is part of a western value system public awareness programs attempt to educate the public without paying sufficient attention to indigenous systems of medical knowledge. For example, in Southern African countries that had plural health care systems it has been found that dispelling anything that is outside a biomedical consensus as ignorance has encouraged powerful counter discourses based on alternate healing traditions and common understandings that pitted the government and its spokespeople

on one side and everyone else on the other side of the debate (Deacon et al., 2005). This argument is relevant to Kerala as well since Ayurveda is a trusted and widely practiced alternate healthcare system in Kerala. Therefore, in societies that have plural health care systems it merits investigating how different epistemological traditions coincide with entrenched social divisions to culturally mediate responses (which may or may not be stigmatizing) toward PLHA. Instrumental stigma based on resource constraints is considered wrong because it violates the human rights of PLHA (Deacon et al., 2005). Provision of free Anti Retroviral Therapys (ART) might prolong PLHA's lives, reduce their burden on caregivers, and allow PLHA to remain productive longer. Within this context, it would be interesting to see whether resource based concerns systematically skew responses toward PLHA and if so, whether these responses have any gender and class dimensions. Although risk and resource concerns (instrumental stigma) and what is considered morally acceptable (symbolic stigma) change over time and vary in different contexts, it is generally slower than the change in medical knowledge (Deacon et al., 2005). Consequently, what is categorized as ignorance might turn out to be sensible precautions and preventive measures that are currently sanctioned as necessary may be later recast as ignorance should medical knowledge change (Deacon et al., 2005). Also, instrumental stigma and symbolic stigma can co-exist (Herek, 2002). Therefore, risk or resource concerns may be cited as an excuse or justification for symbolic stigma or vice versa depending on what is socially/morally appropriate within the context. As Herek (2002) advice, rather than to categorize various experiences of stigma as instrumental or symbolic, painting a vivid picture of the conditions that allow these stigma to unfold would deepen understanding of HIV/AIDS related stigma.

In the above sections, I have provided a theoretical overview of stigma, prejudice and discrimination, how these terms evolved over the decades, and how they are being used in the current literature. HIV stigma co-exists on top of other multiple disadvantages/advantages. Therefore, in my effort to understand HIV related stigma in Kerala I draw on the various conceptualizations of stigma from time to time to uncover the conditions that advantage or impede HIV positives' life outcomes in relation to multiple identities such as gender, social class, relationship ties with family, and so on.

## **Purpose and Research Questions**

The purpose of this study is to understand, through explorations of the experiences of HIV positive individuals in Kerala, whether these individuals experience stigma in relation to HIV/AIDS and how it has impacted their lives and that of their families. An understanding of the impact of stigma can assist the government, NGOs and other concerned stakeholders to provide coordinated prevention, diagnosis, treatment and care programs in order to improve the quality of lives of HIV-positive individuals and their families.

The study will address the following research questions:

1. How does stigma regarding HIV unfold in an asymmetric power situation?
2. How do multiple identities due to one's gender and socio-economic background and regional location impact one's experience of being infected with HIV?
3. How does the HIV positive status of one or more members in a family affect relationship ties within that family and how can the family's response to HIV as a unit be best conceptualized?

### **Chapter III: Kerala – An Overview**

Wedged between the Arabian Sea on the west, and the mountain ranges of Western Ghats on the east, the state of Kerala lies to the extreme southwest of the Indian peninsula (see map 1 below). The state was formed in 1956 on a linguistic basis, bringing together the Malayalam speaking kingdoms of Travancore, and Cochin with the northern state of Malabar of the Madras presidency. While its land area (38,863 sq.kms) forms only 1.1 percent of India, its population (31.8 million as of 2001 census) accounts for about 3 percent of India's population (UNDP, 2005). In fact, with a population nearly as big as Canada's squeezed into an area not much larger than Lake Winnipeg, Kerala could be one of the most densely populated regions of the world. Administratively, Kerala is divided into 14 districts, 63 taluks, 152 community development blocks, and 999 grama panchayaths (see map 2).

Fondly referred to as "God's Own Country" for its lush green vegetation, exotic hill stations, sprawling backwaters, and post-card perfect beaches, its high population is spread across the state, with relatively less urban agglomerations. The territory is divided into three zones – the lowlands, the midlands, and the highlands. The semi-tropical climate, and copious rainfall make Kerala suitable for both food crop and cash crop cultivation. The lowlands, characterized by backwaters, provide the basis for fishing, horticulture, coconut, and paddy cultivation. In the midlands, coconut, rice, cassava, plantain, cashew, rubber, along with spices, are cultivated. The highlands are mountainous in nature, with evergreen tropical forest in the upper range, and plantation crops, such as tea, coffee, and rubber, in the lower range. The lowlands, with 10 percent of the geographical area, are the most densely populated, and highlands, with 48 percent

of the geographic area, are the least densely populated regions (Ramanathaiyer & Macpherson, 2000; UNDP, 2005).

The agro-climatic conditions, and natural resource base support numerous agro-processing industries, of which coir, cashew, wood and edible oil are the most important, especially in terms of employment (UNDP, 2005). Although Kerala is generally classified as “backward” in terms of its industrial development and food crops production in comparison to some other Indian states (Ramanathaiyer & Macpherson, 2000), a striking feature of Kerala’s development is the growth of its service sector (UNDP, 2005). No longer a predominantly agrarian economy, the service sector accounts for the largest shares of its income (55 percent) and employment generation (40 per cent) (UNDP, 2005). Some large-scale industries, based on mineral, chemicals, and engineering, and an increasing segment of small and medium scale industries, based on modern technology and management (for example information technology) have also emerged (UNDP, 2005).

Kerala has a long history of commercial and cultural contact with other civilizations. Internationally reputed as a leading producer of spices, Kerala has welcomed merchants and explorers from the ancient Greece, Arabia, Rome, China, and more recently, the Portuguese, the Dutch, and the English, to its shores (Parayil, 2000). Over the past several centuries, Kerala has been influenced in varying degrees by many of these cultures, and the religions that came along with commerce and trade. As one of the most religiously diverse regions in South Asia (Parayil, 2000), modern Kerala has three predominant religions: Hinduism, Islam, and Christianity. Christians and Muslims accounted for a greater share than in other Indian states, and as per the 2001 census, are

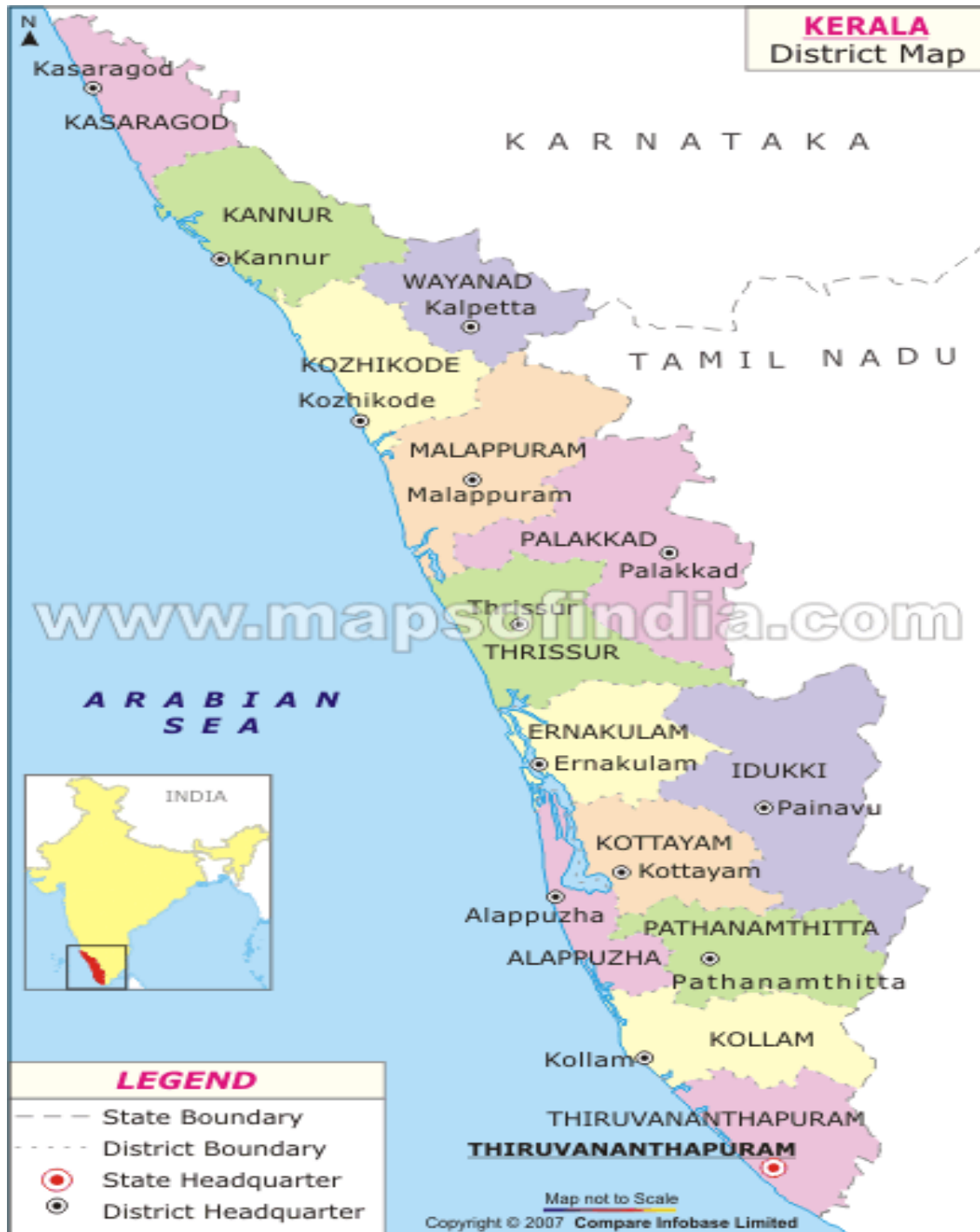
19 percent and 24.7 percent of the population respectively (UNDP, 2005). The remaining 66 percent of the population were mostly Hindus. Christianity and Islam, as practiced in Kerala, are specifically Keralite since they are viewed as intercultural constructions rather than as imported faith (UNDP, 2005).



Map 1. Location Map of Kerala



Map 2. District Map of Kerala



### **Social Reform Movements in Kerala**

Kerala's achievements in terms of various human development indices, and physical quality of life measures are the result of major political, social, and economic transformations. How Kerala became an object of fascination in the development literature since the 1970's, and how it gained a reputation at odds with much of India, and even with earlier accounts of Kerala society itself, is essentially historical. However, it is history that meets the present, and therefore, key features of the transformation: movements against caste oppression, land reforms, role of the communist party and governments in Kerala, emphasis on education, family reorganization, and women's agency, are sketched out briefly in this section. Kerala's image of itself and its policies have been handed down and developed from these intense periods in its early development.

During the 19<sup>th</sup> century and the first two decades of the 20<sup>th</sup> century, Kerala, as elsewhere in India, was an extremely caste-ridden society (Ramanathaiyer & Macpherson, 2000; Parayil, 2000). The traditional caste system in Kerala had some special features and often the worst forms of oppression and persecution were practiced. Complex rules on distance pollution not only included "untouchability" and "unapproachability" but also "unseeability" against some slave castes (Parayil, 2000). Caste determined everything from one's occupation, dress code, type of housing, freedom of movement, public conduct, and level of participation in the society (Ramanathaiyer & Macpherson, 2000). Caste based reform movements arose among many castes in Kerala. The most well known are reform movements among the lower castes, such as the Ezhavas, and the Pulayas (a scheduled caste). Initially centred on

gaining access to schools, hospitals, and public services that had remained inaccessible to low castes, these reform movements gradually addressed other broader issues, such as temple entry, social mobility, and political representation (UNDP, 2005). Sensing threats to their dominant caste position, upper castes, such as the Nairs organized to propagate community, marriage, and property reforms (Parayil, 2000). Similarly Muslims, and Christians also organized to propagate reforms and education among their own communities (UNDP, 2005). By the end of the 20<sup>th</sup> century caste-based movements that had sprung up independently forged alliances and evolved into major political movements that demanded political representation in the state legislature (UNDP, 2005). Today, in Kerala, unlike in several other parts of India, previously oppressed classes are no longer denied their rights, (Ramananthaiyer & Macpherson, 2000) and blatant caste based discrimination has become a tale of the past.

Another key feature of Kerala's development experience is the transformation of agrarian relations brought about through mass struggle and legislative action in the 1960s against one of the most exploitative, and complex social formations in India (Parayil, 2000). As elsewhere in India, landlordism dominated social and economic arrangements in villages throughout Kerala (Parayil, 2000). The legislative process of land reforms initiated when the first communist party came into power, redistributed large tracts of land from wealthy landowners to the small holders and the landless, reducing class-caste concentration in land ownership, and income inequality (Parayil, 2000). Although the land reforms act abolished the feudal system and paved the way for raising rural daily wage rates, establishing trade unions and social security measures for agricultural workers, it did not lead to substantial increases in crop production, transfer

of power to peasants and agricultural labourers or increases in rural employment (Parayil, 2000).

By the end of the second decade of the 20<sup>th</sup> century, the Civil Rights League forged through the alliance of Ezhavas, Christians, and Muslims had become the Joint Political Congress (UNDP, 2005). Political and ideological trends within social reform movements, and their relationship with workers' movements led to the rise of a radical group in the state Congress (Parayil, 2000). This gave birth to the Communist party in Kerala. A combination of nationalism and socialism, strengthened by working class solidarity created a high awareness of human rights among the masses (UNDP, 2005). Backed by an emancipatory political movement, the first communist ministry focused on expanding the state's role in the universal provision of healthcare, education, wealth redistribution, and extensive capability building measures (UNDP, 2005). Although the first Communist ministry failed to accomplish their comprehensive development goals, the enabling environment they created led to a public demand and corresponding public supply of these services, which subsequent governments, left or right, were forced to uphold (UNDP, 2005).

The Royal Rescript of 1817 issued by Rani Lakshmi Parvathi Bai, the female ruler of the Kingdom of Travancore declaring universal education paid for by the state, was the first government policy statement on education in Kerala (Parayil, 2000). Since universal education was never British policy, no comparable statement was made either in the 19<sup>th</sup> or 20<sup>th</sup> century by any other state government in British India (Parayil, 2000). Despite policy initiatives and the activity of Christian missionaries, well recognized for

spreading school education, it required female literacy and social reform movements to establish mass literacy and comprehensive schooling (Parayil, 2000). A common feature of all caste-based social reform movements was their emphasis on education (UNDP, 2005). The historic 1914 strike of agricultural labourers organized by Ayyankali in protest against upper castes who resorted to violence to prevent a Pulaya (outcast) girl from gaining admission to a government school, captured the diverse elements of Kerala's struggle against class, caste, and gender discrimination, and people's demand for the right to education (Parayil, 2000). Unlike many other Indian states, the most basic problem of access to schooling and literacy have been overcome and the difference between male and female achievement levels is much narrower in Kerala than all-India average (UNDP, 2005).

The role of women's agency in advancing Kerala's social and economic development is worth emphasizing. As a result of progressive social attitudes towards girls and women, Kerala's women have made outstanding gains in the fields of education, health care and these achievements are comparable to that of men (Parayil, 2000). Progress in demographic and health indicators such as expectancy of life at birth, infant mortality rate and general morbidity will not have been possible without female literacy and education (UNDP, 2005). In addition to key features such as benevolent maharajas, communism, and Christian missionaries that Kerala shares with many other parts of India, a unique element of Kerala's development is the position of women under matriliney and the legacies of that experience (Jeffrey, 2004). The family organization at the end of the 19<sup>th</sup> century was predominantly matrilineal (matrilineal joint family/ the tarawad system) irrespective of religion, though the system was not matriarchial –

women did not govern the households (Jeffrey, 1992). It is very likely that polyandry (having more than one husband at a time) was practiced, and women were accorded greater freedom, choice, and respect than they would have found elsewhere in the world until the 20<sup>th</sup> century (Jeffrey, 1992). Most importantly, women in matrilineal households had permanent rights to property and residence in their natal tarawads just as any other family member (UNDP, 2005). Thus, women's rights, their status, and position were well established and respected unlike in many other parts of India (Jeffrey, 2004). The matrilineal joint-family system shuddered under direct attacks and ridicules by European Christian missionaries, other caste Hindus in the rest of India since it did not fit the patrilineal all-India Hindu model, patrilineal communities such as Christians, Tamil Brahmins in Kerala, and lower castes (Jeffrey, 1992). As a target of reform for the unusual sexual and property practices it sanctioned (husbands did not have rights over women's sexuality or their property) by a wide array of agencies and social processes (modern education, employment & property laws, public debate), criticisms against matrilineality assumed a moral and economic rationale (UNDP, 2005). Viewed as an insult to man's "natural instincts" towards his wife and children, and a threat to individual ownership of property (UNDP, 2005), the system eventually crumbled and gave way to the "modern" family organization of monogamy, patrilineality, and nuclear families, with the man as the legal-economic protector of his family and the wife as his legal dependent/supporter. Comprehensive social reforms thoroughly transformed marriage and family in Kerala, and reworked them well within a framework of patriarchy. The new norms on gender, sexuality, and domestic economy that operate within the patriarchal marital system clearly undermine women's rights to property and

participation in paid employment through a variety of culturally and legally sanctioned practices/policies (for example, the dowry system) increasing their dependency, vulnerability and conformity to patriarchal gender codes (UNDP, 2005). Nevertheless, the remarkable latitude matriliney allowed played a major role in creating conditions that favoured women's education, upward mobility, and entry into salaried employment unlike the rest of India (Jeffrey, 2004).

### **Development, Sustainability, and Success: The Kerala Experience**

A combination of five factors – contributions of Maharajas toward education and health, the role of Christian missionaries in spreading education, the presence of the communist movement that raised rights consciousness among the vulnerable sections of the society, social reform movements, and the role that matriliney played in elevating the status of women – all contributed to improving living standards in Kerala (Ramananthaiyer & Macpherson, 2000). Although the impacts were more pronounced in the southern kingdoms of Travancore and Cochin, Malabar made significant progress post-independence (UNDP, 2005). A study sponsored by the United Nations in 1975 on the state's social and economic development, conducted by Centre for Development Studies in Thiruvananthapuram, assured Kerala a special status in international debates and contributed to the chain of events that culminated in paradigm shifts in development thinking (Parayil, 2000; UNDP, 2005). Since then, Kerala's development experience in terms of physical quality of life measures, and human development indices have been well documented. The life expectancy at birth of 73 years in Kerala is far above the all-India average and is comparable to countries such as Malaysia, China and South Korea that are well on their way to economic development (UNDP, 2005). The female-to-male



ratio of 1.058 is substantially higher than any other Indian state and is identical to North America and Europe (UNDP, 2005). Positive results in literacy, education, health, status of women, and marginal urban-rural difference in all social and demographic factors are another important aspect of the pattern of development in Kerala (Ramananthaiyer & Macpherson, 2000). Although its per capita income lagged behind all-India average till recently, the state ranked first among Indian states in the Human Development Index (HDI) in 1981, 1991, and 2001 (UNDP, 2005). Such pattern of “lopsided” development, high social development despite low economic development, has elevated Kerala’s development experience to the status of a “model”, referred to as the “Kerala model of development” (UNDP, 2005), “social justice model” (Franke & Chasin, 1995), “an enigma” (McKibben, 2004), and an “exemplar of the basic needs approach” (Hellar, 2001). However, the fiscal crisis of the 1980s and the uncertain flow of remittances from non-resident Keralites in the Gulf, led many to question whether continued state financing of social services was indeed possible in the face of a shrinking economic base and a fragile industrial sector (UNDP, 2005). Cross-country analyses suggested high economic growth with low human development permitted movement toward a “vicious cycle” rather than a “virtuous cycle” (UNDP, 2005). However, as Kerala’s economy revived after the late 1980s due to enabling conditions, such as demographic dividends, economic reforms and emigration, the mutually reinforcing impacts of social and economic development became evident. Although the fears over the sustainability of “Kerala model of development” seems to have receded, Kerala faces some serious challenges such as educated unemployment, lack of quality in public service provision, horizontal disparities between social groups and emerging health and social issues

(UNDP, 2005). As Kerala enters the new “virtuous phase” in its development, this study sheds light into the lives of a marginalized group in Kerala - HIV positives from the lower income classes.

## **Chapter IV: Research Methods and Procedures**

### **Research Design**

This study employed an exploratory qualitative research design in order to gather original empirical data regarding the complex nature of stigma and HIV. A qualitative approach was deemed most appropriate for this research for several reasons. First, it is well suited for studies that are exploratory in nature where relevant variables and their relationships to one another are yet to be identified (Patton, 2002). Given the lack of published literature that addresses my research questions within this particular cultural context, this study is considered exploratory. Second, the qualitative approach is most suitable for studying processes and meanings from the participants' perspective (Patton, 2002). Meanings can be defined as the values, beliefs and theories people use to guide their behaviour and interpret their experience (Patton, 2002). The value of focusing on meanings in research is based on the principles of Symbolic Interaction: that people act toward things based on the meanings that those things have for them; that meanings arise out of social interactions, and that one manages these meanings through one's interpretive process (Blumer, 1969). Despite the large body of published studies on the topic of stigma, "much of the research on stigma as a social process has focused on negative stereotyping and on public opinion surveys of those who are perceived to stigmatize others" (Stuber et al., 2008). What is implied is the lack of studies that focus on the experiences of the stigmatized and the meanings they give to those experiences. Finally, qualitative methods allow researchers to understand people's behaviours and/or verbal responses as time-bound, situation, and context-specific experiences. My research sought not only to describe the participants' stigma experiences, but also to explain these

experiences by exploring their meanings from the participant's perspective and the local context. Qualitative methods helped me to understand the flow of their experiences and to ground it within their perspective. My goal was to assist the participants to recount their life stories before and after HIV. As Patton (2002) pointed out, personal narratives "reveal cultural and social patterns through the lens of individual experiences."

Of the many qualitative research methods available, I used ethnography to address my research questions. Ethnography, the earliest tradition of qualitative inquiry, is based on the basic assumption that "any human group of people interacting together for a period of time will evolve a culture", and "understanding culture in relation to change efforts of all kinds" is important (Patton, 2002, p. 81). Using ethnography facilitated the understanding of experiences and actions within a specific cultural context, and allowed me to uncover shared meanings. What makes the method most suitable to this study is that the findings are interpreted and applied from a cultural perspective.

### **Site Selection**

Despite the low prevalence rates when compared to other Indian states (Elamon, 2005), the stigma and discrimination people living with HIV/AIDS face appears to receive substantial media attention and coverage in Kerala. In fact, it was several such reports, particularly the controversial "Benson and Bency case" where two HIV positive children were denied schooling that prompted me to explore the topic of stigma and discrimination in Kerala.

Being a Keralite, I was very well aware that most often nothing works in Kerala without the right contacts. Therefore, before leaving Canada I had established contact with a care home for HIV/AIDS patients in central Kerala and had obtained written permission to interview their residents. I had also initiated a back up plan – to build contacts with NGOs in Kerala - in case there were last minute disappointments. My initial encounters with the care home gave me a taste of the situation of people living with HIV/AIDS in Kerala. Encircled by cement walls about 15 feet in height, the modern three-storied building that housed approximately 100 residents was situated in about an acre of land amidst plantain and coconut trees. On my first visit, as the security guard on duty pushed back the stiff iron gates and as I entered with two of my relatives and the director of the care home, a woman, possibly a resident, who had been cleaning a raw coco stick to make a broom, dropped her things, ran inside, and quickly disappeared behind the curtains. I later learned that residents avoided contacts with the outside world, since many of them had been “dumped” here by their families or had “come on their own to die in peace.” Their privacy and security were not to be compromised. For each visit, I was to be allowed in only with a “pass,” issued at the main office after the staff checked with the supervisor of the care home. Doing face-to-face interviews became the major hurdle. One after another, the supervisor presented her concerns, but expressed her willingness to work out a solution. I took the time to explain why interviews were important for this study, clarified her questions on the risks involved, agreed not to audio tape the interviews, but take down notes, and promised to schedule (or reschedule) the interview times according to their conveniences. Despite influential contacts, and written permission granted “from above”, I realized I would have to work really hard to translate

that into reality. After nearly a month of negotiation, wading back and forth through multiple layers, it dawned on me that I was fighting a losing battle when the closest they would agree on was filling in open-ended questionnaires.

After a discussion with my thesis committee, I thought of broadening the scope of my research to include the perceptions and experiences of the general public toward people living with HIV/AIDS, in case I failed to recruit sufficient HIV positive participants. Meanwhile, I continued to receive similar disappointing responses from a few other care homes I had contacted - “We encourage you to come and interview us, but the residents – they don’t wish to be disturbed. They will not talk with strangers. It is too shameful for them.” No amount of reassurances I made seemed to get me past the “gatekeepers.” None of the textbooks I read on qualitative research taught me as much about the value of creating an atmosphere of trust than these critical periods. In this situation, building trust essentially meant building trust with the gatekeepers and not just with the study participants. This study will not have been possible without the generous guidance and support of Mr. R. Satheesh Chandran, Assistant Director of SOMA, a Kerala based organization that offers management services for development projects. When I heard Satheesh introduce the study and me “as a genuine case” over the phone, I knew half the battle was won. It was finally through Satheesh that I was able to get in touch with networks for people living with HIV/AIDS in Kerala and interview their members.

## **Recruitment of Participants**

Kerala has three prominent networks for people living with HIV/AIDS – Council of People Living with HIV/AIDS in Kerala (CPK+), National Network of People Living with HIV/AIDS (NNP+), and Kerala Positive Women’s Network (KPWN+). I was introduced to the leaders of each of these networks. A social worker at the CPK+ head office introduced my study and me to other district office co-ordinators. Based on their knowledge about their members, the district co-ordinators helped the social worker draft a list of possible participants in each district. The HIV positive person’s willingness to be interviewed, and whether he/she had serious “issues” or “experiences of stigma and discrimination”, was the major recruitment criteria. Rather than draft a list of possible participants, NNP+ recommended another strategy to recruit participants. NNP+ co-ordinators advised me to attend the monthly group meetings they organized at various districts and select participants from those who showed up at these meetings. I had also followed leads I came across while doing fieldwork. While collecting data in Northern Kerala, a relative of mine introduced me to a NGO that worked among MSMs (men having sex with men) and sex workers. This chance encounter earned me an interview with a HIV positive MSM. Interviews with the director and a social worker at this NGO were particularly beneficial as it gave me a good background of the situation in Malabar (Northern Kerala), an area I was entirely unfamiliar with since I am from Southern Kerala.

## **Sampling and Selection**

The selection criteria for a study are determined by the research questions. My initial research questions were focused on families – whether individuals experience stigma and how the family as a unit respond to the opprobrium of stigma, if that was a reality for them. Thus, my early recruitment efforts focused on selecting as many couples and individuals from the same family as possible. Attempts were also made to accommodate a diversified sample in terms of age, gender, social class, religion, and place of origin (urban or rural). The strength of diversified purposeful sampling is that “any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared dimensions of a setting or phenomenon” (Patton, 2002, p. 235). Therefore, high-quality, thick descriptions of individual cases, and important themes that cut across cases that derive their significance from having emerged out of diversity, strengthen the findings (Patton, 2002).

Finding participants from various social classes posed the greatest challenge. I learned that HIV positives that got in touch with the networks were mostly from the low-income class. The low-income class was most in need of the financial, social, and emotional supports the networks provided. Middle and upper classes had other support options. Since I relied on the networks to recruit participants, the majority of the participants were from the low-income class. Selecting participants from southern, central and northern districts ensured a greater pool of participants from the three major religious groups – Hindu, Christian and Muslim. The Muslim population is concentrated in the Northern districts. Although urban-rural differences in development are marginal in Kerala compared to other Indian states, group inequalities are still a matter of concern



(UNDP, 2005). Therefore, participants were also selected from tribal communities, a marginalized population group in Kerala. There was not much difficulty to find participants from both genders.

After I interviewed a number of participants, I felt their tone and attitude toward HIV and stigma were starting to sound similar, repetitive, and formal. These participants were mostly “positive speakers”. Employed or volunteering with networks or NGOs, “positive speakers” are HIV positives that are encouraged and trained to speak to the public openly about their illness and their experiences. Since more interviews with positive speakers were not likely to illuminate new themes (data saturation, Strauss & Corbin, 1998), I turned my attention to recruiting participants who were not positive speakers. Although my efforts yielded moderate success, it gave me a distinct flavour of the situation of HIV positives that lived in the community, but lacked the awareness and assertiveness of the positive speakers.

In an ideal situation, the sample size is determined by data saturation when interviews with participants do not yield any more new themes (Patton, 2002; Strauss & Corbin, 1998). This is to ensure that sufficient, complete, and relevant data are obtained. Depending upon the study’s purpose, methods, time and resource constraints, sample size in previous qualitative studies that focused on HIV related stigma among adults had varied widely, from 1 to 256, although 15 and 12 were the median and mode values respectively (Sandelowski, Lambe, & Barroso, 2004). Keeping in mind the flexible and emergent nature of sample size in qualitative research (Patton, 2002), the initial sample size of 20 was revised as the fieldwork unfolded. Subsequently, 31 HIV positives were interviewed. While wrapping up my fieldwork, a new theme emerged - participants who

viewed their experiences more positively, and so were more inclined to conclude they had not experienced stigma. This new theme seemed to invalidate my initial insights, and offered an alternate explanation to my current understandings. Given the time and financial constraints, I was not able to pursue this lead further. Spanning nine districts, recruitment and data collection took place over a four-month period in 2008. The following two tables provide a profile of the sample.

Table 1. Characteristics of Sample in counts (N= 49)

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Interviews	
HIV Infected	
Positive Speakers	19
Non-Positive Speakers	12
HIV Affected (Caregivers)	2
Key Informants	5
Informal Conversations	11

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Table 2. Profile of HIV Positive Participants in percentages (N = 31)

Characteristic	Percentage
Age	
18 – 30	29
31 – 40	45
41 – 50	20
51 – 60	6
Gender	
Male	45
Female	55
Region	
Northern Kerala	71
Central Kerala	16
Southern Kerala	13
Religion	
Hindu	61
Christian	23
Muslim	13
“No Religion”	3
Education	
Illiterate	3
Literate and Grade 10 or below	84
Above Grade 10 (Pre-Degree/ Some degree courses/Diploma)	13
Occupation	
Working with HIV+ve Networks	52
Manual/Clerical	23
Trades/Small Business/Student	16
Not Employed	6
No Response	3
Income	
Low Income	77
Middle Income	23
Years Since HIV Diagnosis	
1 – 4 Years	65
5 – 9 Years	26
10 Years and Above	9

## **Study Setting**

Interviews were carried out in a variety of places and settings to accommodate the convenience, comfort, and privacy of the participants and myself. Members of CPK+ were mostly interviewed in CPK+ district offices on days and times most convenient for the participants. Most offices had spare rooms or areas that afforded privacy. Since participants usually knew how to find their way to the district offices and had good relationships with the staff, there was also some degree of familiarity and comfort with the arrangement. On a number of occasions when interviews could not be arranged in offices, interviews were also conducted in the participants' homes, in the company of family members and CPK+ staff. The presence of staff members not only made it easier to locate the participants' homes, but also helped to build rapport with the participants' and their families and put them at ease. Interviews in the presence of others had some benefits and limitations. For example, when I expressed interest to interview someone from the tribal settlement in one of the northern districts, I was surprised and frustrated when a jeep full of people joined me. Situated inside the reserve forest about two hours by road from the nearest town, the tribal settlement is almost at the end of a scenic route, perhaps the most popular tourist attraction in that area. The proverb "if patience is sour, then its result is sweet" best describes that interview experience. The interview was a memorable one - not in terms of what the participant had to say, because the participant hardly said much, but in terms of what everybody else said on behalf of the participant. Despite being a "member of the board of directors of CPK+" and a "representative of the tribal colony", the participant's hesitation and others' eagerness to put words in her mouth spoke volumes about the voice of the voiceless. Several unplanned situations,

such as this one, gave me insights into the decision-making patterns and power relationships that may not have been discernable had these interviews taken place in the privacy of offices without the company of others. As venues where people with varying degrees of power interacted, district level monthly group meetings for PLHA and other discussion forums I attended also presented similar opportunities to interview participants, observe physical surroundings and social interactions in an unobtrusive way. Also, the presence of staff during interviews sometimes made it difficult for participants to hide certain facts. Due to the nature of their long-term associations, some staff knew intimate details of certain participants' lives, which they would bring up during interviews. While interviewing couples and members of the same family, it seemed that the presence of the partner or family member was more of a hindrance than support. However, except for two couples interviewed separately in an office setting, all the other couples and families were interviewed together.

### **Data Collection**

Over the course of four months, I spoke with 49 people and gathered data using face-to-face semi-structured interviews, questionnaires, informal conversations, observations, and field notes. As table 1 indicates, of the 49 people spoken with 11 were informal conversations. My purpose for being in Kerala usually generated a variety of comments from my relatives and friends about what they thought of HIV/AIDS, and their opinions about the people infected with the illness. These opinions and comments had been particularly useful for me to reflect on, and to locate my stance toward people living with HIV/AIDS. Face-to-face semi-structured interviewing was considered the

primary data collection tool because I was interested in gathering detailed, sensitive, person-centred information from the participants (Patton, 2002; Wengraf, 2001). Such interviews also allowed me to clarify the participants' responses and observe non-verbal communication.

An interview design based on Wengraf's (2001) biographic-narrative interview method (BNIM method), which focused on the "elicitation and provocation of story telling", was used. BNIM method can be used to address a variety of research questions. I was interested in individual biographies because the individual was treated as a sample case of a person living with HIV/AIDS, and their history was expected to show how stigma and discrimination unfolded in the social context of Kerala. I began interviews with a request to the participant to share with me their life experiences, giving them the choice to start wherever they liked, and to go on talking as long as they wished. This first question was designed to elicit the full narrative in the participants' own way, with minimal interruption from my part. Although most people found it comfortable to narrate their stories for about 10-15 minutes, I had considerable difficulty facilitating the two participants from the tribal community to speak for a length of time. It was hard for me to resist the temptation to give too many directions and take control on these occasions. After the participants were given a chance to narrate their stories as they wished, the second session was focused on extracting more stories about the topics that were raised in the initial narration, using as much as possible the language/key words/phrases the participants had used. During the third session, topics that have not been mentioned so far were asked, with probes if necessary, giving strong directionality to the flow of the interview. Although BNIM recommends conducting the third session on a separate day

after the first two sessions have been analyzed, due to the participants' schedules and my own, all three sessions were conducted on the same day for most participants, except for the first two. Interview guides (Appendix A) were prepared in advance and outlined the topics to be covered during the interviews (Wengraf, 2001). Though I referred to the interview guide throughout the interview, the exact wording of the questions, the order in which they were asked, and the probes used varied with each interview. However, the first question that sought to elicit the full narrative was similar across the interviews. Interviews lasted approximately twenty minutes to two and a half hours and all except 5 out of the 31 interviews with the HIV infected were audio taped. After their interview, participants filled out a demographic questionnaire (Appendix B).

Interviews with the 5 key informants and the 2 caregivers were unplanned activities, but nonetheless provided background information on the general situation of HIV/AIDS and stigma within the social context of Kerala. Therefore, these interviews were informal conversational type that "relied on the spontaneous generation of questions in the natural flow of an interaction" (Patton, 2002, p. 342). Descriptive information about the interview situation and the observation of physical surroundings recorded in the field notes were most beneficial to clarify the participants' responses. For example, a participant claimed he was reconciled with his family. Had I not seen the plastic shack he lived in and the clay tile roofed, brick walled house he pointed to as his family home, I would not have much reason to doubt him. Although it was only about ten in the morning, it was unbearably hot inside his shack, which was perched up a huge rock. It goes without saying what life would be like for those inside during the monsoon season. Despite what he claimed, I kept wondering to myself what could be preventing

his family from inviting him, his wife and their child over to their house, which was just a stone's throw away from his shack.

Field notes were done as soon after the interviews as possible to help me reflect on my personal bias, record descriptions about the physical and social surroundings, analyze the study's progress, and refine the interview guide, if necessary. Extensive note taking seemed to distract the participants, and affected my ability to follow their responses. Therefore, note taking was reduced to jotting down short phrases or words that indicated the main points in their narrative that would remind me of the participant's statements I wished to explore further. When I conducted the interviews in northern Kerala, a research assistant had accompanied me. On such situations, because there was another person available to take down notes, extensive field notes were taken. Also, detailed field notes were taken when participants refused to have the interviews audio taped.

Arguably, there are other non-narrative methods that are suited to address my research questions. Therefore, I list some of the advantages and limitations of the narrative method. A key argument used in support of narrative methods is that they present the researcher "embedded and tacit assumptions, meanings, reasonings, and patterns of action and inaction" (Wengraf, 2001, p. 116). In other words, many of the assumptions, meanings, purpose, and feelings that have organized and organize a person's life or a society's life are difficult to access directly. The advantage of the narrative method is that "precisely by what it assumes and does not focus upon, narrative conveys tacit and unconscious assumptions and norms of the individual or a cultural group." For instance, unlike most participants who chose to begin their



narratives from the time they were diagnosed with HIV, there were few participants who began their narratives from a different point in time, such as from their birth, their marriage etc. Had it not been for the narrative method of interviewing, these differences in how people living with HIV viewed their lives, and how the illness and its stigma affected their worldviews may not have been as obvious and as easily discernable. On the other hand, an argument against the “validity” of narrative methods is that because interviewees are likely to experience themselves “at risk” within the interview interaction, they will have an interest in presenting their life world in one way rather than another to the interviewer. Therefore, “the self-presentation of the interview is also essentially a self-preserving self-presentation” (Wengraf, 2001, p. 117). “By attempting to reconstruct the memory of the past, a narrated life history becomes a “retrospective illusion” determined equally by the past, the present, and the future. It is not only the person one has become that speaks, but also the person one would like to be in the future” (Osterland, 1983, as cited in Wengraf, 2001, p. 117). Also, some narratives are likely to be attempts to modify the identity of the narrator, rather than present a self-preserving account. I have taken both these arguments into consideration during the interview interactions and data analysis. This has helped me recognize narratives that were primarily concerned with “displacing the blame” from themselves and their in-groups to the out-groups, and those that suggested that the narrator was attempting to forge a new identity or “reinvent” themselves in the wake of emerging challenges.

## **Data Analysis**

The iterative process, and “the fluid and emergent nature of naturalistic inquiry makes the distinction between data gathering and analysis far less absolute” (Patton, 2002, p. 436). Possible themes and ideas for analysis and further data collection began to emerge from the first few interviews. As the interviews could not be transcribed immediately, I listened to the voice recordings repeatedly and reviewed field notes to help guide the subsequent interviews. I also discussed my methods and emerging ideas with my research assistant who had experience doing ethnographic research in Kerala. Similar discussions were also held with my thesis committee members. These discussions helped an ongoing process of refining and refocusing questions and deepening insights into patterns that seemed to have appeared.

As each interview was translated from Malayalam and then transcribed verbatim to English, it was reviewed for accuracy. Checking the Malayalam transcriptions by listening to the interviews, and transcribing them myself to English provided an opportunity to get immersed in the data and experience emerging insights. These insights, along with methodological notes that critiqued how analysis progressed over time, were recorded as memos (Strauss & Corbin, 1998).

“The challenge of qualitative analysis lies in making sense of massive amounts of data, reducing the volume of raw information, sifting trivia from significance, identifying significant patterns, and constructing a framework for communicating the essence of what the data reveal” (Patton, 2002, p. 432). The interviews yielded 310 pages of transcripts. In addition, there were about 90 pages of field notes and memos.

The goal of my data analysis was to transform the raw data into an accurate and meaningful account of the impact of stigma and discrimination on people living with HIV/AIDS in Kerala. This process was accomplished by the following basic categories of organizing and reporting data: description, conceptual ordering and theory as described by Strauss and Corbin (1998). However, the study findings have not been developed to the level of a formal theory. The three processes of description, conceptual ordering, and building theory were not mutually exclusive steps, but were experienced as fluid, simultaneous processes with a fair degree of overlap among them.

Description is “the use of words to convey a mental image of an event, a piece of scenery, an experience, a scene, an emotion, or a sensation; the account related from the perspective of the person doing the depicting” (Strauss & Corbin, 1998, p. 15). Field notes taken at the site of each interview, memos that recorded emerging insights, informal conversations and excerpts from the participants’ transcripts provided the basis for describing the situation. Efforts were made to provide sufficient descriptive detail so as to allow the reader to understand the basis of my analyses and interpretations.

Conceptual ordering is “the organizing and rating of data according to a selective and specified set of properties and their dimensions” (Strauss & Corbin, 1998, p. 15). To facilitate data storage, easy retrieval, coding, comparison and linkage, a qualitative software program, NVivo 8 was used. A detailed “line by line analysis” of each transcript, a process of identifying concepts (units of meaning), grouping them according to their salient properties, and comparing them along relevant dimensions with other concepts already identified was done as a first step to coding. The concepts that were grouped together to form a category were assigned labels. As the category developed

more clarification and specification, subcategories were added. The process of identifying concepts, forming categories and sub categories, and assigning them labels were repeated until all the transcripts were coded this way. As an overarching theme emerged through reflecting on the literature, rereading of transcripts and writing, these categories and sub categories were regrouped later.

Finding an overarching theme that tied the coding scheme together, the process of “integrating and refining theory” (Strauss & Corbin, 1998), or the meaning making process of “inquiring into and interpreting causes, consequences, and relationships” (Patton, 2002) across these life stories was a challenging process. Even though some degree of interpretation was involved in coding, the process of transcending the factual data and inquiring into what can be made of them involved speculating about the themes, their underlying reasons and extending them beyond the boundaries of a single life story. Literature reviews, comparisons across interviews, field notes and personal reflections guided me through this process. For instance, although I had realized ‘positive speakers’ were a unique subset of the sample population during my conversations with a key informant, it was finding a study that analyzed ‘positive speaking’ in other Indian states that sparked the idea of building a theme around ‘positive speakers’. However, reflections on informal conversations that had touched me deeply and reviews of field notes guided me through the process of identifying the theme on knowledge, ignorance and HIV related stigma. The literature on stigma and prejudice suggests the host of disadvantageous circumstances the stigma of an illness creates around a person, whether or not anyone treats this person in a discriminatory way, can be called structural discrimination (Elamon, 2005; Link & Phelan, 2001). Consequently, informed by the

literature, the two sub themes on positive living and positive speaking and knowledge and ignorance were placed under a broader category and were labelled as structural factors underlying stigma and prejudice (Theme 1). Theme 2 was also created through a similar iterative process – reflecting on the literature, comparing the transcripts, reflecting on informal conversations, writing, and further revisions in relation to the literature and comparisons across transcripts.

### **Ethical Considerations**

One of the basic requirements of studies involving human subjects is the responsibility of the researcher to adhere to high ethical standards. In addition to the measures employed during recruitment and data collection (e.g. informed consent (Appendix C), verbal and written assurances of confidentiality), several other strategies were employed to protect the rights of the participants. Approval to carry out the study was obtained from the University of Manitoba Joint-Faculty Research Ethics Committee (Appendix D). Interview data were protected at all times to ensure confidentiality. In order to protect the privacy of the participants, their real names or other identifying information have not been used in this thesis. Access to the data was limited to my thesis committee, research assistant (during field work), and myself. We all adhered to the same terms of privacy and confidentiality. Currently, the transcriptions and voice recordings are held in a secure location accessible only to myself. Electronic files pertaining to this study are stored in my laptop and all files are password protected. They will be stored in a locked file for seven years after the completion of the final report.

Participants' well being was of utmost importance during the data collection process. Participants were informed about the study purpose, interview procedures,

voluntary participation, and confidentiality. Those interested to participate were requested to indicate their consent by signing the consent form written in Malayalam. In the case of two illiterate participants, a verbal consent was obtained and a witness signed the consent forms on behalf of the participants. Participants were informed that their participation is voluntary; that they could withdraw any time, take a break during the interview, or choose not to answer a particular question. Five HIV positive participants and a caregiver expressed discomfort with the interview being audio taped; they were not pressured, and with their permission field notes were taken. A procedure was established for situations in which participants' experienced emotional distress; specifically, the interview would be stopped until they regained their composure and expressed interest to continue. They also had the option of postponing or terminating the interview. This situation occurred once. The participant became upset and started crying. Her relative who was with her at the time comforted her. When she regained her composure and indicated she was ready to continue, the interview was resumed. Participants were not compensated with money. However, they were reimbursed for their travel expenses and other costs, such as on occasions they had accompanied me for study related purposes.

## **Chapter V: Findings**

The study findings are presented as two main themes: structural factors underlying stigma and prejudice, and cultural and moral factors underlying stigma and prejudice. Each main theme begins with a brief introduction of what that theme is, why it is called so, and its relation to the sub themes. The theme introductions are followed by the sub themes – two for each main theme.

### **Theme 1: Structural Factors underlying Stigma & Prejudice**

The host of disadvantageous circumstances that the stigma of an illness creates around a person, whether or not anyone treats this person in a discriminatory way, is called structural discrimination (Link & Phelan, 2001). For example, institutional racism refers to “accumulated institutional practices that disadvantage minority groups even in the absence of individual discrimination or prejudice” (Link & Phelan, 2001). In the field of HIV/AIDS related discrimination, a study that focused on institutional level discrimination in Kerala found that the lack of clearly enunciated and enforced legislation and the absence of written institutional policies left ample room for selective interpretation which resulted in widespread discriminatory practices toward PLHA within the health care sector (Elamon, 2005). Similarly, the stigma of HIV/AIDS influences legislation and internal policies in other life domains such as education, housing, employment and property rights, affecting the structure around a person and leading the person to be exposed to a host of unfavourable circumstances. In this section, I explore the impact of two such policies/practices – positive living, and positive speaking – on the lives of PLHA in Kerala.

**Positive living and positive speaking: humanizing the HIV virus.**

As part of their 2009 – 2010 campaign an anti-stigma strategy that KSACS (Kerala State AIDS Control Society) plans to focus on is the message of “positive living” (KSACS, 2009). Positive living emphasizes the normal lives many PLHA are capable of leading with appropriate treatment and care. Implied in this campaign is the assertion that even those who suffer from potentially deadly illnesses are capable of fulfilling their family obligations and contributing productively to society. Perhaps the rhetoric and realities surrounding current anti-stigma and prevention methods may have informed and influenced KSACS to revamp its communication strategies. It may also be a response in concordance with global efforts and multi-national agreements that call for greater representation of PLHA in prevention, treatment, and care planning, so as to reduce stigma and encourage PLHA to realize their rights and responsibilities (UNAIDS, 2005). KSACS acknowledges their current efforts have concentrated on spreading the message of HIV prevention (KSACS, 2009). Ajay, a well-known HIV/AIDS activist in Kerala comments on KSACS’s current awareness strategy:

At first IEC (Information, Education, Communication division of KSACS) used to be shown in Kerala with the picture of an octopus. Talked about how and when does one get infected. It also said people would die within 2 years if they got infected with HIV.

The major thrust of current public awareness campaigns seems to be raising awareness about the four channels of HIV transmission (through unprotected sex, blood transfusion and blood products, sharing infected needles, and mother to child transmission), advice on consistent and correct condom usage, and clearing common



misconceptions on how the HIV virus spreads such as reiterating that it does not spread through casual contact. The last message seemed to be the hardest one for people to understand according to participants. All the participants recalled situations were their family; friends and neighbours avoided or minimized physical contact with them. These situations were particularly acute during the diagnosis phase and tended to change over the course of the illness. Many participants referred this lack of trust and ignorance of biomedical explanations as stigma. For example, other people's reluctance to use the same cups or plates that they had used was a common occurrence that many participants cited to convey they have been discriminated in their homes. Several participants who worked for HIV positive networks pointed out that public awareness strategies have focused on warning and frightening people so as to aid HIV prevention. Exclusively focused on prevention, these messages instilled fear, aversion and intolerance toward PLHA. However, taking a hint from their current efforts KSACS believes it is important to showcase the normal lives that many PLHA lead. When public health programs provide special services to PLHA (for example, ART clinics, condom distribution) these services often become the markers of HIV and are stigmatized (Deacon et al., 2005). Even when public health programs do not single out PLHA for special treatment and may have their best intentions at heart, society's perception of public health messages impact the provision of these services and they may have unintended consequences.

Another anti-stigma strategy that is increasingly being practiced in Kerala as well as in many other parts of India is Positive Speakers' Bureaus (PSBs) (Finn & Sarangi, 2009). Globally promoted as a professional public education resource following the signing of 1994 Paris AIDS Summit Declaration, GIPA policy (Greater Involvement of

People with HIV/AIDS), PSBs encourage and train willing HIV positive individuals to speak to the public openly about their illness and their experiences (Finn & Sarangi, 2009). PSBs seem to be a key component of KSACS's interpersonal communication strategy, especially since PSB advocates both in Kerala and elsewhere maintain that PLHA are best suited to invoke a better understanding of HIV and address the stigma and myths surrounding the virus (Paxton, 2002). Employed or volunteering with HIV positive people's networks and NGOs, public "positive speaking" is not only a public education resource but has also become a means of livelihood and a way of life for the many "positive speakers" in Kerala. Called upon to "humanize" the HIV virus positive speakers lend a voice and a face to HIV prevention and anti-stigma messages rather than information relayed through more impersonal media. Using positive speakers as public education resources have been reported to be beneficial in both western and non-western countries (Paxton, 2002; Pitts & Jackson, 1993).

From the outset the niche that positive speakers had carved out for themselves within the PLHA community was obvious. Positive speakers were more informed and articulate about a variety of issues facing PLHA than non-positive speakers and commonly spoke in general and abstract terms often drawing on their experiences as public educators. All the participants who identified themselves as positive speakers were of the opinion that stigma and discrimination is one of the key issues facing PLHA in Kerala. Surprisingly, even the word "stigma" appears to be in their everyday parlance since many referred to issues commonly classified as stigma and discrimination such as isolations by family and discrimination in hospitals by the English word "stigma". While not untrue, I felt many positive speakers were using a "public voice", a guarded voice

such as the one we would use while speaking to a large audience as opposed to an “inner voice”. Whenever I heard positive speakers say they haven’t experienced stigma as other people have or sensed they avoided references to their own experiences, I have looked for ways to reach their inner voices. Talking about the issues they were facing in a matter of fact, logical manner conveyed the positive aspect of grappling with a difficult situation but covered up the struggle behind it.

In the following sections I explore the constitutive effects of positive speaking and KSACS’s new focus on positive living in terms of HIV subjectivity and the onus placed on PLHA to be visible in the fight against HIV. I also explore the contribution of positive speakers in challenging the social structures and health practices that constrain PLHA from achieving complete health and actively participating in the society. An emphasis on positive speaking in the light of country and global level policies to involve PLHA in the struggle against HIV/AIDS is an effort to highlight the unique role that positive speakers play in Kerala. Also, since more than half of the participants in this study are positive speakers it is worthwhile to focus on this special subset of the sample.

***Defined by an illness: the onus of being the face and voice of HIV/AIDS.***

There was considerable consensus particularly among positive speakers about the need for PLHA to be publicly open and involved so that positive and non-positive communities alike would recognize and understand HIV in terms of its scale, dangers and marginalizing effects. Although opinions varied as to how much public visibility and disclosure was considered appropriate, as a commonly held-to-principle, being visible in the fight against HIV/AIDS stigma ideally meant the disclosure of one’s HIV status in

all spheres of one's life, including family and one's community. In general, positive speaking was believed to bestow three major benefits – to impart a greater understanding of the 'reality' of HIV/AIDS, to confer individual psychological gains such as improved self-esteem, and to have the opportunity to be considered survivors who have learned their lessons. Each of these benefits is explored in detail below.

*Imparting a greater understanding of the reality of HIV/AIDS.*

Along with participation in mutually supportive HIV positive networks and rights campaigns, positive speaking emphasized the HIV positive community's role and responsibility to share their experiences of HIV/AIDS and the stigma they have understood. Rita, a HIV positive woman employed with a PLHA network, commented:

Here in (Name of District), there are about 49 people as our members. Of that maximum 10 people have their status disclosed in their community and in their families. All the rest hide their status. Our own members are hesitant to talk to others because of this. Why do they have to be hesitant to tell others that they have this illness? They don't even say that it just happened that way but it's not my fault. Maximum of ten members have disclosed their status to their families and in their communities. All the rest hide it and continue on without telling anybody. To come here also, they give other reasons. When someone phones them here, they give the same reasons. In my opinion, why do they have to hide it from the others?

In the above extract, Rita bitterly complains about those who selectively disclose their HIV positive status while maintaining their membership with PLHA networks. Implied

in the conversation was the obligation of PLHA, particularly those who were associated with PLHA networks, to disclose their identity at a pace and content level that is “ideal” without taking individual comfort levels into consideration. By remaining silent or unwilling to defend themselves with appropriate justifications those who hide their HIV positive status are portrayed as shirking their responsibilities and possibly undermining efforts to reduce stigma. A growing body of research suggests that considering the high costs associated with challenging prejudice individuals may decide that the best option for them is to ignore prejudice (Levin & Van Laar, 2006). The decision to challenge or ignore is also context and situation specific. But silence and inaction has a price. Targets of prejudice may feel that they have “let down” their group, or worse as Rita argued they are criticized for not standing up for their “rights” and may ruminate about their inaction leading to cognitive distraction and lower performance if they do not express their dissatisfaction in situations tainted with prejudice (Levin & Van Laar, 2006).

*Conferring beneficial psychological effects.*

Not only is positive speaking construed as imparting greater understanding of the “reality” of HIV but also as having beneficial psychological effects on the speakers themselves. Ajay and Sameera, two positive speakers, commented:

It’s the fear. The positive person has to accept himself at first that he/she is positive. That’s how he can prolong his life. The person from Thrissur cannot come for long to Trivandrum to buy his medicines. It’s the fear, the tension. In that situation, no medicine will work. No matter what medicine he is taking, his CD4 count will fall. He won’t be able to eat well. So ART will not benefit.

When we are anxious, we have difficulty eating – when there are emotional and physical difficulties. Even if you are a rich person, you can buy (medicines) from another state or another country only for a short time. Because of the stigma inside, that he is being isolated, going anywhere will not help.

Two days before going to Prathyasa Bhavan, in return for all my hardships, like a divine blessing, I got a job - as a positive speaker in the Prathyasa project. I only have a high school education. May be because of that, I hadn't ventured out or spoken to people. I was someone without any awareness or ability. It's not that I am able now, but at least I am confident to speak this much.

In the above extract, Ajay draws a connection between fear due to stigma and disease progression. The stress and the anxiety of maintaining one's HIV positive status hidden fearing stigma and discrimination (called anticipated stigma) is believed to have a negative influence on one's psychological well being which may in turn make it difficult to keep HIV/AIDS under control (Alonzo & Reynolds, 1995). This logical explanation consolidates the public positive speaking platform and shores up support for the PLHA community to go public. Sameera's story hints at another benefit of positive speaking that is also associated with public speaking in general – gaining confidence.

*Being the survivor and the afflicted.*

In the previous section I have highlighted the talked up need for PLHA to assume a greater role in the prevention and anti-stigma campaigns through organized public speaking and greater public visibility. In this section I unpack some of the implications

of bearing witness to the HIV positive life. The following extracts are from interviews with positive speakers working for PLHA networks.

Sameera recalled: ...if you go to conduct classes in the rural areas, I have noticed they don't know anything. After talking to them, "Has anyone of you attended classes on HIV/AIDS? In the radio or in the TV? Have you seen anyone?" "No, No." .....When I tell them I am positive...they are actually innocent. Their eyes fill up with tears. We cannot blame them even if they stigmatize. Couple of days ago, when I went to a village to do a street play, after the classes, the women there wouldn't let me go. Their stigma is the lack of awareness.

Anil commented: People are starting to understand. Their stands are changing. I can work now. When they understand this patient can work, they change their positions. I think in the society it can only change over time. Each person will live these many years. Our lifestyle is also going good. We can live as a family instead of breaking up. We have to show these things to the people.

Naveen recalled: It was a time I learned what life really is. I felt...usually people tell you there is no after life. But this is my second life and I have lived 9 years now. It's 9 years in my second life. When I got infected, a new life, a second birth had begun. Actually, I have learned to live like a human being now.

Because I learned to understand other people and their difficulties and understood that such a society existed amongst us, when I started to work in this area.

Across the interviews positive speakers referred to an idealized state of health sound in body and mind that HIV positives can aspire to or achieve through committed effort and

adequate support. This “empowered” or “idealized” health included a positive outlook on their illness, personal circumstance, social functioning, and hope for the future. It is this idealized, fully functioning life that is to be offered to the “ignorant” public through positive speaking and positive living to challenge prejudicing attitudes. Sameera’s experience illustrates how the HIV virus is exemplified and made “real” in the eyes of the audience via public speaking. She is a middle class housewife who contracted HIV from her husband. Through this personalized message the risk of contracting HIV is better related to as “something that can happen to anybody” rather than to members of at-risk groups people may have difficulty identifying with such as truckers or sex workers. The real-life, public display opens up the possibility for HIV positives to be perceived as normal, everyday individuals. In the extract that follows in particular the characterization of the speaker as productive, self-sufficient, dependable, rational, articulate, and healthy, not only conveys a normalized image but also portrays the speaker in ideal terms. Unlike a couple of other male positive speakers who also emphasized HIV positives needed to earn their living, Anil added it was important to have an “intact” family. KSACS’s new focus on “positive living” may also be construed as an effort to normalize PLHA by capitalizing on the message that PLHA are capable of working and taking care of themselves so they will not be a burden on their employers and caregivers. Rather than obsessing with death PLHA are showcased as someone who presumably works and has a life. This message appears to be in vogue as several participants stressed how much they valued their ability to work in spite of the illness and how stigma and their illnesses affected their employability, earning capacity, ability



to provide for the family and standing in the community. Men were particularly aware of the positive message their status as “employees” can transmit to society.

Naveen exemplifies PLHA who identify themselves as both normal and as survivors. Here the making known of the HIV positive life hinges on two distinct yet inter-related subject positions: the normal, “easily related to” individual, and the diseased but alive survivor (Finn & Sarangi, 2009). In a study that analyzes positive speaking in India, Finn and Sarangi (2009) argue that through the enforced process of normalization PLHA are obliged to display themselves as survivors who have earned their way into the realm of “normalcy” as heroes of psychological adjustment and assimilation while always being someone tainted by a blemish and thus never the “same” as a “normal” person. Obviously, straddling these inter-related, paradoxical subjectivities of “self-as normal”, so as to be perceived normal, and “self-as other”, so as to signify the importance of avoiding HIV, is not without a purpose. The “normalization” is for the purpose of stigma reduction and maintaining “otherness” for HIV prevention. Finn and Sarangi (2009) contend that the ambiguity surrounding the development and management of an HIV positive identity of “self-as normal” and “self-as the other” to serve the dual purposes of stigma reduction and HIV prevention can ironically confine PLHA to “live off” the very stigma that they themselves and other like-minded collaborators involved in the fight against stigma are aiming to counteract. Although social interventions that appropriately structured intergroup contact are known to reduce bias at the individual level and the pursuit of common goals are considered vital tools to effectively reduce prejudice (Dovidio et al., 2005), the possible “(re)stigmatizing”

potential of these “humanizing” strategies should not be overlooked (Finn & Sarangi, 2009).

Although they are few I find it hard to dismiss the subtle yet compelling stories I have heard about the struggle of managing the paradoxical subjectivities of “self as normal” and “self as other”. Unsurprisingly, high on the agenda of most positive speakers was the twin goals of HIV prevention and stigma reduction. Many were equally fervent about raising awareness among the public about consistent condom usage and correcting myths that HIV does not spread through casual contact. However, it was evident that the paradoxical roles they are required to handle, as the composed survivor and the afflicted patient was distressing for some participants. The following extract taken from my memos illustrates the distress succinctly. Being leery of any unwanted public attention the participant refused to have her voice audio taped.

Meenakshi recalled: KSACS set up a workshop, which was documented and televised. The camera focused on her blinking eyes in particular and the message broadcasted was “ there may be pain behind those eyes”. The program also repeatedly stressed the word “ HIV” and “ AIDS” multiple times. Their faces were also focused upon. Now she is scared whether her status will be revealed even to people who don’t know about it. KSACS had previously told them that they will not have to talk in front of the camera, but just attend a class KSACS organized. The program officers will do the talking. It so happened that when the program was telecast, camera focused on those in the audience close enough for them to be individually identified. Every moment she fears someone in her

tailoring class might recognize her from the KSACS TV program and her status will be revealed.

Meenakshi ruefully related the unfortunate position she was squeezed into as a participant for a workshop KSACS organized. As the wife of a prominent PLHA leader in one of the northern districts who also worked closely with KSACS in some of their projects, her participation in the workshop KSACS organized will have been expected. Although the KSACS program may have intended to invoke a better understanding of PLHA by addressing stigma, the undue stress it placed on someone unprepared and possibly untrained to face such challenges embodies the HIV positive life of “self as normal” and “self as other”. Interestingly enough her story exemplifies the experiences of others who had also responded to exhortations “to come forward and bear witness” from government organizations, media, and the PLHA community themselves. While there were a variety of reasons for these individuals to disclose their HIV positive status publicly, the anger and the bitterness of being misled into revealing their identities based on partial or false information was a common feeling all of them expressed. Acting on good faith, sometimes on the hope that they may be able to get a job with HIV positive networks or on the belief that they were doing “the needful”, some of those who disclosed their HIV positive status found themselves facing challenges with minimum support. Some felt the hassles they were facing on a daily basis after disclosure far outweighed any rewards they had received by going public. The timing of the disclosure may have also been important. Many of the participants who responded to the call to go public did it during the early phases of their illness and at a time they were most uncertain about their future such as during the time of their diagnosis or when they were

“dumped” in care homes. The overemphasis on being open and involved in the fight against HIV places the responsibility to challenge prejudices on PLHA while downplaying the consequences of being visible and ignoring the need to prepare and provide ongoing supports to those who choose to disclose their HIV positive status. The message underlying the positive living campaign may also be a potentially contentious issue. The positive living campaign highlights the ability of PLHA to lead a normal life. However, unless social inequalities that constrain PLHA to lead a normal life are also addressed the campaign would have little meaning.

Some researchers argue that the current understanding of stigma may have contributed to this narrow focus (Parker & Aggleton, 2002; Stuber et al., 2008; Yang & Kleinman, 2008). Research on stigma as a social process has mainly focused on negative stereotyping and the vast majority of the studies limit the negative effects of stigma to individual psychological processes and coping strategies (Stuber et al., 2008; Yang & Kleinman, 2008). In her book “Bright-Sided”, Barbara Ehrenreich argues that the infatuation with positive-thinking and the harsh insistence on taking personal responsibility could lead to self blame, victim-blaming, political complacency and cultural flight from realism (Ehrenreich, 2009). We can find close parallels between the message underlying positive-speaking, positive living and the ideology of positive thinking. Desired dispositions and values such as cheerfulness, confidence and hope have become so entrenched that positive thinking or the discipline of trying to think in an optimistic way has found its way into the domain of health as well. Optimism is found to improve health, confidence, resilience and overall well being (Scheier & Carver, 1993). However, this rational explanation has extended beyond its reach to the idea that positive

thoughts can somehow help us to gain health, wealth and prosperity. Therefore, positive thinking is thought to be an endeavour well worth the effort even at the expense of suppressing or denying negative emotions.

The emphasis on self-reliance and our ability to cultivate positive-thinking which would in some mysterious ways ultimately lead to desired physical outcomes (Ehrenreich, 2009) has produced copious interventions targeted at increasing empathy and altruism in the general population and enhancing the coping skills of stigmatized groups (Parker & Aggleton, 2002). As a global strategy perhaps it is not surprising to find the echoes of the positive thinking ideology in positive speaking and positive living campaigns for the PLHA in India. The push to portray an idealistic, positive image and the argument for the psychological benefits of going public reflect how the positive thinking ideology has been influential. Appealing to invoke sympathy in the public at the expense of sidelining broader issues such as dominance, oppression and struggles of power and privilege may have muddied the scenario rather than contribute to a lasting change. Kerala Positive Women's Network's (KPWN+) criticism of KSACS also points in this direction. KPWN+, one of the major PLHA networks in Kerala, had accused KSACS of "flaunting people living with HIV/AIDS as their mascots", without allowing them any meaningful participation as outlined in the GIPA policy (KPWN+, 2009). Consequently, they argue that the involvement of PLHA has been reduced to a façade. Obviously, it requires more than paying lip service to actually realize greater participation of PLHA as outlined in the GIPA policy. Legitimizing the idea that power struggles do occur at inter-personal, family and organizational levels, admitting the narrative of limited opportunities as opposed to the myth that people have the freedom to

make rational choices what ever their circumstances, coupled with constant vigilance and action, are required to overcome broad resistance to include PLHA in the decision making process.

*Positive speakers as change agents.*

This theme would be incomplete without exploring the unique contribution of positive speakers in Kerala. Each time I cast the PLHA community as the “victimized” and everyone else as the big, bully “perpetrator” I felt I was lying – writing only partial truths. The binary language of victim/perpetrator is inadequate to capture the ambiguous and often conflicting accounts of lived experiences (Ronai, 1995). It downplays the simultaneous role that perpetrators may play as protectors and abusers and ignores how victims resist and benefit by turning adverse situations to their advantage. Over the decades, the discourse of victim/perpetrator appears to have shifted in favour of PLHA with blame squarely on the shoulders of the perpetrators. In such a climate it is tempting to analyze the stigmatizing potential of anti-stigma strategies such as positive speaking. It is too simplistic to assume that stigma is a hegemonic process and is a servant of the dominant class always used to perpetuate social inequalities. Those who are marginalized also stigmatize each other and other dominant groups. Power struggles among various PLHA networks and internal group rivalries based on class and gender divisions were apparent during PLHA network group meetings and interviews with participants. Based on power differentials, such as gender and class, stigmatization can occur among peer groups just as easily as it occurs between the marginalized and the wider society (Deacon et al., 2005). However, powerful groups may be able to express

stigma more widely and affect discrimination (Link & Phelan, 2001). Despite shortcomings, encouraging PLHA to take a more active role to realize their rights and responsibilities through various strategies such as organized public speaking have enabled them to challenge social structures and health practices that constrain them.

Unlike some HIV positives that were forced to disclose their status and maintain a public visibility beyond their comfort levels, there were some PLHA actively involved in challenging oppression and dominance and so viewed the positive speakers platform as a springboard to further the rights of PLHA. Thus, the exposure and public visibility that arise as a result of public speaking may not be equally damaging to every positive speaker as this argument downplays the HIV positive people's capacity to resist stigma or be makers of their own destiny. As one of the participants, a well known positive speaker and founder of a network for PLHA pointed out, many active members in PLHA networks come from the working class who have an interest in getting "the system" to work for their benefit, unlike the rich who do not care enough because their money can satisfy all their needs, or the poor (the tribal people, at the bottom of the hierarchy), too distraught or "ignorant" to be disturbed. Even though public awareness building is the major thrust of positive speaking, many positive speakers also go on to become advocates who challenge existing systems and governments to fulfill their commitments to the PLHA community. In a state such as Kerala recognized for its caste-based social movements and militant trade unions (Rammohan, 2000) any social injustice, real or perceived, warrants a call- to-arms. In such a climate, it is not surprising to find a PLHA community fully cognizant and confident of the bargaining power of their collective

voices. The following extract typifies the spirit of that power, the overriding tone of a positive speaker's talk.

Naveen commented: For sure, organizations are good for us. If I sit in front of the Collectorate (District Administrative Office) and shout slogans, will anyone notice me? If I go with 10 other people and ask, we may be just noticed. When 100 people go, a positive step may be taken. When 100 changes to a 1000, something is certain to happen.

Donning the mantle of the public educator, positive speakers, in their various capacities as peer educators, co-ordinators, or community outreach workers also advocate for reforms, policy changes and new legislation in a variety of sectors such as health, education, employment, protection services and property rights. A noteworthy example is the case of Ajay, a positive speaker turned activist and founder of a network for PLHA. Diagnosed with HIV about 15 years ago, Ajay returned to Kerala from another state financially and emotionally broke. HIV/AIDS was a relatively new disease at the time, so Ajay was rewarded with sparse information and limited support in his quest to be informed. Ajay's debut as a positive speaker during a world AIDS day conference and ensuing media attention cost him his job. Subsequent media appearances for TV programs KSACS had organized cost him his family's support. Unable to concede to his family's demands "not to get involved or do unnecessary activities" in return for "food, money, and shelter" Ajay left home. In the following years with help and support from friends Ajay set up a network for PLHA that is expanding into other districts from its home base in the south. Among the most notable of his achievements is the case before Kerala High Court. During May 2007, Ajay had met with an accident and



was rushed to a well-known private hospital. He had multiple fractures on his left leg so the doctor in charge said a surgery was unavoidable. As soon as his HIV positive status was revealed the response turned discriminatory. Nurses and attendees turned away. The hospital discharged Ajay without treatment on the excuse that they did not have sufficient facilities to do a surgery despite the fact that any hospital having an emergency care unit is supposed to have such facilities. Besides, this particular hospital is one of the best-equipped private hospitals in Kerala. Ajay was then referred to a nearby government hospital from where he received his subsequent treatments. Ajay lodged a complaint with the National Human Rights Commission (NHRC). Upon investigation, NHRC accepted explanations KSACS and the hospital authorities submitted and dismissed Ajay's petition. A rights-based NGO founded by a team of doctors and social activists in Kerala took up his case and filed a petition before the Kerala High Court challenging NHRC and KSACS. The court has issued legal notice to both parties (FIRMINDIA, 2009). My brief sketch of Ajay and one of the sensational court cases on PLHA can only suggest the reality of the work positive speakers and PLHA networks are capable of doing in Kerala. The multiple levels of stigma PLHA experience internally as existential despair, socially, as shunning and callousness, and institutionally as disregard, can constrain them but does not determine their fate (Buseh & Stevens, 2006). In fact, as some scholars have pointed out, although stigma might result in an initial status loss, eventually some PLHA might even gain status as they disclose and become legitimate spokespersons for minority or marginalized groups in the process (Deacon et al., 2005). However, the varieties of experiences that exist along a continuum from the strong

insistence on assuming a positive identity to keeping a low profile suggest the need for a more nuanced PLHA identity.

### **The “informed” and the “ignorant”: knowledge and ignorance in the context of HIV/AIDS**

Another structural factor underlying HIV related stigma is the loss of face the less educated, underclass experienced particularly during their interactions with institutions dominated by the literate and the educated. Since most of my participants were relatively under educated (grade 12 education or below) by Kerala standards the threats to their dignity as competent adults to act intelligently in their social world and their efforts to resist social pressures to be seen as less than fully human were palpable. Contrary to their expectations that stigma is a result of ignorance due to lack of education which also implied awareness about HIV/AIDS, many participants were shocked to be stigmatized by the educated themselves. Surprisingly, for several participants’ values such as empathy and understanding went hand-in-hand with education and awareness of HIV/AIDS. They expected those who have had formal education to be aware of HIV/AIDS and to be empathetic to the afflicted. Driven to despair and often at their wit’s end those who approached the health care sector hoping to find solace were awakened to the rude reality that empathy and understanding are not guaranteed there either. Undoubtedly, all those who blamed the educated for their feigned ignorance and callousness also reported they had experienced stigma within their own social class. But, what is emphasized here is the shock and disbelief some of them

experienced when their expectations of the educated were shattered. The following extracts explain this theme succinctly:

Sameera recalled: A positive person is hurt the most when those educated and aware behave cruelly. If there was none... if you go to conduct classes in the rural areas, I have noticed they don't know anything.....When I tell them I am positive...they are actually innocent. Their eyes fill up with tears. We cannot blame them even if they stigmatize. Couple of days ago, when I went to a village to do a street play, after the classes, the women there wouldn't let me go. Their stigma is the lack of awareness. Those who are educated show it after they are aware, it may be their ego, you can call it that too. Such as what we generally show to sex workers. If you talk with the others, they will understand. That's what I have experienced. I am not talking about everyone. If one out of a hundred does this, then it affects everybody else.

Ajay commented: First of all, we are the most literate; we are more knowledgeable, more educated. So we think we have nothing more to learn about these things. It's these other people who have AIDS. So it's for him to do. We are hesitant to discuss sexuality. It's okay to have sex but to talk about it, or work in that area, we are terribly hesitant. So they are afraid of the society. Because I am positive, what my parents fear most is the society. They fear their neighbours. That is their main stigma.

Narayanan commented: To summarize, the average person is not concerned. Those who have little education are not bothered. They don't see this as a big

problem. It's those who know a bit about society who are disgusted. For those who don't know about society, for those who work to earn their daily bread, what is HIV/AIDS? They don't show any hatred against us and they are not interested about that either. It's those who know about society and those who read newspapers who show disgust. This is my opinion. It's those who are educated who show disgust.

Sameera added if she were in a position to disclose the names of "VIP team members" (upper classes) in her network no one would discriminate them. Although my initial plans were to interview participants from the upper classes as well I realized the challenges of recruiting them much later on. Hard-pressed for financial and emotional support, the majority of those who enrolled with positive peoples networks were the poor, the less educated and the "lower classes". The "financially well off" I was told usually visited private clinics that were better at keeping their "dirty little secrets" and had their ART medicines delivered to their homes. In the unlikely event of approaching a government run voluntary counselling and testing centre (VCTC) or ART centre, the "well off" choose not to "make public appearances" but quietly got their medicine supply and disappeared without getting in touch with the networks. Since I relied on the positive peoples networks for my pool of participants, the majority of the participants were from the lower income groups. The situation was not so different at the care homes I approached during the initial stages of this project. The majority of the residents were from lower income groups who were supposedly "dumped" or had come voluntarily to these places "to die in peace". Due to the skewed nature of the sample I cannot help but wonder how the "well off" experience stigma. Some of the study participants who had

long been involved with positive peoples' networks claim "the well off" experience severe stigma. Citing the example of a Malayalam movie actress one of them argued the "fear and anxiety" of keeping her HIV positive status a secret eventually led to the actress' death. Better access to resources placed the "well off" in a more favourable position to keep their HIV positive status concealed, perhaps forever. Being the target of government run HIV/AIDS programs and media attention, the public visibility lower income groups receive entrenched their tarnished images as the disease burdened, morally tainted "at-risk" group.

Educated society's traditional downgrading of the less educated, combined with class and caste prejudices all contribute toward the acceptance of ethnocentric stereotypes of the less educated. As some participants pointed out the educated believe "they are somehow invulnerable to the disease" and therefore assume themselves to be fundamentally different from those afflicted. This feeling of moral superiority or "ego" as Sameera called it creep up in day to day interactions between people at the level of words, gestures, emotions, meanings, behaviours and threatens relationship ties in their shared social space. When those who draw distinctions are also able to make it stick because they control major life domains such as employment, health care and education, the distinctions they draw have real consequences for those at the receiving end. Although the stigmatized and the stigmatizers are positioned differently within structures of power, status and stigma, as members of a social network, peer group, or systems of care, they are bound together in getting things done and in addressing the illness and stigma (Yang et al., 2007). Interventions that have so far targeted increasing awareness and providing technical know-how on HIV/AIDS fail to acknowledge "ignorance" that

refuses to be dispelled “no matter how many awareness classes are conducted”; and the highly tactical, yet apathetical responses that are played out as a result. Participants were quick to point out doctors in government run ART centres who chastised them for anything and everything, “whether they came late or early to appointments”, counsellors who cared about nothing else other than making sure their clients used condoms when having sex, teachers who cared less whether children of HIV positives learned or not even though they were forced to let these children into their classrooms, and local politicians who used the fear of HIV/AIDS as a ruse to turn villagers against PLHA to drive their personal agendas. In each of these cases the stigmatizers were provided sufficient awareness about HIV. In fact, some were in positions of power and responsibility to protect and provide service to PLHA. The clandestine manner in which some others operated as the kind and helpful on stage, but cunning and callous behind the curtains, made them a force to be reckoned with, unseen, unexpected and powerful. As Link and Phelan (2001) argue, when current modes of stigmatization are challenged, blocked or become socially inappropriate to use, those who stigmatize simply switch to new mechanisms, making stigma remarkably resilient and difficult to eradicate.

Despite the educated society’s traditional downgrading of the less educated, both the educated and the less educated are questioning the intelligibility of their shared social world. As Sameera and Ajay pointed out, the less educated do recognize efforts to undermine their competency and threats to their dignity. In no way is the extent of stigma experienced and the resistance put forth uniform across major life domains. While some were competent in actively challenging stigma wherever they experienced it, be it with an employer, teacher, or a health professional, others hesitated confronting

the more powerful but felt comfortable negotiating with those from similar social backgrounds. As one of the participants explained, although both the cleaner and the nurse in the hospital openly showed aversion to HIV positives, she felt she could explain to the cleaner since “the cleaner came to do the job despite the fear of HIV” but thought it was pointless to do the same with the nurse since “they avoid us and make it a big issue if they know.” Having neither the economic, social, cultural nor political clout of the doctor or nurse, it goes without saying that everyone, including the HIV positive and the hospital authorities had more to lose if they challenged these powerful groups than the cleaners. Also, unless backed by the HIV positives lobby where their petition is linked to the greater cause of advancing HIV positives rights and their argument is presented with all the “colours” that come with it, the “lowly” HIV positive lacks opportunities to make her case before the nurse or doctor. They simply do not move in the same social circles. Also, unlike with those in similar social positions where relationships are based on mutual dependency, being at the receiving end afforded little leeway to question those more powerful. Furthermore, if one actively avoids the other during the limited periods their worlds intersect or circumscribe the relationship within the parameters of “official” boundaries, the divide deepens. In contrast, whether by choice or lack thereof, the fact that the cleaner showed up every day to do the job not only offered more opportunities for the HIV positive to make her case but was also interpreted as an expression of understanding and as an attempt to narrow the divide.

The contradiction that shocked several HIV positives – that formal education need not guarantee civilized behaviour – signals the existence of two discourses about Kerala. On the one hand, Kerala contributed to paradigm shifts in development thinking

boasting high quality of life indicators including demographic, health, education, nutrition, and infrastructure indicators despite low per capita incomes; highly profiled as the “Kerala model of development” (UNDP, 2005). This celebration of the Kerala model and accompanying euphoria as the “most advanced state in India” continues well into the present permeating highbrow debates and tea-stall conversations alike (Sreekumar, 2007). On the other hand, critics of the Kerala model thrust another reality of Kerala – of crumbling infrastructure, of rampant corruption, of unemployment, of a culture of bribes, *bandh* (strikes), and “quotation gangs” (unemployed lured into organized crime) – to point out that the inverse relationship between social and economic development is unsustainable (Sreekumar, 2007). These contradictory scripts about Kerala, as utopia and as dystopia, gave rise to a new narrative about Kerala – Kerala as a paradox (Sreekumar, 2007). As I think about the two competing scripts about Kerala what immediately comes to my mind is the recent extension to Kerala Tourism Development Corporation’s tagline “God’s own country” that boasts Kerala as a tropical paradise (“emerald backwaters, lush hill stations”) and as an organized society (“India’s cleanest state”). The new tagline coined and popularized by the “parody-song” industry (extremely popular comic genre in Kerala widely circulated as audio-cassettes) mirrors the Kerala paradox: “God’s own country, Devil’s own people.”

HIV/AIDS is the recent addition to a host of symptoms that signal Kerala’s dystopia (Sreekumar, 2007). Since HIV/AIDS is understood in Kerala as a disease resulting primarily from unsafe heterosexual sex its prevalence is attributed to transgressions of social norms and immorality interpreted widely as social collapse and degeneracy. Hence, as many participants pointed out the stigma they experience is their



moral wage or “punishment for their sins”. It is well established that health benefits and positive demographic changes accrue from the universalisation of basic education (UNDP, 2005). However, as seen within the context of employment, property rights and gender relations in Kerala, systemic discriminatory practices are not necessarily transformed in more equitable directions by literacy or greater access to education alone (UNDP, 2005). The pervasiveness of stigma that the less educated PLHA experience is yet another challenge to the much-glorified straightforward relationship between literacy and development. The following segment briefly traces the role of education in Kerala as discussed in detail in the UNDP Human Development Report on Kerala .

Education plays a unique role in Kerala’s development experience. Kerala’s emphasis on education dates back to reform movements in the 19<sup>th</sup> and early 20<sup>th</sup> centuries. All reform movements be it among the lower and outcasts, upper Hindu castes, Muslims or Christians emphasised education as the key to their liberation, social change, and success. Each community opened their own educational institutions raising funds from within the community in addition to government’s investment in education. The impacts of social reforms were felt immediately in schools as they opened their doors to all castes paving the way for weakening one of India’s most rigid caste systems. Rising school enrolments led to sharp increases in literacy by the second decade of the 19<sup>th</sup> century. Gradually, caste-based social movements organized into political movements. With the advent of the communist party working class solidarity, human rights awareness and socialism strengthened enriched by education and popular literary movements. The first communist ministry sought to strengthen the state’s role in the universal provision of education and health care. Although they failed to realize their

comprehensive development goals this enabling environment led to increased public demand and corresponding public supply of these services. These aspirations and measures became institutionalized as subsequent governments, whether left or right, were mandated to uphold them. By 1970s, over 60% of Kerala's population was literate compared to all-India average of 30%, and education claimed almost 40% of the state's expenditure. As per 2001 census, literacy rate in Kerala was 91% compared to all-India average of 65%. Also, the difference between male and female literacy achievement levels was much narrower in Kerala (6%) than in India as a whole (22%). There were favourable outcomes in the health front as well. The vast network of primary and community health centres extending even into remotest areas of the state raised the general health of the population on par with those of many developed nations. Moreover, Kerala has a vibrant political society well aware of their rights compared to the rest of India.

Despite the impressive track record of low rural-urban and inter-district disparity in human development in Kerala compared to the rest of the country, social group differentials persist (UNDP, 2005). Poverty, low landholding, poor health and persistent deprivation characterize several social outlier groups such as the fisher folk communities, cashew and coir workers and scheduled castes and tribes. In terms of education, the high aggregate levels of literacy mask illiteracy and lack of education beyond the primary level among the most deprived sections of the population (UNDP, 2005). In addition, while there were positive changes in demographic and health indicators due to improved education, lack of employment opportunities created a frustrated educated workforce who had been raised on the motto that education was the

key to success. The result – educated unemployment and out migration. In fact, if we were to re-evaluate human development in terms of a different set of indicators such as freedom, equality, degree of control over life choices, and dignity the well recycled stagnant image of “God’s own country” would expose a disgruntled population forced to inhabit the peripheries of this picturesque landscape. Lack of quality in both social and economic infrastructure development is a well-recognized problem in Kerala (UNDP, 2005). Frequent blackouts despite 100% rural electrification, narrow, poorly maintained, underdeveloped roads that boast connectivity between countless villages, and under funded, inadequately staffed, over stretched public health care, and schools that traverse the entire length and breadth of the state are few examples of quality problems plaguing Kerala. As the private sector steps in to fill the void left vacant by the state in terms of provision of essential services those left behind are the most deprived and the least deserving.

An UNDP (2005) report suggests the lag behind public provisioning is the lack of awareness among the general public as to their right for quality in addition to availability and accessibility of services. As per the report the public remains blissfully unaware of their right for quality public provisioning, despite their compulsive demand for quality services from the private sector. However, to my understanding, awareness of their rights and demand for quality services both from the public and private sector has always been part of the social landscape of Kerala. The accusations of educated society’s feigned ignorance and callousness toward PLHA and outrage at the inferior quality of service they were receiving are examples of the average Keralite’s awareness of their rights and unceasing demand for quality services. Seen from this angle, HIV/AIDS, and PLHA

networks' lobbying for improved services are not new additions that signal Kerala's dystopia but social reform platforms that have the potential to challenge successive governments to live up to their commitments and revitalize a fragmented civic society that is yet again realigning itself to the changes in its environment.

## **Theme 2: Cultural and Moral Factors underlying Stigma and Prejudice**

In the following sections I seek to understand stigma through an examination of how one's moral standing is lodged within a local context. Yang and Kleinman (2008) argue an articulation of stigma as a moral process may broaden our understanding of the role of moral experiences embedded within local contexts in the stigma formation process. In a setting such as Kerala where familial and social network connections determine one's moral standing in the local context, moral contamination threatens what matters most for those in a local world and jeopardize the individuals' and their families' ability to mobilize social capital to acquire essential social statuses. Through an in-depth analysis of how one's moral standing hinges upon: (1) objective bases, such as physical appearance and cultural perceptions and judgements about its associated health connotations, moral values, behaviours, identities; and (2) intangible bases such as immoral behaviour as a cause of HIV infection; I seek to illustrate how one's moral standing, prejudice and stigma are interwoven in Kerala. In the first two sections I explore the role of physical attributes as an index of health in building caste, class and community identities in pre and postcolonial Kerala. In the third section I relate an experience that drew my attention to the role of physical attributes within the context of HIV related stigma in Kerala. In the following sections I discuss and analyze how

physical attributes influence perceptions of HIV risk and how a stigmatized identity waxes and wanes with a change in physical appearance, at least in some contexts. The final segment explores how “immorality” as a cause of HIV infection influences HIV related stigma. I believe an in-depth analysis of both tangible and intangible bases can also shed light on how unconscious bias plays a part in fuelling stigma and prejudice.

### **Physical appearance and HIV related stigma.**

As a universally valued concept health is undoubtedly a desirable attribute. But, as a culturally defined concept physical appearance as an index of health also includes cultural perceptions and judgements about associated moral values, behaviours, and individual and collective identities (Philips, 2004). Several ethnographic studies have documented the role of physical attributes such as fair skin colour, and plump (not fat) body as one of the many interlinked and interdependent variables entering into class, caste, and communal identities in India (Philips, 2004). Although they were not a more important factor than behaviour or social conduct for making moral and social categorizations, historical and literary evidence from India suggests that Indian rulers were already using general physical characteristics and moral values as a basis for identification and classification long before colonial rule (Bayly, 1999 as cited in Philips, 2004). Colonists used racial mythologies built around skin colour, physical features, attire, and conduct as tools of power to distance themselves from the locals and mark out the “Aryan North” from the “Dravidian South”, the high from the low castes, and the martial and ruling class from the others (Forbes, 1813, as cited in Philips, 2004). Ethnologists of colonial era describe Dravidians or South Indians on the whole, with the

exception of upper castes such as Brahmins and Nairs in Kerala, as “dark, stunted, and hardly attractive” (Risley, 1915; Rothfeld, 1928 as cited in Philips, 2004). In contrast, upper castes are portrayed as fair skinned, handsome, impressive, and self-restrained (Risley, 1915; Rothfeld, 1928 as cited in Philips, 2004).

Thus, colonial theorizing extended beyond classifications based on physical characteristics to ascribe moral qualities to people of different castes, classes and communities even though more recently these theories have been dismissed as erroneous (Dirks, 1989 as cited in Philips, 2004). Apart from Hindus, other communities in Kerala such as the Syrian Christians also adopted the aesthetic standards of a superior community. Kerala Christians, primarily sub divided into Syrian Christians and non-Syrians, use genealogical (pedigree, clan), spatial (area of origin), temporal (time of conversion /origin), income, occupation and educational achievements as markers of identity and distinction (Philips, 2004). Although the term “Syrian” denotes the use of Syriac language in their liturgical services, the term has come to refer to a caste-like community that proudly traces its origins to upper castes such as Nambudiri Brahmins and Nairs of Kerala (Aiyar, 1926, as cited in Philips, 2004). The privileging of aesthetic standards of the superior community benefited Syrian Christians as well since they were also assigned upper caste status due to their physical resemblance with the Brahmins and Nairs (Aiyar, 1926 as cited in Philips, 2004). Although it is unclear how much physical characteristics influenced subdivisions among the Muslims, another major religious group in Kerala, the wealthy trader and landowner Muslims seemed to have been considered like “honorary Nairs” while labourers, fishermen, and petty cultivators formed the lower castes and classes (Kurien, 1994). While contemporary Keralites may

experience caste membership and identity in an attenuated way, physical characteristics along with associated caste or community memberships legacies of pre-colonial and colonial pasts continue to shape cultural perceptions and identity.

There is a tendency in the literature to view stigma as the result of lack of information or ignorance of biomedical knowledge, although some scholars do take the knowledge-power nexus into consideration (Deacon et al., 2005). In countries where plural healthcare systems exist, such as in Southern Africa it has been found that educational interventions that were solely grounded on biomedical knowledge of HIV/AIDS encouraged the development of powerful counter discourses that were rooted in traditional healing practices and understandings of society (Deacon et al., 2005). In Kerala where numerous health care systems such as Modern Medicine, Homeopathy, and Ayurveda co-exist, different epistemological traditions coincide with entrenched social divisions in interesting ways. Physical characteristics as an element of health find articulation in ayurvedic health practices of Kerala. As a system of medicine widely practiced in Kerala, Ayurveda is used to secure well-being, positive health, and longevity (Osella & Osella, 1996). According to Ayurveda, a balanced body (balance between “hot” and “cold”) is believed to manifest culturally valued physical attributes such as fair, smooth skin, loose, flexible limbs, plump (not fat) body and black hair (Osella & Osella, 1996). “Hot” and “cold” by themselves cause negative physical states which unless controlled could lead to undesirable physical attributes such as thinness, dark, coarse skin, facial blemishes, and brown, wavy hair (Daniel, 1984 as cited in Philips, 2004). In fact, fair skin, black hair and plump body are regarded as desirable attributes particularly for women in most South Indian communities (Philips, 2004). Thinness and

dark skin are also regarded as the personification of suffering and rejection and are often associated with the poor, low caste peoples toiling away in the sun (Egnor, 1980 as cited in Philips, 2004). Physical and moral health is interconnected as per ayurvedic philosophy since physical health may be seen as the most tangible manifestation of moral health (Philips, 2004). While the association between physical and moral health may have receded into the realm of private discourse one only has to look at the ever-increasing number of beauty products flooding Kerala market each staking a claim to fair skin, black hair, or plump body to understand the cultural preoccupation with fair skin and other physical attributes.

During the initial phases of my project, while I was still trying to establish contact with HIV positive networks in Kerala, I met the general secretary of a large network in his office to discuss my project. Coming out from the meeting, a relative of mine who had accompanied me but had not participated in the meeting commented, “It sure looks like he has the illness.” Her opinions during our bus ride back home were tinted with a mixture of caution and contempt. Contempt at the PLHA for raising their voice to secure what they are not entitled to, for they “deserved their fate” and were from ignorant “lower classes” who she hoped were being guided by “educated people” in their endeavours. Cautionary allusions permeated her whole argument that marked her disapproval of “these people” and her intent to distance herself from them. I received her opinions with scepticism and guilt. I felt torn between my guilt for failing to offer enough counter arguments that challenged her disregard for PLHA but at the same time justified my inabilities by the thought that as a well-educated, well-to-do, upper class Syrian Christian woman my relative responded just as anybody else in that community



would. I realized later on that my own preconceptions of PLHA were not very different from hers. The general secretary's frail appearance fitted with my preconceptions of PLHA and along with it framed what it means to be a "healthy" person belonging to one of the "respectful", "well-to-do", "upper" classes.

A theme that resurfaced several times in interviews and in informal talks was the prevailing misconception that HIV infected are thin, unhealthy looking, unattractive individuals, and therefore easily identifiable. The following account by a HIV positive support worker on the experiences of conducting HIV awareness classes in the villages exemplifies this theme:

Sameera recalled: After talking to them, "Has anyone of you attended classes on HIV/AIDS? In the radio or in the TV? Have you seen anyone?" "No, No." "What do you think a positive person looks like?" A good number of them have told me "It is a skinny, bare bones and skin only body, nearing death kind of a situation".

Several studies conducted elsewhere have pointed out physical appearance as an indicator of health influence perceptions of HIV risk and consequently jeopardize local ways of avoidance and transmission of HIV (Brown & Hill, 2005; Ezekiel, Talle, Juma, & Klepp, 2009). A study on the constitution of antiretroviral therapy (ART) in the local discourse among youth in Tanzania found that ART medications made the youth gain weight and consequently these bodily changes affected perceptions of risk (Ezekiel et al., 2009). In the rural areas people know each other very well and so it was possible to tell a HIV positive body from an uninfected one since vital signs such as wasting, frequent coughs, and colds are not easy to be missed. However, the therapeutic consequence of

ART in the body often made the HIV infected fat that was confused with recovery and health. In Kerala, physical appearance and cultural perceptions and judgements about its associated health connotations, moral values, behaviours and identities can influence peoples' perceptions of risk in interesting ways. The following extracts recounted by HIV positive support workers illustrate two facets of this variable:

Shivan recalled: Let me talk about a friend's...a recent experience. He works in the north as a pilot. It is because he is well educated that he became a pilot. In that situation, while working as a pilot, some tests were done - HIV positive. With this result, he got in touch with us and spoke to us. Whenever we talked, he would say there are no chances for him to get AIDS. "I haven't gone in those ways." ... He would repeat over and over again that he hadn't involved in any ways that would infect him with HIV/AIDS. At the end of it all, it was when we asked again that he finally said it. " At a house near mine, lived an Air Force officer's wife, who is a widow. She is a plump, fair lady. I had an affair with her".

Balakrishnan commented: ...what used to be shown was the figure of a skin and bones AIDS image. Media has got a huge role to play in this. For example if they show me – then there are two problems. If I say I have been living without any problems for the past ten years, what would they think? "Oh, okay, what's wrong with being a positive?" Because although it has been disclosed that they are positives there are negative men going after positive women. They are not at all scared.

Apparently the pilot Shivan referred to was under the impression that he could not get HIV from an upper class (“Air Force Officer’s wife”, “fair”), “plump” woman, all characteristics of healthy (and probably uninfected) individuals with “clean” morals and values. At the other end of the spectrum, the “skeleton like figures” and the “sensational stories created out of them” as several participants cited became associated with ill health and HIV/AIDS particularly in the media. How would the image of a “healthy” looking HIV positive influence perceptions of risk? Would individuals neglect the warnings now that they realize previous messages had over inflated risk? These are the questions Balakrishnan raises. Stout, fair, energetic and confident, Balakrishnan could make most natives question their misconceptions of PLHA. In fact, it was meeting individuals like him that helped me dislodge my own stereotypical views. In a social context where “skeleton like figures” have long been used to instil fear and aversion so as to aid HIV prevention, but are increasingly being replaced by “normal, healthy” looking images so as to reduce stigma, the argument that Balakrishnan raises is relevant. This argument points at the alternative perspective on stigma.

The alternative perspective on stigma hints at the potential benefits of employing stigma as a useful social control tool to discourage unhealthy behaviours (Stuber et al., 2008). The central idea is that the pressure to conform to social norms and the fear of stigmatization would force individuals to correct their unhealthy behaviours thereby bringing direct benefits to themselves and indirect benefits to society (Stuber et al., 2008). However, as Nussbaum (2004, p. 232) pointed out it is not the force of stigma but the nature of the emotion that makes stigma a bad public policy and “ for the state to participate in this humiliation...is profoundly subversive of the ideas of equality and

dignity on which a liberal society is based.” Behind the seemingly virtuous motives of anger against immorality and vice lie primitive instincts to induce fear by shaming and humiliating others so as to remain in control (Nussbaum, 2004). Linked with other differences such as social class and caste stigma’s cruelty is most prominent in the creation of a landscape of fear. In the following section I analyze the role that physical attributes play in creating and maintaining a stigmatized identity based on fear and how it ebbs and flows with a change in physical appearance.

Fear of loss of face and the potential for social exclusion not only for themselves but also for their near and dear ones forced most participants to manage their HIV stigmatized identities throughout the course of their illness. Most participants had limited choice or control over disclosure during the initial stages of their illness since diagnosis and disclosure occurred unexpectedly when they were in the company of family or significant others. Unlike a situation that allowed them to prepare and progressively disclose their HIV positive status to those they trusted, many were left at the mercy of those who happened to be around when the news was revealed. Unsurprisingly, some understood and were supportive while others were not. However, as the initial hoopla died down and as individuals received a better picture of “who are on their side” stigmatized identities and responses became more situation specific. As an indicator of their health physical appearance is an attribute that many participants continually managed to keep their stigmatized identities more or less conspicuous. A couple of female participants found losing weight, “becoming darker in complexion” and repeated inquiries of why they were becoming so by acquaintances quite perplexing. Although these women handled such intrusive questioning tactfully without drawing

attention to their illness such as by suggesting, “ it might be because of my work and the commute”, these women feared their changing bodies could arouse suspicion in the neighbourhood. While their HIV positive status was well known and tolerated within their families they were particularly alert to cues and situations that triggered their stigmatized identities and made it more visible. Curiously, the obsession with weight and cure and its connection to the feeling of being included or being “normal” may explain some participants search for “quick fixes”. Desperate to find a cure, several participants, particularly men, related tales of responding, one after another, to newspaper advertisements and rumours that promised “miracle cures”. Prominent among these alternate treatment options is medicines manufactured by Fair Pharma, a pharmaceutical company well known for its controversial role as the manufacturer of “ayurvedic” remedies for a variety of illnesses including HIV/AIDS. Priya, a PLHA support worker explained what she had heard Fair Pharma medicines could do:

.... You will put on weight. Your skin complexion will become fairer. When you are in this situation, you will become dark like coal. Because your blood is very...you won't have blood. Even your blood will look black. In that kind of a situation, when you take this medicine it will work. When we regain a bit of our health, we will say we are negative.

Consistent with the images of ayurveda as quackery and potion pushing particularly among many modern medical professionals in Kerala, some participants referred their encounters with so-called “ayurvedic treatments” as mistakes on their part and deliberate attempts by alternate healers to exploit their vulnerabilities. “Ayurvedic” medicines Fair Pharma offered for HIV/AIDS were found to help with weight gain and to improve skin

complexion. In a context where weight gain and a fairer complexion implied better health such a sudden revival was easily confused with being cured of HIV. In addition, there were also accusations that alternate healers manipulated test results and backed up their claims with testimonials to create an impression that once their medications were taken as prescribed patients were cured of HIV. The bodily changes seen to result from medications in terms of putting on weight and turning the skin fairer were not just confined to alternate treatments. A HIV positive support worker narrated stories of PLHA flocking to visit a doctor based at a medical college hospital in Southern Kerala for the discreet and confidential service he offered for a hefty fee. Apparently, the doctor is reported to prescribe higher doses of medicines (called “second line” by participants) initially without checking their CD4 counts which would make “even those very sick fresh within a month”. Patients’ bodies “would swell up” and so it would appear that they had gained weight. When these patients switched their treatment to ART (also called “first line”), which was offered free of charge in government run ART centres “their bodies failed to respond”. Taking a higher dosage of medicine worked in the short run especially because it satisfied people’s desire to look “plump”, “fair” and “healthy” at the earliest so they can be ‘normal’ again, but seemed to backfire in the long run.

The longing to look and feel a certain way is understandable when one considers that attitudes toward PLHA can shift to their advantage as the infected person gains weight and becomes more “normal”. Naveen remarked there have been noticeable differences in some people’s attitudes toward him after he put on weight:

They doubt whether I have this illness now. In their eyes, I have returned as the person I once was. I am reaching my former self now...if a person who is 79

kilos becomes 45 kilos, what would it be like? From that situation, I have reached 73 kilos. The difference is already evident. So they have also changed. They might think I may not have it anymore. That may be the reason. I am allowed to participate in many things - there are noticeable changes.

Previously excluded from many activities Naveen found that he has been invited back into the fold as his physical appearance and presumably his HIV status had changed. Naveen's situation raises some interesting questions. For stigmas related to illnesses, such as HIV/AIDS how do the sense of stigmatized identity vary with the activity or remission of the illness? Alonzo and Reynolds (1995) trace the nature of stigma over the course of HIV/AIDS. The stigma trajectory they propose charts successive declines through four phases ending in physical and social death. Although this trajectory does link the experience of stigma with the biophysical dimensions of HIV/AIDS the linear decline from one phase to the next leaves little room to suggest experiences of stigma wax or wane with the activity or remission of the illness. Considering the easy availability and accessibility of ART and its impact in prolonging life and causing weight gain (Ezekiel et al., 2009), there is a greater potential for individuals to keep identities concealed, be reintegrated back into previously excluded groups, or be excluded again as their physical appearance change with the activity or remission of the illness. Thus, experiences of stigma can wax and wane as the HIV positive person oscillates between illness and health. However, the devaluation members of stigmatized groups experience are also context specific and not everything is tied to the illness per se. Naveen's apparent rebound to health did not help him reintegrate with his family in a way he expected. Despite many awareness classes and counselling his family "chose

not to accept him”. Naveen also described his family’s response as strategic and opportunistic:

When I began to make money, my family has gradually started to...nobody abandons an HIV+ if he has money power. Until they stop getting the money, they want him. They abandon him only after that. If someone is able to work, then they will hold onto that person - so they can extract that money from him. That’s their only intention. That’s what is happening to me also. They don’t need me. But they need my money. They are not willing to accept me. But they want my money. I am aware of that. I know my family is exploiting me. But because I work for others in addition to what I do for them, I am not worried about my life.

Experiences of stigma are more or less salient in situations that trigger or deactivate particular stigmatized identities (Levin & Van Laar, 2006). In situations that allow Naveen to maintain a concealed identity due to his “normal” physical appearance it is reasonable to assume that he is less affected by HIV related stigma. However, despite his improved physical appearance his identity is still conspicuous in some other contexts such as in his family. Considering how the context and the situation can trigger particular stigmatized identities helps define individual responses, levels of comfort, and experiences of stigma (Levin & Van Laar, 2006).

In sum, physical appearance and cultural perceptions about its associated health connotations threatens what matters most for people in the local context – their moral standing and social status. In a context where physical appearance is also tied to caste and class membership moral condemnation can give rise to stigmatizing community beliefs. The previous paragraphs highlighted how the fear of loss of face prompted initial



self-treatment through visits to alternative healers and private clinics not only to protect privacy and be cured, but also to look and feel a certain way so as to reclaim lost status and community membership. This help-seeking behaviour along with deteriorating quality in government health facilities (Elamon, Franke, & Ekbal, 2004) delayed treatment at public ART centres despite the fact that medicines were provided free of cost. Stigmatized identities are also context and situation specific where attributes such as physical appearance become more or less salient. Furthermore, physical appearances influence HIV risk perception and many engage in risky behaviour because they perceive risk differently, like the pilot Shivan talked about, and choose to forgo or delay HIV testing fearing intense community rejection thus greatly fostering medical non-compliance and transmission opportunities.

### **Immorality as a cause of HIV infection and the family context.**

The historical, political, and cultural contexts of information sources make information more or less trustworthy (Deacon et al., 2005). Since knowledge about a stigmatized disease carries literal, ideological, and contextual social meanings, lack of awareness or reporting ignorance about modes of transmission can actually be used as a justification for prejudice based on immorality or symbolic stigma (Herek & Capitano, 1998). Many cultures hold the view that immorality gives rise to HIV positive status (Yang & Kleinman, 2008). The following extracts illustrate that the moral weight associated with HIV/AIDS stigma in Kerala even supersedes concerns of infection from the disease itself, other illnesses, and other perceived causes of infection which are primarily rooted in lack of information about HIV transmission:

Anil commented: Then there's the question of how one gets infected. Most of them are associated with sexual transmission, that kind of an attitude – “Oh, he is a bad person”. Sex is there in everyone's life. Even the person who is saying this, although nobody else says it; he also has it. But he thinks, “ It is spread through sex, which means his ways were corrupted. That's why he got it.” That type of thinking and hatred is there in his heart like a stain.

Question: Have people asked you anything about how it spreads?

Maya: Many people have asked me how and where I have got it from. They want to know whether we got it through a sexual relationship. So I tell them this is how I got it. Many people have asked me, “ How did this happen? Where did you get it from?” But they haven't asked me how this can spread.

Question: Is it because it spreads this way that people have...

Maya: It may be so. That may be why there is generally contempt. But for other diseases, even if they are more serious, for example if you have cancer you are sure to die. Although cancer is painful, nobody has anything against it. But people despise this. The others (illnesses) can be disclosed.

Question: At your home and at your husband's home, do they know how it spreads?

Suma: No matter how many times they are told, they won't understand. No matter what we tell them, they won't accept it.

Question: What if doctors tell them?

Suma: They have all told them. The health inspector had come. But they still won't accept it. Do you know how many times I have also told them? At the end, I felt so foolish. No matter how many times you tell them, they won't listen or accept it. "You will have so many excuses to make sister", that's what they say. I have told them many times. In the end, I have quit.

Anil's and Maya's comments highlight the moral burden a sexually transmitted disease particularly HIV/AIDS places on them. That stigma occurs interpersonally despite all efforts to educate as Suma explained illustrates how loss of moral standing remains key. Because moral contamination also stains family members and distant relatives family ties are threatened resulting in potential social exclusion of individuals and families. Extreme discrimination even towards those linked with HIV positives were also reported – e.g., uninfected children of HIV positives repeatedly denied schooling, uninfected children treated with scorn by health professionals. Participants from various age groups, gender, social class, religion, place of residence, and sexual orientation cited the perception that immoral behaviours caused HIV infection was a critical factor that fuelled HIV/AIDS stigma in Kerala. Moral judgements were often based on behaviours commonly associated with HIV/AIDS such as commercial sex, drug use, or as some participants pointed out, due to conservative norms that prohibited the discussion of sex and sexuality within Kerala society. While there is clearly a prejudice against sexual immorality in Kerala (Elamon et al., 2004), it is difficult to say how much this influences social action or inaction. Perhaps, the most concrete expression of it is to be found in the division of PLHA into two moral categories – "the guilty" and "the innocent". Moral contamination associated with HIV/AIDS is greatly compounded by the view common

across cultures that there is a distinction between the “guilty”, those who got infected through voluntary but immoral or irresponsible behaviour, and the “innocent”, such as children, blood transfusion “victims”, and faithful wives of unfaithful husbands (Alonzo & Reynolds, 1995; Muyinda et al., 1997). Even the so-called “guilty” participants admitted they were worthy of blame, but argued the “innocent” deserved better treatment than they did.

Disease stigmatization stacks meanings and values onto a biological phenomenon such as a disease and draws heavily from dominant group representations which often gain greater currency in the society and shift blame onto marginalized groups following existing lines of inequality (Deacon et al., 2005). For example, the guilty are considered blameworthy because they contracted HIV through indulgence in immoral behaviour that is associated with marginalized communities such as sex workers.

The moral contamination associated with HIV/AIDS has particular relevance within the family context. Although family members’ responses toward PLHA were based on resource constraints and moral concerns, gender and social class were found to impinge on them. The following comments by Francis and Savithri illustrate how gender influences moral concerns.

Francis recalled: For many of them they get infected through their husbands. I have heard it is 85 %. The husbands may die before (they do). After their death, it may like, “ How can this be possible?” Then the wife and children will be severely stigmatized. It’s not there now. This is the situation in 2003-2004. It is less now. There are people willing to accept these things.

Savithri explained: .....our panchayath member and ward member are all on our side. They said, "It's not she who has brought this disease. It's her husband. There are other people infected like that here. How can we isolate people like that? Shouldn't they also live in this community?" they said. There is good encouragement like that.

A number of research studies conducted in other Indian states and other Asian countries found women were more likely than men to experience HIV related stigma and discrimination which included ridicule and harassment, physical assault, being forced out of their place of residence and subjugating their needs to provide care for their husband and children (Bharat et al., 2001; D'cruz, 2004; Paxton et al., 2005; Tarakeshwar et al., 2006). However, contrary to these findings HIV positive status was found to bestow protection for some women while it invited ridicule and rejection for some male participants in this study. Although all male participants reported they had strained relationships with their spouses and other family members at some point because they were assumed to be morally suspect, one participant pointed out the earning capacity of the HIV positive person was a critical factor that influenced family responses. All male participants, both single and married, were in a position to earn their living. Even though family members expressed anger and resentment toward male participants whose lifestyles of drinking, squandering money and "loose morals" had invited shame and dishonour into the family they were forgiven and tolerated particularly by their spouses. But financial independence did not always mean a warm relationship and two male participants who had been separated from their wives were

particularly aware of this. Sometimes family members clung on just for financial gains with minimum emotional investment in the relationship.

As Francis pointed out, findings from other studies conducted in other Indian states (Bharat et al., 2001; D'cruz, 2004; Tarakeshwar et al., 2006) also suggested women were blamed for infecting themselves and their husbands, particularly by their in-laws, in the cases where the cause of their husbands' deaths were largely unknown. These studies found that women mainly relied on their natal families for support and care although in some cases husband's families kept them on until their son's death. In this study, 4 of the 18 female HIV positives interviewed reported their relationships with their in-laws had improved gradually after their husband's deaths. In all these cases families disapproved of their sons' lifestyles (drinking, squandering money, deceit, and not caring for the family) and had estranged relationships with them even before they had become infected with HIV. Once these men became infected with HIV, their spouses and children had to bear the ridicule and isolation that was really targeted at their husbands. With the exception of three cases, women, by and large were given the concession of being the "innocent" victim, and were protected and cared for by either their natal families, husband's families, or both. But, men received no such considerations and most were assumed to be morally culpable, even as their own families and their in-laws cooperated with them, perhaps grudgingly.

The literature on gender prejudice is replete with examples of discrimination against women, including unconscious bias or benevolent prejudice that operates insidiously and stealthily under the social radar to undermine the progress of agentic women (Dovidio et al., 2005). Assigning blame based on morality and the two moral

categories (“guilty versus innocent”) created out of it implicate the importance of unconscious gender beliefs as barriers to gender parity, care, and support, albeit in the reverse direction. As Savithri explained, the belief that men are morally culpable for bringing on the disease lingered on and was found to intentionally and unintentionally affect the quality of care and support they received from their families. In sum, the victim-perpetrator narrative was found to selectively favour or bias one group or the other. Although women received family support, one could argue that the innocent victim image portrays women’s absolute vulnerability to HIV/AIDS due to male dominance and economic dependency (Jolly, 2010). While men enjoyed relatively more freedom and financial independence, the guilty verdict transmits an image of cheating husbands passing on the virus to their faithful, unsuspecting wives. The solution that evolved in the process - of penalizing husbands- in reality hurts not just the men. It hurts the family - men, women, and children.

This study also brought to light interesting dynamics with respect to the class of the HIV positive person. There was a perception among the general public that HIV/AIDS is a disease of “low class, criminal minded” people who intentionally infected others. Cautionary remarks signaling danger such as “some of them can poke you with infected needles” and veiled criticisms laced with triumph and relief at “those kinds of people being driven out of our neighborhoods” were not so uncommon whenever I mentioned my research project to relatives and friends. A HIV positive support worker recalled she was shocked and hurt when a Panchayath president (village council president) asked her after her speech at one of her public awareness classes whether she had been a sex worker even though she was a housewife from a middle-

class family who had got infected from her husband. In fact, male participants frequently used the statement “I hadn’t gone in those ways” to suggest they had not engaged in immoral behaviors but had got infected through means beyond their control.

In several cases the sound financial background of the HIV positive person or their families did not guarantee better care and support. All the male participants were in a position to take care of themselves and make some financial contribution to their families. They received varying degrees of support and care from their spouses and families. In the case of male participants, familial values, family orientation towards caregiving, and emotional bonding with their natal/marital families were found to underlie the quality of care and support they received. Although the respondents did not point out a single predominant motive, innumerable reasons such as love, a sense of duty, lack of choice, humanitarian concerns or social reasons could be the basis of the quality of care they received. Despite availability of financial resources, low emotional bonding and estranged relationship with their natal families even before they were infected with HIV resulted in minimal support and care for two male participants from middle class families. In both cases these men perceived they were being disrespected and humiliated. So they chose to sever ties with their marital and natal families. On the other hand, even if they belonged to the lower income group and believed their son was somehow responsible for his illness, caregivers and family members were not deterred by the lack of resources and would often go out of their way, even to the extent of incurring loan and debts, to provide the best quality of care and support. In the case of wives the sense of spousal duty, love, and perhaps their own well being and survival came out vividly. Most wives (HIV positive and HIV negative) were found to provide



care and support to their HIV positive husbands, although in two cases the wives (both HIV negative) separated from their husbands blaming them for the shame and dishonor the illness brought.

For female participants, the perception that they were innocent, and family and caregiver orientation to providing care were found to be the predominant factors underlying the quality of support and care they received. In the case of female participants all except three were considered “innocent victims” of their fate. The majority of the women were supported and cared for by their natal/marital families. In the cases natal/marital families did not provide adequate support, women sought out those who sympathised with them and relied on these kinship networks for financial and emotional support. In some contexts the presence of the wife and children who have been innocently infected afforded care and support to their morally suspect husbands as well, particularly from the wives’ families. Interestingly, in the case of the two women considered “guilty”, lack of financial resources was not a major consideration for the quality of care they received and the stigma experienced.

One of these cases is a woman from the tribal community, a group considered to be at the bottom of the social hierarchy in Kerala. Perhaps due to their “ignorance, and general lack of awareness of HIV/AIDS” as an HIV positive activist described, or the apathy, poverty, illnesses and death that plagued their community, HIV related stigma or the quality of care received did not appear to be a pressing concern for the tribal woman. A HIV positive activist working with tribal communities described the situation as thus: “They don’t know about HIV. Then how can they have stigma? They have no knowledge about these things.”

Despite adequate financial resources available to her natal family, one female participant and her children received limited support from them. Although her aged and dependent parents and younger sister supported her, they were forced to adhere to the dictates of the older brother who refused to believe her and continued to fear HIV could spread through casual contact “no matter how many times he is told or who told him”. The situation is similar with her in-law family as well. Although informed about the modes of transmission by health care professionals and PLHA networks, members in her natal and marital families who controlled family resources continued to believe HIV could spread through casual contact, and meted out minimum support on this basis. Thus, despite adequate economic resources with her natal and marital families, the participant reported she, her children, and her mother-in-law who accused her of promiscuity were forced to relocate multiple times, in part due to the discrimination her children faced at school, conflicts with neighbours, and also in search of a job for herself.

In a setting such as Kerala where family connections predominantly determine one’s moral standing in the local context, a blow severe enough to distort the family’s reputation threatens what matters most for those in a local world. Moral contamination subsequently jeopardizes the individual’s and his/her family’s collective capacity to mobilize social capital to acquire essential social statuses. Familial ties are the glue that binds the individual to the wider social network and when that is threatened it creates ripple effects. When family members themselves expressed doubts and gossiped to the neighbours, it jeopardized the HIV positive person’s relationships with the family and the community.

Sathyan's comment below summarizes the importance of family ties and its relation to HIV stigma.

And talking about stigma...at first, it was there. The difficult thought of what would happen if it became known in the community. Because people used to view HIV in such a strange way. But my family members found out immediately after I did. Everyone knew that this is how it is. Nobody opposed, nobody said anything. That was because there was a good relationship with everybody. They were not able to isolate me. So, there was good support from the family. Because of that they themselves provided the medicines and supported me - because of that relationship.

The family's response as a unit also points out some of the limitations in current theoretical models. Social control and psychological theories suggest it is fear arising from concerns of self-preservation and/or dominance that drives stigma and prejudice. But, rather than fearing social exclusion if PLHA choose to hide their HIV positive status from their families out of love and respect for their loved ones because they do not want to hurt them, how does that fit into a power-control model? In the spirit of cooperation, harmony, and group solidarity, if PLHA accept their restrictions or even self-impose them and their actions are culturally supported, are they being stigmatized? In other words, if self-sacrifice is viewed as "power" are they being exploited? The following extract illustrates this.

Maya recalled: The family thought only he was infected. They asked me, "If it were just him, only he would have got a job with them (with HIV positive networks)." They started asking me how I could also get a job. I told them, "

That's because there are few HIV patients" Even then I didn't tell my family.

Wouldn't they be so upset when they hear this?

Maya withheld her HIV positive status from her family not out of fear that she, her husband and child will be ostracized, but out of great love for her family. She wanted to protect them from the potential embarrassment and disappointment they might have. Some other participants also related situations where they went willingly to care homes out of concern for the future of their unmarried children or other family members. In such cases, family members and the participants believed self-imposed seclusion was the appropriate recourse to safeguard everyone's best interests. In much of the vast literature on stigma and prejudice, the tendency is to view power and love as polar opposites. Thus, in the absence of love, power leads to exploitation and dominance. What is implied in such conceptualizations of stigma and prejudice is the abuse of power that stems from the fear arising out of concerns for self-preservation. But, power could be just as exploitative and its impacts similar even if it arose out of other concerns such as love or the instinct to protect others. The hues and shades of power are best pictured when it incorporates more emotional resources in addition to the fear factor that forms the basis of current conceptualizations on stigma.

## **Chapter VI: Discussion and Conclusions**

### **Implications of the Findings and Directions for Future Research, Policy and Practice**

This research provided insight into the impact of stigma and discrimination on the lives of individuals and their families living with HIV/AIDS in the state of Kerala, India. In order to explore the impact of stigma and discrimination, there were three research questions designed to attain first hand knowledge and perspectives from the study participants. The first question was to examine how stigma and discrimination unfolded in an asymmetric power situation. The second question was to uncover how multiple identities due to one's gender, socio-economic background, and so on, impact one's experience of being infected with HIV. The third question was to discover how the HIV positive status of one or more members affected relationship ties within the family and how the family's response to HIV as a unit is best conceptualized. In the following three sections, I will discuss the relationship of the findings to the research questions and the available literature. Implications for future research, policy and practice are also discussed. Exploring micro-level interactions and the broader issues of power, dominance, and exploitation (whether intentional or unintentional) stems from the prejudice research tradition and understands stigma as a social process. Social control theories (Link & Phelan, 2001; Parker & Aggeleton, 2002) that use power asymmetry to conceptualize stigma define asymmetry on the basis of social and economic resources. Examining stigma and discrimination in asymmetric power situations showed insight into the relationship between stigma, discrimination, and power as it unfolded in various circumstances with different social and economic resources. In addition, findings also

highlighted the nexus between knowledge, power, and stigma that find sparse mention in the available literature on stigma and prejudice.

While it is understood that formal education and training could increase one's knowledge and subsequently lead to better social and economic resources, the findings pointed out how knowledge itself is a resource that allowed stigma to unfold along existing social hierarchies. A focus on the broader picture as social control theories suggest without ignoring what stigma meant for micro-level interactions as Deacon and colleagues (2005) advocate, has provided insight into how existing social inequalities foster stigma, and how stigma perpetuates existing inequalities within the context of HIV/AIDS. In support of the recommendation to bridge stigma and prejudice research traditions (Stuber et al., 2008), findings focused on both internalized oppression and structural forms of oppression. Findings revealed how structural forms of oppression percolated into interpersonal and micro-level interactions and led to internalized oppression. As the prejudice research studies suggest (Dovidio et al., 2008), findings also revealed that unintentional forms of bias could exist even in the absence of overt forms violence and exclusion. For instance, although policies and practices such as positive speaking and positive living aimed to reduce stigma and aid prevention, they had differential impacts on PLHA based on their knowledge, power, and status within the PLHA community. The strategies lead to unintentional consequences for at least a few individuals who had limited knowledge of their situation or were not in a position to voice their disagreements. Thus, they were forced to straddle the interrelated subjectivities of the composed survivor and the afflicted patient. The varieties of experiences that exist along a continuum from the strong insistence on assuming a

positive identity to keeping a low profile suggest the need for a more nuanced PLHA identity. Future research could shed more light on the varieties of PLHA experiences and identities. Current policies and practices embrace a blanket approach that encourage all PLHA, particularly positive speakers, to disclose their HIV positive status so as to reduce stigma and aid prevention. While these policies are well intentioned, a narrower, piecemeal approach that also considered the personal circumstance of each individual, and took into account the consequences of going public may be more appropriate. A narrower approach can safeguard the interests of the PLHA, and can send a strong message to the general public that we genuinely care about the well being of our ill members. Such a message is bound to reduce stigma and aid prevention in the long run.

A finding that highlighted the knowledge-power nexus is the loss of face the less educated, underclass experienced during their interactions with institutions dominated by the literate and the educated, and their outrage at poor quality public services. Contrary to their expectations that stigma is the result of ignorance due to lack of education which also implied awareness about HIV/AIDS, many participants were shocked to be stigmatized by the educated themselves. Some participants remarked that they were more disturbed by the stigma they experienced at the hands of the educated, but considered stigma due to ignorance (typically linked to the undereducated and the lower classes) as more tolerable.

This insight has both research and practice implications. Although some theories address stigma as a social process (Link & Phelan, 2001; Parker & Aggeleton, 2002), and some others conceptualize stigma based on its functional aspects (Herek, 2002; Herek & Capitano, 1998), lack of understanding about scientifically identified ways of

HIV transmission is usually termed stigma or “ignorance” in much of the available literature. Similarly, current educational interventions address stigma as the lack of knowledge in biomedical understandings of HIV/AIDS. Future studies and interventions should move beyond this narrow understanding of HIV related stigma. HIV related stigma should also be addressed as a situation specific process, a thinking that is poorly reflected in current intervention programs (Yang & Kleinman, 2008). For example, the variations in how PLHA experience stigma depending on the social class and status of the perpetrator (educated versus under educated) suggests the need to develop interventions that are specifically tailored to the situation rather than the exclusive over reliance on the provision of updated biomedical information. In fact, if we were to expand our conceptualization of stigma beyond current understandings, it would reveal scores of situations that could not be tackled by the provision of updated biomedical information alone, but are best dealt with if the underlying prejudices (such as those based on moral concerns) are also addressed.

HIV related stigma co-exists on top of other multiple disadvantages/advantages. The importance of exploring how HIV related stigma coincide with multiple identities has been emphasized in several studies (Campbell et al., 2007; Nyblade, 2006; Stuber et al., 2008). In regard to how multiple identities due to one’s gender and social class impacted one’s experience of HIV/AIDS, there were two major findings. The first finding (theme 2, sub theme 1) related to how cultural perceptions and judgements about physical appearance and its associated moral values entered into class, and community identities. This finding also highlighted how the fear of loss of face prompted initial self-treatment through visits to alternative healers and private clinics not only to protect



privacy and be cured, but also to look and feel a certain way so as to reclaim lost status and community membership. While both men and women reported they were concerned about their physical appearances (losing weight and becoming darker in complexion), it was predominantly men who had visited alternative healers in search of quick fixes and alternate remedies. Most importantly, the finding sheds light on how unconscious prejudices such as physical appearance influenced perceptions of HIV risk, and how a stigmatized identity waxed and waned with a change in physical appearance. Several studies have explored whether the sense of a stigmatized identity varied with the activity or remission of HIV/AIDS (Alonzo & Reynolds, 1995; Brown & Hill, 2005; Ezekiel et al., 2009). The findings were consistent with that of these studies that had suggested that a stigmatized identity indeed evolve over the course of the illness. However, unlike the stigma trajectory proposed by Alonzo and Reynolds (1995) that charts successive declines through four phases ending in physical and social death, the findings suggested a stigmatized identity waxed and waned with a change in physical appearance as the HIV positive oscillated between health and illness. These findings have both research, and practice implications. More studies are needed to clarify the nature of the stigma trajectory over the course of the illness, and uncover the various factors entering into the evolution of a stigmatized identity. These findings also highlight the importance of the visual image and its impact on the stigmatized identity. Current interventions such as the positive living campaign have realized the importance of the visual image, and have incorporated this understanding into their messages. HIV positives are no longer portrayed as the “skinny” and the “near dead” figures, but as “normal” looking people from every walk of life. Drawing on the insight that cultural perceptions and judgements

about physical appearance and its associated moral values entered into class, and community identities could enhance these interventions. Inquiring into alternate health care systems in Kerala, such as Ayurveda, in addition to biomedical knowledge, and investigating how they coincide with entrenched social divisions could also be beneficial.

The second finding (theme 2, sub theme 2) provided insight into how another prejudice (which may be intentional or unintentional), immorality as the cause of HIV infection entered into family/caregiver decisions regarding the use of family resources for the treatment and care of the HIV positive member. Gender and social class impinged on family decisions in numerous ways and some similarities and differences were found from the available literature. Research on HIV related stigma and discrimination in other Indian states (Bharat et al., 2001; D'cruz, 2004; Tarakeshwar et al., 2006) suggested women were more vulnerable particularly because they lacked economic resources and were considered a burden. There were certain differences between the literature and the study on this particular finding. Both men and women were found to be vulnerable to stigmatization, albeit for different reasons. In general, the findings highlighted the need to consider that while unconscious gender beliefs bestow protection on one gender it might deprive another gender of the support they needed. For example, while most women were deemed innocent victims and bestowed protection by their families, by and large men were assumed morally suspect and deprived of the emotional support, love, and care they needed. However, because all men were capable of earning their own living, they were financially independent unlike some of the women who depended on their families and so had to follow their dictates.

The present research also brought to light an interesting dynamic in relation to the social class of the HIV positive person and their perceived mode of infection. It was found that the mere availability of financial resources did not guarantee care and support to HIV positives from middle and upper classes, and the lack of resources did not deter family members from the lower income groups to provide the best possible care to their care receivers. The findings on how gender and social class impinged on family decisions to provide support and care illustrate the debate on risk, resource, and moral (symbolic) stigma. As Herek and Capitano (1998) pointed out, moral stigma is based on deep-rooted prejudice, identities, and power relations in the society. It is difficult to be dislodged. Risk and resource concerns may be easier to address. Keeping in mind that risk or resources concerns may be used as a justification for moral concerns and vice versa, specific interventions that address each concern are needed. Interventions should also take factors such as gender and social class into consideration. Above all, we would need to understand that education is much more than providing factual information about HIV/AIDS.

In regards to the third research question, it was found that how the family stood together and responded as a unit impacted not only relationship ties within the family, but also with the wider society. In a setting such as Kerala where family network and other connection based exchanges determined one's moral standing in the local context, moral contamination threatened what mattered most for those in a local world and jeopardized individual and collective capacity to mobilize social capital to acquire essential social statuses. In the current literature stigma is understood as a social process. Conceptualizing stigma as a moral process as well has both research and practice

implications. If one considers stigma as a moral process, it would mean that stigma is also an emotional process that does not always respond to rational interventions. This also suggests the need to look beyond providing just factual information about HIV/AIDS. Emotional resources such as love, respect, group harmony and solidarity find sparse mention in the available literature on stigma and prejudice. For instance, social control theories consider social, and economic resources as variables entering into an asymmetric power relationship. Dominance and exploitation are primarily driven by fear – fear of self-preservation. But, if we were to expand this understanding to incorporate the multitudes of emotions that can impact power relations in addition to fear, HIV related stigma and discrimination could include forms of exploitation and dominance such as subtle control and benevolent paternalism. More research, particularly cross-cultural studies that shed light on the different conceptualizations of power may be beneficial.

### **Limitations of the Study**

There were several limitations to this research project, including those associated with recruitment of participants, sampling, my limited experience as an interviewer, and data recording.

I had relied on two networks for people living with HIV/AIDS in Kerala to recruit participants for this study. The recruitment strategy one of the networks recommended was to draft a list of possible participants in each district based on the HIV positive person's willingness to be interviewed, and whether this person had serious "issues" or "experiences of stigma and discrimination" as those who were in charge of

preparing the list perceived. Thus, several of the participants were recruited based on other people's awareness and perceptions, and not on their own perceptions of the stigma experience.

In an ideal situation, the sample size is determined by data saturation when interviews with participants do not yield any more new themes. While wrapping up my fieldwork, a new theme emerged - participants who viewed their experiences more positively, and so were more inclined to conclude they had not experienced stigma. This new theme seemed to invalidate my initial insights, and offered an alternate explanation to my current understandings. Given the time and financial constraints, I was not able to pursue this lead further. Moreover, the majority of the participants were from northern Kerala. After my initial plan to interview the care home residents failed, out of the fear that I might have difficulty finding enough participants, I interviewed as many participants as I could find during the 10 days I travelled to northern Kerala. This was a physically and emotionally exhausting experience. The results may have been more diverse had I waited and recruited more participants from central and southern Kerala instead.

Contrary to my expectations, I did not feel that I was inexperienced and nervous during the first few interviews. I also did not feel more relaxed with each subsequent interview. However, I learned that doing more than an interview in a day interfered with my ability to focus, relax, and build rapport with the participant. Consequently, I may have missed opportunities to expand upon participant responses, particularly during my hasty northern Kerala visit. My best interviews were the first two and the last one when I

did only one interview in a day, felt less hurried, and was not too anxious about the type of responses I was receiving.

In some cases, I may have missed important content since I was not able to seek clarification from the interviewees after the interviews. For example, in a couple of situations the recording device failed to record. In such cases, I had to rely on the field notes. I was the only coder. Therefore, I could not compare my findings with another researcher.

## **Conclusions**

With this research, I believe I gained a deeper understanding of the impact of stigma and discrimination on the lives of people living with HIV/AIDS in Kerala, India. My knowledge of the topic evolved from my initial understandings of stigma that were primarily based on media reports to include arguments and outlooks previously unknown. To sum up, this research project has highlighted the need to develop a more nuanced understanding of HIV related stigma that extends beyond the current conceptualization of stigma as “ignorance” or lack of awareness about modes of HIV transmission. Refining current understandings of HIV related stigma could guide research, policy, and practice. It can also assist governments, NGOs and others concerned to provide coordinated prevention, diagnosis, treatment and care programs to improve the quality of lives of HIV positives and their families.

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## Appendix A

### **Interview Guide** (was translated to Malayalam)

#### Subsession 1

I want you to tell me about all the events and experiences in your life, which are important for you, up to now. Start wherever you like. Please take the time you need. I'll listen first, I won't interrupt. I will just take some notes while you talk.

#### Subsession 2

Could you describe that situation (event)?

Could you tell me about any situation or incidents involving that person (person)?

Can you recall any experience involving that situation (situation)?

Can you recall any experience when you felt like this (feeling)?

Can you tell me about any experiences you have had when you were in that place (place)

## Appendix B

### Demographic Questionnaire (was translated to Malayalam)

Today's Date:

Interviewee Name:

Place of Interview:

Age:

18 – 30  31 – 40  41 – 50  51 – 60  61 – 70  70 & Above

*Native place:*

Village  Small Town  Town  City

*District:*

*Socio-Economic Background:*

Lower Class  Middle Class  Upper Middle  Upper

*Education:*

Up to Grade 10  Pre-degree/Degree/  
Diploma  Post Graduate  Professional  
Degree

*Occupation :*

*Religious background :*

- Hindus (Indicate Caste):
- Christians (Specify category):
- Muslims:
- Others (Specify):
- Atheist:

*Status of HIV Progression:*

- Less than one year

- 1 - 4 yrs
- 5 - 9 yrs
- 10 yrs and above

## Appendix C

### Informed Consent Form (was translated to Malayalam)



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umanitoba.ca

The impact of stigma and discrimination on individuals and their families living with HIV/AIDS in Kerala, India

#### Statement of Consent

I, -----, have read/ have been read this consent form and accompanying information. I have had the opportunity to discuss this research study with Ms. Maria James and have had all my questions answered in a satisfactory manner. I also understand the risks and benefits involved in this study. Ms. Maria James and/or other staff members at (name of HIV positive Network) have not unduly influenced me to participate in this study. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that the information collected in this study will be kept confidential. I also understand that the data may be published, presented in public forums and may be reviewed by the University of Manitoba Joint-Faculty Research Ethics Board for quality assurance purposes.

Participant agrees to participate in the in-depth interview and to answer the questions asked.

Yes

No

Signature of Participant: \_\_\_\_\_

Name of Participant: \_\_\_\_\_



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### Statement of Consent

In the case of illiterate participants:

I, the undersigned, have witnessed the consent process for the participant, (Name of Participant) and believe that the participant has understood and has knowingly given his consent.

Signature of the witness: \_\_\_\_\_

Name of witness: \_\_\_\_\_

In all cases:

I, the undersigned, have fully explained the relevant details of this research study to the participant and believe that the participant has understood and has knowingly given his consent.

Name of interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of the interviewer: \_\_\_\_\_



