Chapter 2
Understanding and Exploring HIV/AIDS and Discrimination

The previous chapter presented the nature of the problem under investigation, outline of this book, objectives and research questions. Research projects are expected to be methodologically sound, ethically transparent, theoretically underpinned and empirically grounded. This chapter analyzes the methodological and theoretical issues. This research is primarily based on qualitative data obtained from both primary and secondary sources. Interviews with participants were conducted using both open- and closed-ended questionnaires and checklists. The study placed emphasis on in-depth interviews, using ethnographic techniques to obtain information on life histories of immigrants and refugees, both before and after migration. The process was facilitated through partnerships with community organizations that work with immigrants, refugees and asylum seekers on issues of HIV/AIDS. An extensive review of relevant existing literature and databases to consider mortality and morbidity rates preceded the field research.

This chapter is divided broadly into two sections. The first section reviews and critiques the main theories relevant to discrimination and stigma. The second section sheds light on the methodology followed in the research. The objective is to present a theoretical framework that constitutes the basis for achieving the objectives and establishing the main arguments of this book.

Conceptual Issues

Theoretical models have greatly advanced the understanding of how stigma affects people through a broad array of psychological processes and social mechanisms. HsinYang and Kleinman (2008) argue that while these theories have generated much knowledge by highlighting different routes by which stigma acts upon the individual, the majority of theories limit the negative effects of stigma to individuals.

Social psychological models of stigma primarily deal with the aspects of 'social identity' applied to an individual, through examining the situational stimulus that

individuals respond to (Crocker et al. 1998). Sociological models describe the social domains of stigma as occurring when objects in the social world obtain meaning through symbolic interaction (Goffman 1963), while other authors describe these social dimensions as occurring through institutional, structural and hegemonic forms (Parker and Aggleton 2003).

Link and Phelan (2001) indicate that stigma is present when elements of labelling, stereotyping, separation, status loss and discrimination occur together. We employ two stigma-related theories—the concept of 'secondary deviance' (Lemert 1967) and 'modified labelling theory' (Link et al. 1989)—to highlight the possible linkages. The concept of secondary deviance considers whether and to what extent responses to behaviours that are initially viewed as problematic generate additional, secondary differentness that further sets the person apart from the mainstream (Lemert 1967). Thus, to the extent that institutional policies and practices aimed at controlling one set of behaviours disadvantage people with respect to the capacity to work productively, obtain housing, socialize with others and generally function effectively, new elements of differentness are created.

Link and colleagues (1989) built upon and modified the labelling approach of Scheff (1984), although the difference between the two approaches was mainly a matter of emphasis. Figure 2.1 represents the model of Scheff, looking at stigma in relation to mental illness (1984) (adopted from Link et al. 1989). Notable components in the modified approach are the negative consequences of stigma for self-esteem and earning power, as well as vulnerability to new disorders or repeat episodes of existing disorders. When an individual internalizes that he or she is 'a mentally ill person' and incorporates it as a central identity, the labelling of oneself is complete and the consequence is chronic mental illness (Scheff 1966 in Link and colleagues 1989:402).

Thus, a measure of self-perceived discrimination was to ask respondents if any of the following things ever happened to them because of their HIV status by exploring the following issues: (a) You had difficulty renting an apartment or finding housing, (b) you were turned down for a job for which you were qualified or (c) you were refused or charged more for health insurance because of your status. A framework was created to guide the research of stigma themes, experiences and management strategies along the lines described in the literature. The three central columns of the framework (Fig. 2.1) represent enacted stigma, perceived
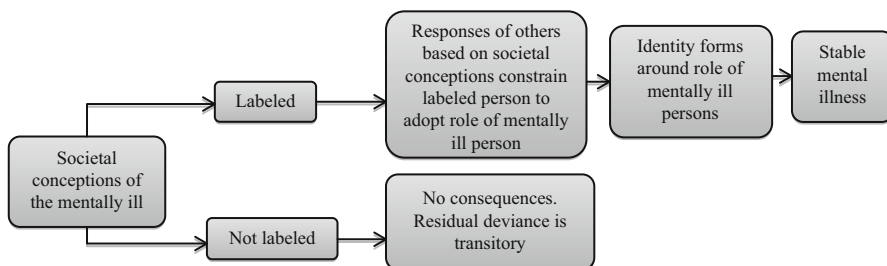
Fig. 2.1 Scheff's labelling approach

stigma and internalized stigma. The headings represent the major themes that emerged in support of each construct, women's experiences of stigma and management strategies they described.[1]

A conceptual framework of stigma would be incomplete without acknowledging both the dynamic nature of stigma and the role of organizations designed to deal with societal problems. These issues represent the newest foci of research, and while that presents a challenge to identifying the forces at work, they cannot be ignored (Basnett 2001; Cresswell 2005; Reidy 1993). While 'institutionalized stigma' (Corrigan and Kleinlein 2007) is not limited to the healthcare system, organizational norms in the healthcare system can, even inadvertently, enact prejudice and discrimination while paradoxically aiming to care for those suffering illness.
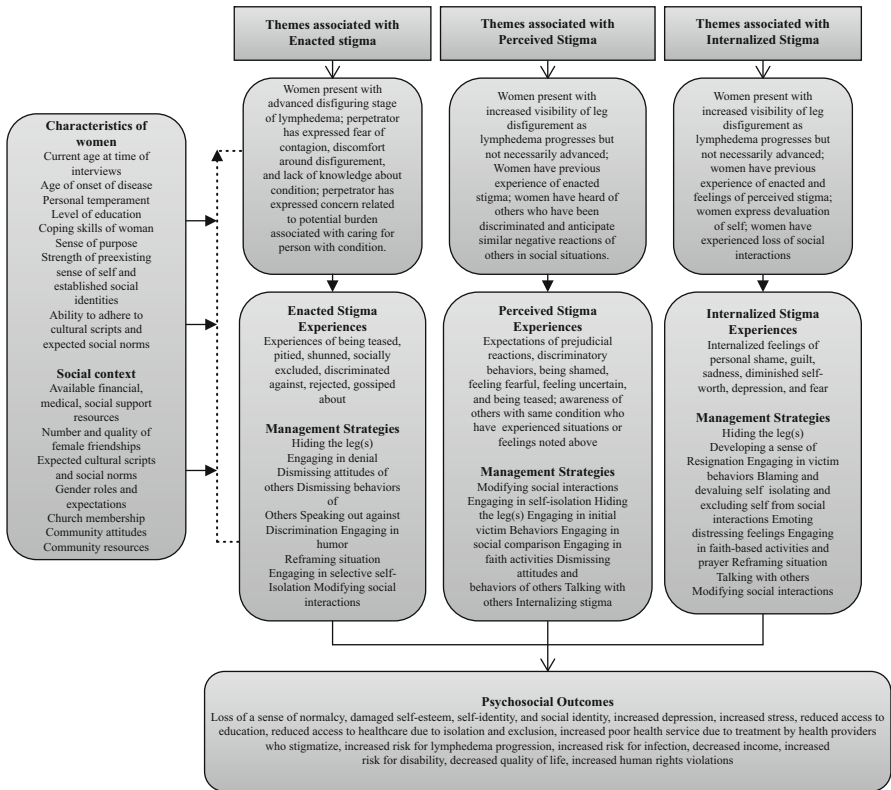
Some societies place great value on appearance, and ugliness and disfigurement are sometimes attributed to sin. It was noted in a study (Ullah 2011), where one participant stated 'that some people say I did something bad that made me ugly'. This is of relevance to PLWHA as the illness, particularly in its later stages, can result in noticeable physical changes and disfigurement. Person et al. (2009) in their study reveal that enacted stigma based on physical appearance can also be a contributor to loss of work and income. They described a case of a young Ghanaian woman with severe disfigurement, who experienced social and economic discrimination and income loss when people refused to shop at her stall following her disfigurement (Fig. 2.2).

These experiences of enacted stigma and feelings of perceived stigma contribute to internalized stigma. In addition, the woman's identification with a sick role, along with the loss of social interactions, contributes to devaluation of the self. Internalized stigma is experienced as a process of self-labelling with feelings of fear, guilt, shame, sadness, depression and diminished self-worth. Internalized stigma of this nature may be further heightened in the case of HIV/AIDS due to the moral judgments often normatively associated with the condition. The moral weight associated with HIV/AIDS stigma in China, for example, is greatly compounded by views common across cultures that immoral behaviours give rise to HIV cases. Mak et al. (2006) in their Hong Kong study revealed much greater stigma among the general population towards HIV/AIDS when compared with tuberculosis and SARS (Mak et al. 2006). Such moral judgments commonly focus on behaviours perceived to be associated with HIV, such as drug use, commercial sex or homosexuality (Fig. 2.3).

Despite the existence of strong legislation in China that protects confidentiality and guarantees access and equality of treatment, stigma continues to take place during healthcare practice (Yang et al. 2005). The continuation of stigma at an interpersonal level, despite legislative protection, illustrates how one's loss of moral standing remains a key. Some physicians in southern China contested treatment of HIV/AIDS patients as 'a waste of medicine on a morally contaminated individual' (Jing 2006:167). Another study in Yunnan Province shows that 30 % of healthcare workers were 'unwilling' and 81 % 'preferred not' to treat HIV sufferers (Hesketh et al. 2005; Yang et al. 2005). Ullah (2011) found similar results in a study in Bangladesh.

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[1] For more on types of stigma, please see Chap. 3.

Themes associated with Enacted stigma

Themes associated with Perceived Stigma

Themes associated with Internalized Stigma

Characteristics of women
Current age at time of interviews
Age of onset of disease
Personal temperament
Level of education
Coping skills of woman
Sense of purpose
Strength of preexisting sense of self and established social identities
Ability to adhere to cultural scripts and expected social norms

Social context
Available financial, medical, social support resources
Number and quality of female friendships
Expected cultural scripts and social norms
Gender roles and expectations
Church membership
Community attitudes
Community resources

Women present with advanced disfiguring stage of lymphedema; perpetrator has expressed fear of contagion, discomfort around disfigurement, and lack of knowledge about condition; perpetrator has expressed concern related to potential burden associated with caring for person with condition.

Women present with increased visibility of leg disfigurement as lymphedema progresses but not necessarily advanced; Women have previous experience of enacted stigma; women have heard of others who have been discriminated and anticipate similar negative reactions of others in social situations.

Women present with increased visibility of leg disfigurement as lymphedema progresses but not necessarily advanced; women have previous experience of enacted and feelings of perceived stigma; women express devaluation of self; women have experienced loss of social interactions

Enacted Stigma Experiences
Experiences of being teased, pitied, shunned, socially excluded, discriminated against, rejected, gossiped about

Management Strategies
Hiding the leg(s)
Engaging in denial
Dismissing attitudes of others Dismissing behaviors of
Others Speaking out against Discrimination Engaging in humor
Reframing situation
Engaging in selective self-Isolation Modifying social interactions

Perceived Stigma Experiences
Expectations of prejudicial reactions, discriminatory behaviors, being shamed, feeling fearful, feeling uncertain, and being teased; awareness of others with same condition who have experienced situations or feelings noted above

Management Strategies
Modifying social interactions Engaging in self-isolation Hiding the leg(s) Engaging in initial victim Behaviors Engaging in social comparison Engaging in faith activities Dismissing attitudes and behaviors of others Talking with others Internalizing stigma

Internalized Stigma Experiences
Internalized feelings of personal shame, guilt, sadness, diminished self-worth, depression, and fear

Management Strategies
Hiding the leg(s)
Developing a sense of Resignation Engaging in victim behaviors Blaming and devaluing self isolating and excluding self from social interactions Emoting distressing feelings Engaging in faith-based activities and prayer Reframing situation Talking with others Modifying social interactions

Psychosocial Outcomes
Loss of a sense of normalcy, damaged self-esteem, self-identity, and social identity, increased depression, increased stress, reduced access to education, reduced access to healthcare due to isolation and exclusion, increased poor health service due to treatment by health providers who stigmatize, increased risk for lymphedema progression, increased risk for infection, decreased income, increased risk for disability, decreased quality of life, increased human rights violations

Fig. 2.2 Conceptual framework of health-related stigma as described by women with HIV/AIDS (Sources: Adopted from Person et al. 2009)

The theoretical framework for the understanding of AIDS-related stigma has developed over a decade of ethnographic research (Castro and Farmer 2005). The psychosocial field has clarified the cognitive processes that lead to labelling and stereotyping. However, as Castro and Farmer have noted in their review of the literature, most psychological research focuses more on:

individualistic perceptions and attitudes than on the broader social context in which such perceptions are grounded. Most of these studies discuss the implications of these beliefs—in terms of misunderstandings, misinformation, and negative attitudes—as far as efforts to change the perceptions of the stigmatizers are concerned. (Castro and Farmer 2005:54)

More recently, some anthropologists (Smith 2011; Adam 2011) have challenged approaches that emphasize cognitivist explanations of stigma rather than the structural violence that generates the social inequalities in which stigma is invariably rooted (Castro and Farmer 2005). According to Stuber et al. (2008), stigma is generally conceptualized as negative labels and pejorative assessments, social distancing and discrimination that can occur when individuals lack power. Much research on
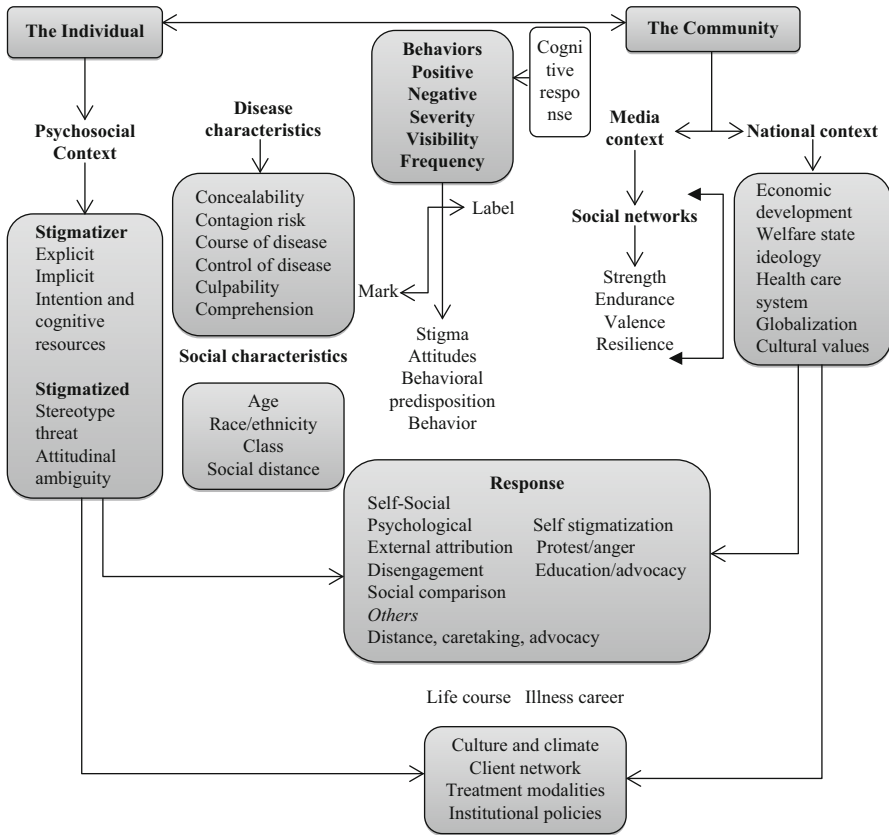
Fig. 2.3 Framework Integrating Normative Influences on Stigma (FINIS) (Source: Pescosolido et al. 2008)

stigma has drawn upon a framework developed by Goffman, which risks viewing stigma as a static individual attitude, rather than a dynamic and contested social process. Castro and Farmer argue that this has 'seriously limited the ways in which stigmatization and discrimination have been approached in relation to HIV and AIDS' (Castro and Farmer 2005:54).

Stigma, Discrimination, Prejudice and Xenophobia: Do They Overlap?

Stigma refers to the situation of an individual who is 'disqualified from full social acceptance' (Goffman 1963). The stigmatized individual is 'reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman 1963:3). The term stigma is used by those who experience it, and those who study it. 'Stigma

researchers generally have two different ways of conceptualizing stigma as a psychosocial stressor, which are distinct from the types of stress induced by inter-personal discrimination' (Stuber et al. 2008:352). The stress induced by stigma has been described as the direction of negative societal attitudes towards the self, or the so-called internalization of stigma. The critique is that stigma researchers tend to describe the adverse effects of stigma on persons labelled with a stigmatized attri-bute, explaining stigma by examining the social cognitive elements of the stigmatizer, who perceives a stigmatizing feature, endorses the negative stereotypes about people with the perceived feature and discriminates against the targeted person.

Perceived or felt stigma is the fear of potential discrimination or enacted stigma, whereby someone with a stigmatizing condition anticipates negative consequences from social interactions (Van Brakel 2006). In internalized stigma, the stigmatized persons impose stigmatization processes upon themselves and suffer consequences of distressing feelings, such as shame or guilt, and behaviours such as self-isolation (Person et al. 2009).

Stigma is a mark separating individuals from one another based on a socially conferred judgment that some people are tainted, and this leads to negative beliefs (i.e. stereotypes), the endorsement of those negative stereotypes as real (i.e. prejudice) and a desire to avoid or exclude persons who hold stigmatized statuses (i.e. discrimi-nation) (Link and Phelan 2001).

Generally two types of stigma are observed: enacted and felt. Enacted stigma refers to actual discrimination or unacceptability, whereas felt stigma refers to the fear of such discrimination (Scambler 1998). Causes, actions and consequences of these types of stigma differ. Tuberculosis (TB) patients who are HIV sufferers expe-rience enacted stigma from the community throughout their life. In contrast, most HIV–TB patients experience only felt stigma during a short period. For the HIV sufferers, the enacted stigma greatly affected the patient and the family, psychoso-cially as well as economically. This study found that the common expressions of stigma towards HIV sufferers include keeping a distance from the patient, refusing foods cooked or sold by the patient and prohibiting the patient from participating in social gatherings (for details, see Chap. 4). The type and strength of stigma were closely linked with the type and strength of the categories 'defining oneself' and 'human bond' (Fig. 2.4).

> In Canada, we want to highlight that the human rights of the HIV/AIDS-infected groups are extremely marginalized by laws and policies. (Sandra Chu, a senior policy analyst at the Canadian HIV/AIDS Legal Network 2012)

Increased attention by researchers to the targets of prejudice in the 1990s (Crocker and Garcia 2006) resulted in combining theories of prejudice with theories of stigma. The concepts of stigma, prejudice and discrimination increasingly are used by the same authors in the same texts (Levin and Van Laar 2006). The undesired 'differentness' of a stigmatized category such as race can lead others to both turn away from and actively discriminate against the stigmatized (Goffman 1963). Thus, discrimination becomes an important component of stigma (Link and Phelan 2001). Where social inequalities exist, it is a key feature of intergroup relationships and
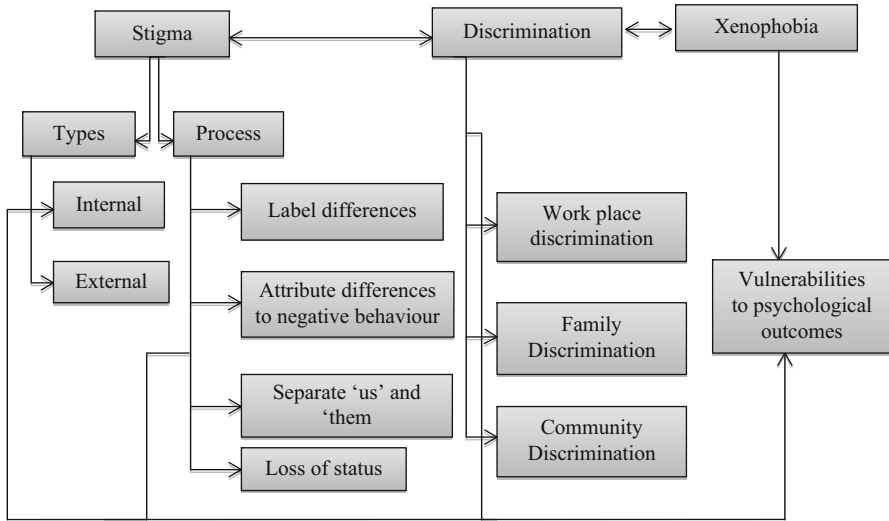
Fig. 2.4 Xenophobia and human rights dynamics (Source: Authors)

serves to reinforce the symbolic boundaries that separate social groups from one another (Jackman 1994).

Prejudice and discrimination are believed to be important contributors to the production of health disparities (IOM 2002; DHHS 2003; USAID 2000). Goffman's stigmas, blemishes of individual character and abominations of the body appear to cover every imaginable form of stigma or prejudice. Similarly, several of the prejudice models are not tied to particular in- and out-groups, and social identity theory is based on research showing that arbitrarily identified characteristics can serve as the basis of discrimination (Tajfel 1970). Clark et al.'s (1999) analysis of the stressful consequences of discrimination should apply to any characteristic that is the target of stigma or prejudice. However, in other cases, this substitution does not make sense. 'Prejudice reflects a general negative evaluation or orientation to a group or a member of a group, whereas stereotyping involves the association or attribution of specific characteristics to a group and its members. Both prejudice and stereotyping can produce discrimination, an unfair or unjustified group-based difference in behavior that systematically disadvantages members of another group' (Dovidio et al. 2008:478–9).

The studies on prejudice versus stigma give rise to another question. Phelan et al. (2008:361–2) ask 'why do particular characteristics become the object of stigma and prejudice, and are there different reasons for different characteristics?' Many of the models examined emphasize that the objects of stigma and prejudice are socially constructed and vary dramatically across time and place (*Ibid.*:362). Phelan, Link and Dovidio believe the reasons that particular characteristics are selected as targets of stigma and prejudice may represent an important variation that was revealed by the comparison of stigma and prejudice models. Goffman adds that there are many

forms and degrees of stigma which were left unexplored and portrays stigma as a universal human experience (1963:127). He explains the incidence of stigmatization by stating that '[W]e construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class' (1963:5).

Disclosure and Racial Disparity

Racial disparities in health may be explained with reference to the differences between genetic populations' susceptibility to different diseases (Pettaway 1999). Socioeconomic differences may directly affect access to healthcare (IOM 2003) and indirectly influence health status through the impact of education on health literacy and health practices (Sentell and Halpin 2006). Studies on Canada suggest that the experience of unfair treatment, unrelated to race, induces stress and adversely affects psychological well-being for multiple social groups (Dion 2001). Empirical studies on the association between perceived discrimination and some indicator of health (Paradies 2006) found a positive association between discrimination and indicators of morbidity (Ren et al. 1999).

A study conducted by the National Center for Health Statistics (NCHS) on racial and ethnic disparities has attracted the attention of scholars in a range of professions and academic areas. Research shows that people who self-identify as 'White' are healthier than members of all other racial/ethnic groups, with the exception of people who self-identify as Asian or Pacific Islander (NCHS 2004). However, in the USA, obvious expressions of prejudice towards minority groups, and towards African Americans in particular, have declined substantially over the past 50 years. Bobo argues that 'the single clearest trend in studies of racial attitudes has involved a steady and sweeping movement toward general endorsement of the principles of racial equality and integration' (2001:269). Furthermore, there is some evidence to suggest that people rarely report experience of racial prejudice (Schuman et al. 1997). At the same time, however, racial disparities remain in economic (Blank 2001), physical (IOM 2003) and psychological health services (Surgeon General of the United States 2001).

The processes of conceptualization of stigma suggest that stigmatization occurs in the context of social forces that are mobilized to maintain specific dynamics of power (Parker and Aggleton 2003). The symptoms of illness 'kept many women out of the job market, locking them into poverty. The inability to work and earn money adds to the pain of living with a mental illness' (Collins et al. 2008). Within this study, there are stories about fathers who punish or rebuke their daughters for marrying darker men. Tensions between darker, poorer branches of a family and fairer, more affluent relatives; friends who marvel at the beauty of a child born with light skin, blue eyes and blonde hair; and perceived rejection of their own dark skin by in-laws with 'good hair' are common. Some of the participants in this study rejected these ideas, but admit that their relatives' ideas about race have influenced their actions in relationships. While women incorporate these experiences into their stories

of relationships, few explicitly acknowledge experiencing race-/ethnicity-based discrimination (ibid). This study indicates the ways in which race, gender and ethnicity further impact the experience of illness, stigma and discrimination. Mentally ill women face a range of negative experiences, such as sexual health risks, that cannot be reduced to their mental illness, but to the intersection of these multiple stigmatized identities (Collins et al. 2008). Efforts to combat stigma and prejudice are ineffective if they do not account for multiple and interlocking identities (Crenshaw 1996). Similarly, the past 25 years of the AIDS epidemic have demonstrated that people who are vulnerable to gender inequality, racism and stigma carry the greatest burden of disease (Farmer 1997).

Given the degree of discrimination and prejudice experienced by PLWHA, social stigma often functions as a barrier to disclosure of one's HIV status. Crocker offered two interesting motivational factors in relation to disclosing one's HIV status: egosystem and ecosystem. Egosystem is made up of self-serving benefits, which boosts one's image. In constructing desired self-images, people present themselves in a certain way to get other people to see them as having particular qualities, so they can obtain resources such as relationship partners, jobs or admissions to college (Baumeister et al. 1996). The ecosystem goals focus on supporting others by avoiding being selfish, self-centred and harmful to others. We agree that fear of rejection leads people to conceal a stigma if they have egosystem goals, but not if they have ecosystem goals. When people have egosystem goals, they tend to enhance self-images and obtain desired social outcomes such as acceptance. Consequently, when stigmatized people expect rejection if they reveal their stigma, they attempt to conceal it from others. Ecosystem goals for disclosing stigmatized identities include consideration of the needs and well-being of others, in addition to the self. Instead of focusing on protecting the self, ecosystem goals focus on supporting others. People with egosystem motivations might be willing to risk disapproval for the sake of creating authentic relationships with supporting others (Crocker 2011). Disclosure and consequent depression have gender implications. Women who have been historically deprived of their due rights and disempowered are more exposed to varied kinds of stressors than men.

The most common barriers to disclosure that were mentioned by participants include fear of abandonment, fear of rejection/discrimination, fear of violence, fear of upsetting family members and fear of accusations of infidelity.

We consider the gendered effect of lying and how HIV status intersects with the power imbalance at the root of sexual assault. We discuss the tension between the need for women to protect both their medical information and their sexual integrity.

The subversion of self-esteem, shame and the desperate need to hide are the central elements of stigma and discrimination that emerge from disclosure of status (Bayer 2008a). Jennifer Crocker has made clear that the extent to which at least some of those who are objects of discrediting could resist the burden of prejudice and discrimination (Crocker, cited in Bayer 2008a, b:464). Healthcare providers are, therefore, faced with the challenge of how to address stigma in its own right if they want to maximize the quality of life for those they treat and maintain the benefits of treatment (Link et al. 1997) (Fig. 2.5).

Fig. 2.5 Impact of stigma
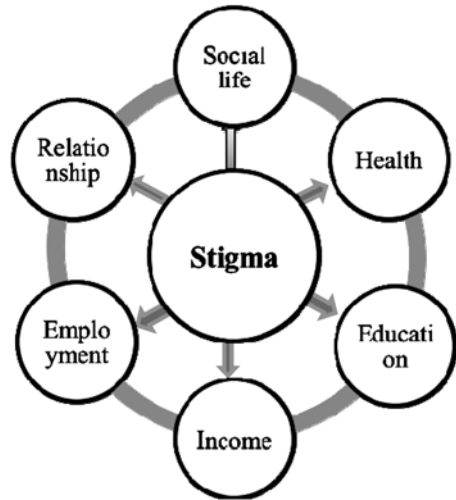
Stigma causes psychiatric morbidity by the fact that it restricts social participation. These variables are hard to measure quantitatively. Measurement of self-esteem, depression and social participation is therefore highly relevant to monitor the impact of stigma reduction interventions (Cardol et al. 1999). The emotional damage, for instance, caused by stigma can have deep ramifications in a person's life. The quality of life can be severely affected in terms of having problems in finding a life partner, building relationships and gaining employment. As an obvious effect of stigma, isolation deprives an individual of education, economic opportunities, socialization, sharing pain and grief with others and access to finance. These facts have a multiplier effect on the lives of those facing stigma. They may contribute to increased disability and reluctance to continue medication and obtain treatment.

Refugee Status Determination as a Burden

For those PLWHA who are refugees or asylum seekers, the refugee status determination (RSD) process itself can be the cause of additional stress and perceived discrimination. Therefore, the refugee status determination process merits attention. This analysis illustrates the extent of the burden the asylum seekers continue to carry until they are successfully granted refugee status. It is pertinent to outline the steps in this process for a better understanding of the potential refugees' experience of tribulations to go through the process. While it is true that claiming asylum in Canada is an easier process than in many other countries for resettlement, it is still a lengthy, complex and cumbersome process. Some reports suggest that some may be using Canada's asylum system to 'jump' the immigration queue (Brennan 2010). Nonetheless, claimants from designated countries of origin are still entitled to

receive a fair hearing at the Immigration and Refugee Board (IRB). Hearings on these claims are expected to be held within 60 days, as opposed to the 90-day time frame for claimants from those countries that are not so designated.

In the event of a negative decision, claimants from designated countries of origin will have an expedited appeal process before the Refugee Appeal Division (RAD). These appeal decisions are expected within 30 days, unless a hearing is held, as opposed to the regular processing time, which is 120 days for all other claimants. A country can be considered for designation only if: the number of claims for refugee protection is equal to or greater than the number of claims specified in the regulations that will be developed later and the rate of acceptance by the RPD is equal to or lower than the rate set out in regulations. In addition, the following criteria will also be taken into account: the human rights record of the country and the availability in the country of mechanisms for seeking protection and redress (Government of Canada 2011).

The IRB considers a number of factors, including the protection available in the country of the claimant and the nature of the claim itself. The IRB then selects one of three possible ways to decide the claim: a fast-track expedited process, a fast-track hearing or a full hearing (Brennan 2010).

The fast-track expedited process applies to claimants from certain countries or for certain types of claims. The refugee protection officer interviews the claimant and makes a recommendation about the claim. A favourable recommendation is forwarded to a member who will decide if it should be accepted without a hearing. A hearing is held if the claimant is not granted refugee protection through the expedited process. Fast-track hearings are held for claims that appear to be simple because they may be decided on the basis of one or two issues. A refugee protection officer does not attend these hearings but may assist the member to ensure that all relevant evidence is presented. Representatives of the UNHCR may observe the hearing. The IRB will assign the claimant to one of these processes—the fast-track expedited process, a fast-track hearing or a full hearing.

Interdiction: These measures block refugees fleeing persecution, many of whom are forced to turn to human smugglers to help them reach a safe destination. In 2003, the Canadian Border Security Agency reported 6,439 airline interdictions.

Judicial Review and Stay of Removal: There are widespread claims that refugees are vulnerable to exploitation by incompetent and unscrupulous lawyers and immigration consultants. The British Columbia government withdrew legal aid for refugee claimants in 2003. Even in places where legal aid is available, it rarely covers a review of decision. If a person is accepted after the process, it only means he/she can temporarily reside in Canada. This does not provide a refugee status or permanent residency. The success rate for a judicial review is between 5 and 10 % (Noii-Van 2007).

Safe Third Country Agreement: The adoption of Canada's 'None Is Too Many' policy on December 29, 2004, effectively closed its land border to refugees, preventing at least 33 % of all refugee claims from ever being heard.

Deportation: Failed refugee claimants are called for an interview with an enforcement officer who sets a deportation date. Often the deadline is within a couple of days, and this can be followed by confiscation of the claimant's health and social insurance

card. They may be detained without notice if they are visibly upset or display a high degree of stress. There are arguable claims that Canada regularly deports people to unsafe countries (Noii-Van 2007). Procedure to deport refugees to an unsafe condition is in clear violation of Canada's obligations under international law.

Without Legal Status: There are up to 200,000 people living without legal status in Canada which may mean that their application for status has been made but no decision has been reached or was turned down. Living without status may also mean that no application has been made at all, either due to fear, misinformation or lack of assistance and resources. It may also mean that someone's arrangement for sponsorship or work permit relationship has broken down. Canada has refused to resolve the situation faced by people without status in Canada including long-term residents who have been living in Canada for years because of a moratorium on removals. Entire families live in a state of constant stress and fear. Workers are exploited. Children of non-status immigrants, whether Canadian-born or not, are denied the right to education. Children and entire families lack adequate and affordable medical coverage. Some refugees have been forced to seek sanctuary in churches across Canada. In March 2004, Canada violated this sanctuary by arresting Mohamed Cherfi in a church (Canadian Council for Refugee—CCR 2005). In 2004, the immigration minister, Judy Sgro, criticized churches offering sanctuary and incorrectly stated that refugee claimants have 'between 6 and 20 avenues of appeal' (Canadian Council For Refugee—CCR 2005:2).

Resettlement: Through the UNHCR, Canada chooses a limited number of refugees who meet certain criteria to resettle in Canada. The country accepts less than 0.1 % of the world's refugees. In 2004, Canada reduced the funding for these refugees and reduced the number to 7,300. Thus, refugee applicants must have enough money to support themselves through government or private sponsorship. Many applications for refugee status are denied because they have small children or have survived torture and therefore do not meet the successful establishment criteria (Noii-Van 2007).

CD4 Count Dynamics

The level of discrimination and stigma often is determined by whether or not the condition of the HIV sufferer has degenerated into AIDS. It is therefore important to understand the transformation stages and the clinical progression towards AIDS. Generally, the clinical indication of this progression relies upon the CD4 count as a measure. CD4 counts and HIV viral load are the best indicators known so far for monitoring the degree of damage to the immune system from HIV and the risk of clinical progression to AIDS. CD4 are the main cells in the body affected by HIV. A normal CD4 count in a person who is HIV− can range from 400 to 1,600 (Srinivasula et al. 2011).

There is another way to check the status. HIV reproduces in the bloodstream. The viral load is a measure of the amount of HIV virus in blood, expressed either as

a number ranging from 48 to 10,000,000 copies/ml or as the log of the viral load. The higher the number, the more quickly HIV will damage the immune system and the more likely one is to feel sick from the HIV infection. When the viral load rises to over 100,000 copies/ml (log 5.0), the medical provider may prescribe medications to combat HIV. These medications bring down the viral load, aiming for less than 48 copies/ml or 'undetectable' (Vajpayee and Mohan 2011:801). The viral load is expected to decrease by 1.0 log after one month on the medication.

White blood cells are produced by the body to fight off infection as a part of the immune system. CD4 cells are a type of white blood cell called lymphocytes, which have a marker on the outside of the cell called a CD4 marker. These are also called 'T cells' and occasionally 'T helper cells'. These are the cells that HIV infects and destroys (Vajpayee and Mohan 2011). Usual CD4 counts for a newborn baby are around 3,000–5,000 and for an adolescent or adult about 700–1,200 cells/ml. If the count falls below 200 cells/ml, the patient is diagnosed with AIDS. This is not a different disease from HIV infection; instead, it means patients are vulnerable to unusual infections that other people do not get, called 'opportunistic infections'.

Usually a medical provider may start medication to treat HIV if the CD4 count falls below 350 cells/ml. However, one can start medication before the CD4 cells drop below 200 because the body responds better to medication when they are commenced at above 200 cells/ml. HIV medicines attack the HIV virus in the body, allowing the body to produce more CD4 cells. The amount of CD4 cells varies and may rise and fall. To determine if a change in CD4 cells is significant, the medical provider may refer to the 'CD4 percentage', that is, the percentage of lymphocytes with CD4 markers on the surface. For example, if the CD4 count was 400 (18 %) and then was 325 (19 %) at the next check, the HIV infection is not getting worse and hurting the immune system more because the CD4 percentage is stable or improving. When the CD4 percentage is less than 15 %, one is still vulnerable to opportunistic infections and should take medication to prevent sickness (Rodriguez et al. 2005; Zhou et al. 2010).

Methodological Issues

Research on refugees is a difficult undertaking, and there is no established method for examining both refugees and HIV/AIDS with a single framework. The challenging nature of research with refugees is made more complicated by the precarious conditions under which refugees reside. Moreover, there are additional issues of sensitivity involved in undertaking research on HIV/AIDS. This study aimed to address a gap in the literature and prepare the ground for designing research based on geographical and political context, and propose alternative strategies for addressing methodological challenges. This is expected to be an important contribution to the methodological underpinnings of refugee research. Ethical issues pose a significant challenge as this research involves human subjects and deals with delicate and sensitive issues. This section also explains the process for

handling confidential research material, developing intersectional analyses and answering specific questions related to multi-strategy research design that are very important for researching refugees.

Methodology

A constructivist grounded theory (GT) approach has been selected as a theoretical and methodological framework to guide this research. Grounded theory is a widely used qualitative research technique that explores social processes and reveals how people anticipate and respond to various life experiences. This approach is crucial for this study as it intends to examine the life experience of the research subjects. GT seeks to inductively distil issues of importance for specific groups of people and creates meaning about those issues through analysis of theory (Mills et al. 2006). Unlike the original grounded theory, first developed by Glaser and Strauss (1967), constructivist grounded theory is not 'objectivist' (Charmaz 2003), which recognizes that the 'viewer creates the data and ensuing analysis through interaction with the viewed' (Charmaz 2003:273), and therefore the data does not provide a window on an objective reality. Thus, the background of researchers influences their interpretations of the data. They cannot avoid being influenced by 'disciplinary emphases' and 'perceptual proclivities' (Charmaz 2003:259).

Grounded theory seeks to foster 'the development of qualitative traditions through the study of experience from the standpoint of those who live it' (Charmaz 2000:522). Rather than beginning with a pre-established theory, a constructivist grounded theory approach aims to develop theory grounded in data that were systematically gathered and analyzed (Strauss and Corbin 1998:25). Therefore, the approach is appropriate for this study, particularly because there is scant information about the life experience of Asians living with HIV in North America. The study has, therefore, designed with the objective of understanding the lifestyle and psychosocial experience of Asians living with HIV. In order to identify a culturally appropriate HIV prevention and treatment strategy for this population, it is important to understand the way in which Asians living with HIV in North America operate within their social and systemic community.

The Interpretative Phenomenological Analysis (IPA) yields good results in analyzing qualitative data. One of the methods this research uses to interpret and analyze field data is embedded within interpretive phenomenology. The primary advantage of this technique is that it facilitates, by exploration, delving into the personal experiences and perceptions of research subjects (Creswell 2003). This technique is useful because of its ontological and epistemological significance and helps to ensure that the participants' subjective experiences are valued and their experiences can be understood by interacting with and listening to them (Fouché 2005). The objective of the discussions with the participants was to understand their daily ordeals in carrying the burden of the disease and related tribulations of stigma and discrimination. Qualitative research designs are best suited to this task of

understanding the complexities of lived 'experiences from the perspective of those who live it and in order to understand this world of meaning, one must interpret it' (Willig 2001:150). Interpretive researchers are interested in what is meaningful or relevant to the participants and how these participants experience daily life. Neuman (2000) argues that social life is a socially constructed meaning system that is based on social interactions and people's definitions of reality (Neuman 2000).

Since the primary objective of this research is to understand the perceptions and perspectives of the PLWHA in relation to enduring stigma, a phenomenological approach is appropriate. This approach helps researchers identify people's perceptions, perspectives and understandings of a particular phenomenon (Creswell 2003; Fouché 2005). The most interesting aspect of this method is the three distinct phases of contemplation: epoche, phenomenological reduction and imaginative variation (Leedy and Ormrod 2005). Epoche is the suspension of presuppositions, assumptions, judgments and interpretations with the intention of being fully aware of what is being presented (Willig 2001). Phenomenological reduction is the description of the phenomenon itself, which includes describing the physical features and the experiential features (Willig 2001). Imaginative variation involves accessing the structural components (such as time, space and social relationships) of the phenomenon (Leedy and Ormrod 2005).

Sample Frame and Sampling

Determining the sample frame is crucial to generating the sample and thus the quality of the analysis. It is a major determinant of the extent to which the samples are representative of the population (Bilsborrow 1998:89). There are currently no reliable statistics on Asians living with HIV in North America in general and South Asians in Canada in particular due to the fact that the disclosure and testing rates for the community are low. In the absence of a list of actual estimates of South Asian living with HIV in Canada, there remains a challenge as to how the sample frame could be defined. The geographical region identified as South Asia includes eight countries—Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan and Sri Lanka. For convenience of sampling, this study covers immigrants from Bangladesh, India, Pakistan and Sri Lanka.

A number of factors are considered to determine the appropriate sample size for a study. In quantitative approaches, they include the level of precision, the level of confidence or risk, and the degree of variability in the attributes being measured (Miaoulis and Michener 1976). The level of precision—sometimes labelled as the 'sampling error'—is the range in which the true value of the population is estimated (Israel 1992; Smith 1983). However, there is always a chance that the sample obtained does not represent the true population value. Degree of variability refers to the distribution of attributes within the population. The more heterogeneous a population, the larger is the sample size required to obtain a given level of precision. The less variable (i.e. more homogeneous) a population, the smaller the sample size

would need to be (Cochran 1963; Mian 1999; Sudman 1976). Given the challenges of knowing the sample frame, we had to choose snowball technique in order to select the sample.

Recruitment of Participants and Interview Process[2]

Most interviews were conducted face to face in person. A few organizations that claimed to have been working with the PLWHA promised to lend assistance in conducting this research. After two years of consistent attachment and constant communication with those organizations, they were unable to present any of their clients to the authors. This is obviously a part of challenge inherent in such kind of research. Participants were recruited through a snowball and purposive sampling method. Some interviews were conducted online through various chat rooms used exclusively by PLWHA. In order to recruit a diverse group of participants, the recruitment process utilized a sample fraction for ensuring the inclusion of a proportional number of South Asian nationalities. Interviews were conducted at different times of the day to ensure accessibility and convenience for the participants. Participants were provided with information on the study, research goals and methodology, and efforts were made to develop trust and rapport with potential participants. Familiarity with South Asian culture and language and personal associations and knowledge made it easier for us to connect with participants and facilitate the interviews (for more information, see Appendix).

Based on the literature and knowledge of South Asian cultures, some specific issues were identified for approaching the research in a culturally appropriate manner. These included issues related to family, social support, dating, relationships, sexuality and awareness about STIs and safer sex practices (Eysenbach and Till 2001). Gender issues are also important here, as this is highly relevant in terms of women's ability to negotiate safer sex and men's feelings of conforming to certain standards of masculinity in regard to sexuality. We used these thematic topics as a general guideline during the interviews to explore participants' lived and psychosocial experiences. However, no specific set of questions were developed for the interviews; rather, unstructured, open-ended questions were used to explore these issues. In doing so, it was possible to solicit not only the factual information required for the study but also allowed participants to attribute meanings and interpretations to events and relationships in their own terms and discuss issues that are most relevant and important to them (Mann and Stewart 2000). This method of unstructured in-depth interviewing was useful in generating insights about participants' experiences of themselves in their own worlds. It also provided an opportunity for us to hear participants' stories in their own terms (Anderson and Jack 1991).

In many Asian cultures, sex and sexuality are sensitive topics that are often excluded from open discussion. As in most cultures, there are many South Asian

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[2] For further details on the interview process, please see Appendix.

men who are attracted to other men physically, psychologically and/or emotionally, and yet did not identify themselves as gay, bisexual or even as MSM. One of the most vulnerable exposure categories in terms of HIV globally is MSM. The sexual practices of MSM include anal sex, which—when practised without protection—carries a higher risk of transmission than unprotected vaginal sex. Unlike communities of openly gay men who are routinely targeted under HIV/AIDS prevention programmes and campaigning, MSM are often excluded or neglected in such interventions, and therefore high rates of transmission and infection remain among this group. Since the onset of the HIV/AIDS pandemic, consistently high levels of HIV infection have been found among this group.

Given the sensitivity of these issues, particularly pertaining to sexuality and sexual practices, rapport building with the interviewees was critical for allowing participants to discuss these kinds of issues without feeling embarrassed or being subjected to judgment. Moreover, it was important that participants were interviewed in locations they found comfortable, to 'allow communication to flow with a minimum of self-consciousness and self-restraint'. Moreover, by feeling more comfortable and less restrained, participant–interviewer interactions were expected to be more direct and may led participants to 'greater self-disclosure even about sensitive issues' (Mann and Stewart 2000:200).

Each interview lasted approximately one and half hours. Before the interview began, the interviewer carefully explained the research goals and methodology to every participant and informed them that they could withdraw at any time during the interview. A letter of consent was reviewed with each of the participants before starting the discussions. To ensure that they met the criteria for participation, each participant was asked to ethnically identify him or herself before the interview began. People who work during the day prefer to be interviewed at night, while students and young people who live with their parents tend to interview more often during the day than at night while their parents were not home. These aspects were given careful consideration.

It is important to nail down the process followed in interviewing using semi-structured questions. Marvasti (2004) and Smith and Osborn (2003) mentioned five phases of this process, only three key phases were followed in this research. Primarily, preparation for the interview involved the construction of an interview guide for field research (Marvasti 2004; Smith and Osborn 2003). The second stage involved serious consideration of the relationship between the interviewer and interviewees, that is, establishing relationships, conducting interviews and dealing with contingencies if the interview did not proceed according to plan. Finally, termination took place when the conditions of the research agreement were met, the proposed objectives were achieved and the saturation point was reached. In some cases, interviews were terminated and participants were offered the opportunity to have a debriefing and feedback session.

The basic principles that were incorporated in all the interviews included respect and courtesy, acceptance and understanding, confidentiality, integrity and individualization. The strategies included observation (both participatory and non-participatory), and care was taken to maintain ethical norms, timeliness and clear

communication with participants. The objective was to address any conflict or misunderstanding promptly. Simple observations throughout the fieldwork process were recorded and included in the reflexive notes. These included describing the research context and the participants, noting participants' nonverbal behaviour during the interviews, interpreting the situation and including a reflexive analysis. These simple observations were not subjected to the stages of Interpretative Phenomenological Analysis (IPA), but were used for their value in describing the research sample, setting and for reflexive insights. Unlike participant observation, this simple observation is not time consuming or labour intensive and does not create an enormous amount of data (Strydom 2005).

Snowballing

The snowballing method was not intended at the outset in order to keep the sample as random as possible. Snowballing carries a risk of adding bias to the data. This technique of sample selection has gained popularity among researchers. However, this technique is useful in difficult research conditions and for obtaining information from population that is hard to reach. As research progressed, the difficulty of accessing the target population group was increasingly realized. It was not easy to collaborate with organizations working among HIV/AIDS patients. Incidentally, an enthusiastic, helpful and cooperative person who became infected around 8 years ago agreed to be interviewed. This person had already been interviewed by a number of researchers. This led us to a number of his friends who were willing to share their experiences. Thus, there was an inadvertent effect of a snowballing technique, and we consider it to be a by-product of the constraints imposed by the nature of this particular research context.

Online Research Participants

The constraints in accessing our target population compelled us to consider alternative methods, and we resorted to exploring online communities and support groups for PLWHA. This was not a planned or anticipated method for accessing the target sample, yet it proved to be very effective in reaching the population that helped us gain insight into another aspect of their life experience. This channel was useful in providing a safe place to find respite from stigma, seek support and build community. In many of these sites, users can upload their profiles onto the system, and they can only be seen by other members and they are able to conceal them at any time. It cannot be claimed that complete interviews were obtained from the people on these sites. Rather, it was possible to complete a few in-depth interviews, while many others were left partially completed. It should be stated that the half-done interviews were not considered as part of the sample. Some participants did not feel well and had to

leave the chat room, and it was not possible to reconnect with them. These chat rooms have separate rooms for HIV sufferers, and that helped to identify the target population. It took a few days to get to know some of the participants. Once a certain level of rapport was achieved, participants agreed to be interviewed. The same procedure and standards (such as confidentiality and ethical issues) were maintained for the online interviews as for those conducted face to face.

The chat rooms could be accessed by any person from anywhere in the world. Therefore, the identification of the participant depended on his and her own desire to disclose honestly. We confirmed that they were living in Canada, that they were of Asian origins (especially from South Asia) and that they were willing to participate in the study. Interviews were conducted after obtaining their consent. Online chat was not considered as interview, but it in fact helped us to get to know each other and at some point we exchanged our telephone numbers and Skype IDs. Some of them agreed to meet and to be interviewed face to face. Some of them were interviewed via Skype. The sites we explored ranged from those broadly targeting gay men wanting to meet one another to those dedicated to PLWHA.[3]

Interviews

Neither unstructured nor semi-structured interview restricts the participants to specific questions spelled out on the questionnaire; rather it offers flexibility and easy integration into the research context (Greeff 2005; Silverman 2006; Smith and Osborn 2003; Ullah 2012). This technique was used to gather information about the social lives of PLWHA (Silverman 2006), to understand the participants' lives and to generate in-depth information (Greeff 2005; Willig 2001). Participants have the opportunity to further expand, modify and add to their answers throughout the semi-structured interview process. The freedom is also there if they need to clarify anything (Marvasti 2004). During the process of narrative interaction, the researcher and participant give and take from each other, and this underlines the complexity of

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[3] www.Gay.com chat room

http://www.hivandsingle.com/

http://www.experienceproject.com/groups/Am-HIV-Positive/19015/forum

http://www.13km.com/—this is an amazing site which is absolutely designed for HIV-positive persons.

www.HIVDating.info—HIV dating site reviews, free to join the best HIV dating service for HIV-positive singles dating and dating with HIV-HIV POZ personals for HIV POZ dating

www.HIVMingle.com—online community for HIV-positive dating, where one can meet other HIV-positive singles for friendship, relationships, love and chat.

www.HIVPositiveMagazine.com—this site welcomes all HIV positive. The mission of this site is exactly the same as the mission of the print version of HIV Positive magazine. The mandate of this site is to help one live a long, productive, fantastic life with HIV.

MenLivingWithAIDS.ning.com—this site is for guys who are infected and their friends.

SOFLpozgroup.com—this is a social group for HIV gay men ages 21–40 in South Florida who would like to meet others like themselves.

the area of interest being explored and, in turn, gains density as the conversation about meaning ensues. Therefore, the interview becomes the 'site for the construction of knowledge, and clearly the researcher and informant produce this knowledge together'. In the construction of such knowledge, the information generated needs to reveal depth, feeling and reflexive thought (Mills et al. 2006).

The semi-structured interview allows for flexibility, unlike the structured interview where questions are adhered to in a consistent and highly structured manner. In structured interviews, the insight gained into the interviewees' world is limited to responses given to the questions that are being asked (Greeff 2005; Marvasti 2004). While semi-structured interviews provide for the relatively systematic collection of data within a reasonable time frame and, at the same time, ensure that important data is not omitted, the in-depth interview is a time-consuming method that generates vast amounts of data that are difficult to manage and organize (Silverman 2006; Smith and Osborn 2003).

Semi-structured interviews are extremely helpful in exploratory studies in furthering and developing the ongoing research questions and framework. In exploratory research, there is ample room to clarify concepts and problems, and it allows for the establishment of a list of possible answers and solutions, which in turn facilitates the construction of more structured interviews. Semi-structured interviews also facilitate the reformulation of ambiguous questions and the elimination of superfluous ones and allow for the discovery of new aspects of the problem by exploring in detail the explanations supplied by participants (Bless et al. 2006).

It should be mentioned that there are some problematic sides of this technique as well. While it offers flexibility and freedom, the personalities of participants may be overly deterministic in the answers being given (Bless et al. 2006). This was obvious during the interviews. At the same time, there is a risk that the interviewer plays an overly deterministic role in influencing the data by recording the information inaccurately—either by translating the ideas of the participant into the interviewer's own words or interpreting the answers according to his/her 'own views or by recording only a summarized version of the answer' (Bless et al. 2006:12). This research required extra care to ensure objectivity. The semi-structured approach to in-depth interviews required more time than it could have been in using a structured questionnaire. However, this was offset by the quality of data gathered.

Data Processing and Analysis

Participants were purposively selected to generate data that fills conceptual gaps in the development of a formal theory. Data collection and analysis proceeded simultaneously and in an interactive manner. Analysis relies upon an inductive approach 'to develop open coding categories and then, through axial coding, to interrelate these categories' that represent phenomena (Creswell 1998:209). The transcripts of the interviews were carefully read, and coding conducted line-by-line to highlight

key phrases that represent themes. Similar coded phrases were then grouped together to develop a list of emerging themes and categories. This helped to further reduce themes and create clusters.

Measuring Stigma

In analyzing the data generated, a key lens of analysis was the experience and perception of stigma by research participants. In order to theoretically organize the experience and perception of stigma, the study focused upon five theoretical domains of stigma: attribution theory and stigma, fear or peril and stigma, policy and stigma, power and stigma, and social norms and stigma. This framework is aligned with Van Brakel's (2006) five categories of health-related stigma: the experience of actual discrimination (enacted stigma), attitudes towards affected people, perceived or felt stigma, self or internalized stigma and discriminatory practices in (health) services.

Stigma and health conditions have become inseparable phenomenon (Van Brakel 2005). HIV is inextricably associated with stigma primarily because of the prevailing discriminatory idea that HIV is a disease that is contracted through immoral activities. Theories of stigma suggest that people who have contracted a stigmatized illness through methods beyond their control (e.g. a person who has contracted HIV through a blood transfusion) are associated with less blame and anger than towards someone who contracted the illness through high-risk behaviours, which in turn guides the inclination to either punish or assist the person (Corrigan 2000). The psychosocial consequences of stigma generate indescribable torment to the stigmatized (Frist 1996; Nyblade et al. 2003).

The effects of stigma include psychological stress, depression and other psychiatric morbidity, fear, marital and relationship problems, other social participation restrictions such as loss of employment or reduced employment opportunities and reduced education opportunities, increased (risk of) disability and advanced disease and risk of being victims of violence. Some examples of the effects are delay in diagnosis and treatment resulting in continuing risk of disease transmission in case of infectious diseases and in more severe morbidity and poorer treatment prognosis in most conditions (Van Brakel 2005; Jaramillo 1998; Nicholls et al. 2003; Piot and Coll Seck 2001). Concealment may result in continued risk behaviour and failure to embrace preventive behaviour among sufferers of conditions such as HIV/AIDS (Adetunji and Meekers 2001; Rahlenbeck 2004) and in poor treatment adherence or default from treatment, as has been reported in leprosy, TB, HIV/AIDS, mental illness and epilepsy (Conrad 1985; Heijnders 2004; Sumartojo 1993; Weiser et al. 2003). It is noticeable that in spite of wide cultural diversity, there is remarkable similarity in the way life is affected by stigma in different countries and health conditions. They include marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities and attendance at social and religious functions (Van Brakel 2005).

Despite the knowledge that we have about the interplay between stigma and HIV, little progress has been made in systematically addressing stigma. It is recognized that many stigma reduction interventions have struggled to effectively measure and evaluate its impact. Obviously, it is not easy to reliably measure such a complex psychosocial phenomenon. Brakel's (2005) review of more than 60 stigma-related papers found that the indicators developed so far apply only in a single particular field of health. Development of appropriate instruments of stigma assessment for a range of health areas would help develop stigma reduction strategies. Since this research is based on a mixed method technique, it is important to have instruments in place in order to undertake quantitative measures, as and where required.

Generic Instruments

Based on his extensive review of the literature, Van Brakel (2005) found only one generic measurement instrument—a stigma scale. The scale contains 12 items and is only one part of a catalogue of instruments used to study different cultural and epidemiological aspects of a health condition. Responses are coded on a 0–3 ordinal scale (0 = no, 1 = uncertain, 2 = possibly of conditionally and 3 = yes). The scale covers only certain areas of life that may be affected by stigma, such as concealment, avoidance, pity, shame, being made fun of, respect and marriage prospects.

HIV/AIDS-Specific Scales

The 'AIDS Attitude Scale' (AAS), developed in the USA, has been used in a number of studies since 1992 (Froman et al. 1992; Froman and Owen 2001). Another scale for measuring public attitude is the 'Attitudes towards AIDS' scale developed in Brazil (Moriya et al. 1994). It consists of 25 items and the psychometric properties have been found to be good. Yet another type of instrument is the 'protocol for identification of discrimination against PLWHA' developed by UNAIDS; this is an indicator based on a checklist of 37 possible ways discrimination may occur (2000).

The 40-item 'HIV Stigma Scale' developed by Berger et al. measures stigma perceived and experienced by PLWHA (Berger et al. 2001). The items are formulated as statements and responses are requested on a 4-point agreement scale. It is possible to test the psychometric properties of the scale in a large sample of population with diverse backgrounds. The indicators in the set measure stigma and discrimination both from the perspective of PLWHA and of the community. Each indicator asks for the number of PLWHA who have experienced a particular type of discrimination or the number of people who have a particular opinion about or feeling towards PLWHA.

Ethical Issues[4]

Ethical issues are not new in social sciences research; however, stricter application of the ethics approval process has become increasingly important in recent times. Research in the past, including those that are often cited nowadays, rarely went through the protocol of ethical approval required today when research involves human subjects. This study involves extensive interaction with human subjects, that is, people living with HIV/AIDS, and required approval of research ethics obtained through rigorous procedures.

Adherence to ethical research processes is highly relevant to this study for a number of reasons. First and foremost, this research involves a vulnerable group of people, and their informed consent and participation is critical to avoid objectifying or exploiting their experiences. Ethical lapses in research can significantly harm human subjects (Shamoo and Resnik 2009), particularly those who are already marginalized or at risk, and research cannot claim to be academically sound if it does not demonstrate ethical treatment of its subjects and data.

Discussions of the importance of ethics in research have identified a number of reasons why ethical considerations are critical in research. Shamoo and Resnik (2009) discuss some of these points. First, adherence to ethical standards helps promote the aims of the research, for instance, prohibitions against fabricating or misrepresenting research data ultimately promote higher standards of accuracy. Ethical standards also promote the values that are essential to collaborative work, such as trust, accountability, mutual respect and fairness. The guidelines for authorship, copyright and patenting policies, data sharing policies and confidentiality rules in peer review are designed to protect intellectual property interests while encouraging collaboration. Ethical norms help to ensure that researchers can be held accountable to the public. Funders feel comfortable to provide research funds when projects can ensure the quality and integrity of research. In sum, ethics processes promote moral and social values such as: social responsibility, human rights, animal welfare, compliance with the law, and health and safety (Social Research Association 2003; Shamoo and Resnik 2009).

The Web Center for Social Research Methods stated that during the 1990s questions surrounding the ethics of medical research took a new turn (http://www.socialresearchmethods.net/kb/ethics.php). In many cases, it has been the lack of attention paid to ethics over the previous three decades that has resulted in the high degree of rigour in today's ethical approval processes. The last few years have witnessed major changes in the ethics of research, but a new consensus is evolving to involve the stakeholder groups most affected by a problem so they can participate more actively in the formulation of guidelines for research (Shamoo and Resnik 2009). This study required similar vetting after a lengthy process of review of the proposal.

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[4] For further information on the ethical processes adhered to in this study, please see Appendix.

Protection of Human Participants

In order to ensure the participation and protection of the research subjects, respondents were provided with background information, aims, objectives and methods of the study. They were informed that participation was voluntary and that they could withdraw from the project at any time. Respondents were also assured of the confidentiality of information obtained from the interviews. Following this explanation, the willing respondents signed a written consent form to participate.

There are a number of key phrases that describe the system of ethical protection created by contemporary social and medical research establishment for trying to better protect the rights of research participants (http://www.socialresearchmethods. net/kb/ethics.php). The principle of voluntary participation requires that people not be coerced into participating in research. Closely related to the notion of voluntary participation is the requirement of informed consent. Essentially, this means that potential research participants must be fully informed about the procedures and risks involved in research and must give their informed consent to participate. Ethical standards also require that researchers do not place participants in a situation where they might be at risk of harm. A broad definition of harm is used in this case to include both physical and psychological harms.

Participants in this study were offered one of two levels of privacy in order to ensure protection of their identities. Confidentiality of all participants is guaranteed, and they are assured that this information will not be available to anyone who is not directly involved in the study. The stricter option available is the principle of anonymity, which essentially means that the participants remain anonymous throughout the study—even to the researchers themselves. Clearly, the anonymity standard is a stronger guarantee of privacy, but it is sometimes difficult to maintain, especially in situations where participants have to be measured at multiple points of time. This type of research must adhere to the principles of honesty, objectivity, integrity, carefulness, respect for intellectual property, openness, responsible publication, confidentiality, social responsibility, respect for colleagues, non-discrimination, competence, legality and human subjects protection (Shamoo and Resnik 2009).

Reliability and Validity

Unlike quantitative research, the validity and reliability of a qualitative study is commonly judged by four criteria: credibility, transferability, dependability and conformability (Lincoln and Guba 1985; Trochim 2000). Quality research must have a degree of reliability in its data and analytical appropriateness. To ensure the quality and reliability of the research, a number of measures were adopted for this study. A field-test of the questionnaire was conducted before administering them to the respondents, and the data was crosschecked. 'The quality of a grounded theory study can be judged through the 'validity, reliability and credibility' of the data

within the standard canons of scientific research' (Creswell 1998:209). In this study, credibility was established through triangulation of qualitative interviews and community consultations. Validation was enhanced through the consultation process with participants to verify and expand the understanding of participants' experiences developed through the data analysis. Dependability was enhanced through the process of data analysis: that is, the data was coded and then, in collaboration with an expert, core categories were developed through mutual consensus (Lincoln and Guba 1985; Creswell 1998).

Anonymity and confidentiality were ensured by not publishing information on the identity of the participant. Code numbers were assigned to the notes for identifying their views and using them correctly. Participants were reassured that information generated from the interviews would remain confidential and would not be used for any other purpose outside of the research study. Access to the audiotapes was limited to the researchers only. Since data collection involved working with HIV/AIDS patients, it was important to outline the extent of time required, the potential impact, limitations and outcomes of the research (Creswell 2003).

Challenges

The topic of this research is extremely sensitive because it deals with human subjects, and a great deal of attention was dedicated to ensuring non-discriminatory and appropriate language and attitudes. The language in the text of the questionnaire and other relevant documents, as well as in the practices and question formation of the researchers, had to be carefully screened. Since this study deals with the South Asian community, sensitive issues needed to be managed with reference to a cultural perspective. Accessibility to the respondents has been a major challenge throughout the course of this research. Community organizations dealing with counselling of PLWHA were considered as important partners in undertaking this research. However, organizations have their specific objectives and interests, and sometimes they are accorded more importance instead of providing full cooperation with external researchers. Building collaborative research partnerships with these organizations was a major challenge and, on some occasions, posed a barrier to accessing research participants. Nevertheless, the cooperation of these agencies was invaluable for the study and contributed to more convincing findings. Finally, the question of representativeness and reliability remains a challenge in undertaking this type of research where the sample frame is unknown, and personal perspectives of both participants and researchers present a risk of influencing the outcome of research.