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## HIV/AIDS serostatus disclosure and stigma in Asian and Pacific Islander women : a call for intersectionality in the treatment of depression

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**Andrea L. Mize**  
**HIV/AIDS serostatus disclosure**  
**and stigma in Asian and Pacific**  
**Islander women: A call for**  
**intersectionality in the treatment**  
**of depression**

**ABSTRACT**

In the United States the prevalence and incidence rates of Asian and Pacific Islander (A&PI) women with HIV/AIDS is increasing. As many as 1 in 3 may not know they are HIV positive. Existing literature using stigma theory revealed that A&PI HIV positive women can experience both positive and negative mental health effects from HIV serostatus disclosure. These findings are an important mental health issue as HIV serostatus disclosure has traditionally been encouraged for the benefit of those diagnosed and their kinship networks.

The present study seeks to examine the correlation found in previous research between disclosure or nondisclosure of HIV serostatus and depression in A&PI women. Due to the paucity of information available, more research is clearly needed. Understanding this impact in Asian and Pacific Islander women diagnosed with HIV/AIDS can assist clinical social workers to provide culturally relevant care, guiding them through appropriate HIV status disclosure while reducing or minimizing their risk for negative consequences including depression.

The present paper demonstrates how an intersectional framework to both empirical research and clinical practice builds upon existing information regarding HIV stigma, and offers social workers a culturally responsive approach to the care of A&PI HIV positive women.

**HIV/AIDS serostatus disclosure and stigma in Asian and Pacific Islander women: A call  
for intersectionality in the treatment of depression**

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**2013**

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## **CHAPTER I**

### **Introduction**

People diagnosed with HIV/AIDS no longer live with a death sentence from the moment of diagnosis. This population now lives longer life spans and often dies of old age or iatrogenic causes related to their medication and treatment for HIV/AIDS. Often people living with HIV/AIDS (PLWHA) are able to live without medication for quite some time and continue to live medically healthier lives than those initially diagnosed in the early 1980s. This is due to early diagnosis and treatment, availability of effective medication therapy, and increased domestic and international funding for support services. Despite these improvements, HIV/AIDS is still a chronic disease with devastating and life-altering consequences. Education has done much to slow the spread of the disease in white, gay men; however, other communities have been slow to develop awareness and/or harm reduction of risk behaviors. One such population in the U.S. is Asian and Pacific Islander (A&PI) communities.

While HIV/AIDS in the A&PI population has not reached the pandemic proportions found in the white, gay, male community in the 1980s and '90s, or the alarming prevalence and incidence rates found in the African American communities in the last two decades, Asian & Pacific Islander communities show that diagnosis rates are steadily increasing (Centers for Disease Control, 2010). HIV statistics released by the Centers for Disease Control (CDC) in 2010 and the United States Department of Health and Human Services Office of Minority Health in 2012, show that prevalence for A&PI individuals has increased while it has decreased for

whites. This information revealed that Asian Americans are 20% more likely to contract HIV/AIDS as compared to whites (United States Department of Health & Human Services Office of Minority Health, 2012). The Office of Minority Health (2012) also estimates just under 9000 cases of HIV infection in Asian and Pacific Islander Americans as of 2009. The Banyan Tree Project (September, 2012) which is an HIV prevention tool developed by the Asian and Pacific Islander Wellness Center states some alarming statistics; of note, it is estimated that 1 in 3 A&PI individuals that are HIV positive do not know their status due to low testing numbers and increasing infection rates. Much like other ethnic groups affected by HIV, 80% of A&PI women who are positive contracted HIV from heterosexual contact. At the same time, A&PI women had the largest increase in incidence rates, or new infections—not just new diagnoses—than any other ethnic group (Asian & Pacific Islander Wellness Center, n.d.). Clearly a range of culturally appropriate HIV/AIDS prevention and support services is needed to address the expanding needs of Asian & Pacific Islanders as HIV/AIDS continues to affect this population.

One important component of HIV/AIDS care relevant to the field of social work is the treatment for depression in those diagnosed with the disease. Diagnosis and treatment of *any* chronic illness often results in depression due to the life-altering effects of treatment and disease management. Chronic illness is frequently associated with stress due to potential threats of physical well-being, body integrity, disability, independence and autonomy, self-concept and social role fulfillment, life goals and future plans, relationship effects, domicile changes/instability, and economic impacts (Falvo, 2005). As a result of these potential stressors, a diagnosis of any chronic illness places individuals at great risk for developing depression. HIV/AIDS as a chronic illness is no exception. Unlike chronic illnesses such as cancer or heart disease however, in addition to the various stressors mentioned, HIV/AIDS also often carries

additional risk for depression due to social stigma and shame (Ownby, Jacobs, Waldrop-Valverde & Gould, 2010). This is especially true in cultures and communities where the disease is primarily associated with activities that carry moral judgment such as intravenous drug use and certain sexual behaviors. The impact of this stigma, either real or perceived, can affect a newly infected person's decision to disclose or not disclose their HIV status to parents, family, and/or friends. This interplay of stigma and HIV status disclosure must not be understated due to the potential for infecting intimate partners and the need for social support in those who are newly diagnosed (Frost, Parsons & Nanin, 2007).

The present study seeks to examine the correlation between disclosure or nondisclosure of one's HIV status and depression. There is a potential for both positive and negative affects related to disclosure of one's HIV positive status. Disclosure of one's status opens the door for exposure to this stigma, shame, abuse, discrimination, and rejection. At the same time, lack of disclosure can result in isolation, fear of discovery, fear of infecting family members and sexual partners, and absence of treatment which could be fatal. The literature suggests that A&PI HIV positive individuals who choose to disclose can experience both the positive and negative factors listed above (Chin & Kroesen, 1999; Kang, Rapkin, & DeAlmeida, 2006; Nyamathi et al., 2011). Since HIV status disclosure can have both protective and potentially harmful effects, understanding this impact in Asian and Pacific Islander women diagnosed with HIV/AIDS can assist clinical social workers to provide culturally relevant care, guiding them through appropriate HIV status disclosure while reducing or minimizing their risk for negative consequences, and likely depression.



## **Theoretical Orientation and Methodology**

The intent of this study is to explore the connection between disclosure of HIV positive status and depression in Asian & Pacific Islander women through the lens of social identity and stigma. The available literature discusses Asian & Pacific Islander PLWHA as experiencing both beneficial and damaging emotional consequences from disclosure of their HIV positive status (Chin & Kroesen, 1999; Kang, Rapkin, & DeAlmeida, 2006; Nyamathi et al., 2011). This factor is highly important as disclosure of HIV status to one's intimate partners, family members, and medical providers is generally encouraged in HIV/AIDS prevention and treatment programs. While the experience of HIV stigma is often population dependent (Ownby, Jacobs, Waldrop-Valverde & Gould, 2010), depression is a correlate of HIV status disclosure in some populations as well, i.e. the gay male community (Frost, Parsons, & Nanin, 2009). Research indicates that the emotional stress of a homosexual orientation coupled with HIV-positive status can result in depression in gay men (Frost, Parsons, & Nanin, 2007). This may be due to the stigma associated with homosexual sex especially outside of geographic regions where variations in sexual orientations are accepted. Extending beyond geography, homosexuality is still a taboo in many A&PI cultures mainly due to the association with loss of social role and lack of family obligation fulfillment (Hahm, 2009).

Much of the available literature employs the use of stigma theory to conceptualize the social risks of HIV disclosure leading to depression. The present paper examines stigma theory as introduced by Erving Goffman in 1963 to explicate this link. Stigma theory explains how individuals cope with rejection, and how they adapt to social identities that separate them from the norm. Goffman (1963) places his emphasis on the loss of group status and acceptance which results in behaviorally adaptive change. While this theory is quite helpful in understanding

group membership and HIV disclosure in the development of depression, the research clearly shows more variables at work in the determination of whether one develops depression after disclosing their HIV status, even within collectivist cultures. Stigma Theory does much to explain the association of depression and choice of HIV status disclosure, but it does not give a full explanation of the experiences of the HIV positive individual. To elucidate these findings and create a deeper understanding of the individual experiences of this underserved A&PI female population, a second theory, Intersectionality, will be employed.

The concept of intersectionality is a conceptual framework rooted in Black feminist theory as first explicated by Kimberlé Crenshaw (1989). This concept addresses multiple social identities including gender, race, ethnicity, class, and sexual orientation, examining how these identities intersect and act upon one another in various settings. While one identity may be most salient and employ status in one setting, a different environment can shift one's salient identity and thus one's status or group value. This shifting is ever in a state of flux as an individual moves throughout the world.

Due to the multiple identities affecting A&PI women that extend beyond their gender and racial group, the argument will be made that intersectionality gives a more complete understanding of their experiences to further elucidate the mixed findings on depression and HIV status disclosure. Since the limited literature suggests that disclosing one's HIV status can have both protective and risk factors for the development of depression post diagnosis (Chin & Kroesen, 1999; Kang, Rapkin, & DeAlmeida, 2006; Nyamathi et al., 2011)., additional information is needed to understand the correlation of HIV status disclosure with mental well-being vs. depression. This understanding is essential when designing the much needed public

mental health treatment modalities and interventions for this underserved, and sadly growing, population of HIV positive Asian & Pacific Islander women.

## **Summary**

Disclosure of HIV status is a personal choice that requires sensitivity to one's cultural group and intersecting identities. Many of the existing U.S. studies on disclosure of HIV status focus on depression in gay, white, male populations (Gore-Felton et al., 2006; Gonzalez, Solomon, Zvolensky, & Miller, 2009; Haller & Miles, 2003; Leserman et al., 1999) and generally include few people of color. Other studies look specifically at African American and/or Latino populations with regard to HIV disclosure and depression (Clark, Linder, Armistead & Austin, 2003). Few studies in the literature (Mobley, 2006; Yoshikawa Wilson Chae & Chang, 2004) examine Asian & Pacific Islanders and their relationship to HIV serostatus disclosure and depression. Even fewer studies (Gu, Lau, Chen, Chen Lui & Lui, 2010; Nyamathi et al., 2011; Nyamathi, Salem, Meyer, Ganguly, Sinha & Ramakrishan, 2012) examine the specific needs of women within these populations, and tend to focus on women outside of the United States.

Literature that does exist on A&PI female populations tends to focus on stigma theory to understand disclosure/nondisclosure behavior as related to depression. While stigma theory is highly relevant, issues of HIV status disclosure are more complex and multidimensional. A sophisticated understanding of the correlation between disclosure and depression is required in A&PI women who are newly diagnosed. Clinical social workers relying on existing literature for evidence based practice methodology on the growing Asian & Pacific Islander HIV positive community in the U.S. must move beyond HIV stigma theory, and employ the conceptual framework of intersectionality to establish culturally supportive and sensitive support service programs.

## CHAPTER II

### Conceptualization and Methodology

#### Definition of terms

While many of the following terms are frequently used in the literature and are quite familiar, the following definitions are provided for clarification. These definitions are contextual defined in the following fashion by the author for use in the present paper.

**Asian & Pacific Islanders (A&PI):** An ethnic category including over 47 different ethnicities originating in geographic regions of Asia and the Pacific Islands. This grouping includes, but is not limited to, the following broad ethnic groups: Chinese, Japanese, Vietnamese, Indian, Pakistani, Sri Lankan, Nepalese, Filipino, Hawaiian, Samoan, Taiwanese, Korean, Laotian, and Cambodian. This is an overbroad category which requires disaggregation of data to understand the complexities of the populations it intends to incorporate. This will be further explained under **Strengths and Limitations** below.

**Chronic illness:** This is a physical or mental diagnosis that lasts for an extended period of time and considered incurable although it is often treatable. The illness may lead to disability and therefore have consequent social role and economic effects on the affected person, their family members and/or their caregivers.

**Cisgender:** One's gender assignment at birth matches a person's gender identification.

**Collectivist culture:** Ethnic groups that emphasize interdependence and group cohesion rather than independence and individualism. One's behavior and identity in the group is an extension of the group as a whole.

**Cultural sensitivity/cultural competency:** The awareness, knowledge and skills of a particular group's norms, values, belief systems, and language. This group may be identified by ethnicity, race, gender, age, sexual orientation, or other unifying characteristics.

**Depression:** This is a decline in mood or affect that affects activities of daily living (ADLs). For the present study this includes the diagnosis of depression and/or the identification of depressive symptoms in the literature through various measures.

**Disaggregation:** In terms of research data, this calls for greater specificity and breakdown of categories for richer interpretation, such as with ethnic categories.

**Disclosure:** When applied to HIV/AIDS, this is the act of sharing one's HIV positive status or AIDS diagnosis with others.

**HIV/AIDS:** This is an inclusionary term used to refer to all variations of Human Immunodeficiency Virus (Type 1 or 2) and Acquired Immune Deficiency Syndrome regardless of the disease stage.

**Individualism:** A cultural belief system which stresses the importance of self-reliance and independence; "white" American capitalist culture and the "Protestant work ethic" are examples.

**Intersectionality:** A conceptual theoretical framework asserting that individuals carry various cultural and social role identities with them that interact and are in a constant state of change. The identification with a particular identity in one setting may be dominant in one setting while it is part of a target group in another setting. These intersecting identities move

within us through subjective experience and act upon us through our interpersonal and structural interactions.

**Seroconversion:** The development of antibodies in the bloodstream in response to the presence of a virus in the body. In HIV/AIDS this occurs when virus is present in the blood stream and the body's immune system begin to create cells to fight the infection.

**Seropositivity:** Showing a positive reaction to a test on blood serum for a disease; exhibiting seroconversion. In HIV this is what is meant by testing HIV positive.

**Serostatus:** This is the presence or absence of antibodies to a particular virus in the bloodstream such as HIV.

**Stigma:** Social disapproval due to perceived or actual violation of cultural norms.

**Target group/target population:** In critical race theory this is a social group that is the recipient of institutionalized oppression. This was formerly known as a minority group; however, "minority" is a misnomer as it implies a smaller number than the dominant group which is often not the case.

**"White" American culture:** A set of hierarchical values in which the primacy of whiteness, male gender, consumerism, individualism, and capitalism, privileges these concepts, resulting in the devaluation of People of Color, female gender and gender variance, minimalism, collectivism, and socialism.

### **Theoretical frameworks**

Two theoretical frameworks will be used to understand the impact of HIV seropositivity on A&PI women in terms of status disclosure and depression.

**Stigma theory:** To examine the relationship of depression and HIV status disclosure in A&PI women the topic will be approached first through the lens of stigma theory. To understand

intragroup identification and social group membership as related to behavioral choice, I will explore stigma theory as first constructed by Erving Goffman (1963). Goffman's theory states that stigma is a quality applied to an individual that decreases their social value or worth. Stigma is the difference between an individual's assumed or perceived social worth and their actual or proven social value. Stigma theory was chosen because it is often discussed in the literature regarding A&PI communities as an underlying reason for risk factors leading to transmission. This includes stigma related to difficulty talking about condom use primarily in heterosexual acts, intravenous drug use (IVDU), engaging in sex with sex workers which is common in migrant worker populations, and men having sex with men (MSM). Identification with these risk behaviors and HIV/AIDS can be stigmatizing in most all ethnic groups, but in collectivist cultures this stigma can take on a new meaning.

A&PI communities tend towards collectivism where the actions of one group member reflect upon the entire group. This is particularly true of family relationships. Anthropologically this can function as a protective factor in families and other social groups by regulating behavior, but psychologically it can cause social isolation with lack of disclosure for fear of shaming one's family. At worst there is fear of ostracism, rejection, and expulsion from the group. When self-identification relies heavily on extended family group membership this rejection or threat if expulsion can be particularly harsh.

**Intersectionality:** To honor and understand this interactional process of identity, the second theory which will be explored to further examine the disclosure and depression phenomenon in A&PI women living with HIV/AIDS is intersectionality theory as explained by Kimberlé Crenshaw (1989; 1993). Crenshaw's theory will be used to explicate how these various intersections of identity act on an individual to influence behavior and concepts of wellness.

While there are many perspectives within the frame of intersectionality, these perspectives can be categorized as social constructionist or poststructuralist. The present paper will adopt the perspective of social constructionism. While poststructuralists argue that use of socially defined categories such as gender and ethnicity can marginalize groups rather than liberate them, Anderson and McCormack (2010) state that, disregarding these categories altogether can serve to further alienate individuals. In essence, while *race* may not exist as poststructuralists state, social constructionists affirm that *racism* does exist and acts upon each of us. Therefore, negating the vocabulary used to describe identity by claiming it is incapable of explicating the true experience of oppression and production of socially constructed identity can be counterproductive in the political arena of public health.

The social constructionist perspective does not deny the complexity of human experience, but provides a language and conceptual framework to deepen and enrich the conversation, ideally allowing for improved access to social programs and public health services. Thus, examination of these social constructs of identity is necessary to understand human experience and function, better informing the practice of social work. For example, "Black", "Haitian American", "transgender" and "female" are terms created and defined to identify and separate, thus oppress. Poststructuralists argue that by encouraging acknowledgement of these various identities we maintain and deepen the power structure further victimizing the oppressed. Social constructionists argue that a Black, Haitian American, transgender female experiences multiple forms of oppression regardless, but by naming these identities she may name her experience of oppression providing a mode of empowerment.



## **Method of evaluation**

The connection to stigma and identity has been explored with regard to status disclosure and HIV/AIDS risk behaviors in A&PI communities (Chandra, Deepthivarma & Mahjula, 2003; Chin & Kroesen, 1999), however, research has not given as much attention to disclosure and the potential resultant depression. Depression developing after HIV seroconversion may have many causes, (i.e. having a chronic illness and resultant disability, reduced self-esteem, social isolation,); one study (Kang, Rapkin & DeAlmeida, 2006) has operationalized particular HIV-stigma factors. In addition, an HIV Stigma scale has been developed showing good efficacy with various ethnic groups (Bunn, Solomon, Miller & Forehand, 2007).

Stigma theory helps explain how identification and group belongingness affects behavior, however examination of ethnic social group membership does not fully explain behavioral choice or rates of depression as correlated with disclosure. Individual complexity is flattened and at worst misunderstood without taking multiple layers of identity into account. Individual experience is greatly affected by multiple roles and types of group membership acting upon one another. Some of these identities are chosen such as employment, while others, such as skin color, are not. Some of these multiple layers of identity may carry privilege while others may signify oppression. One identity may be most salient at any given time depending upon the setting; this salience can change day to day or even moment to moment as individuals move throughout the world. Identity is both an internal and external process which affects one's interaction with society.

Stigma theory and intersectionality theory will both be examined with one building upon the other, to understand the current state of HIV/AIDS disclosure-related depression and suggest a more informed culturally expanded conceptualization for the future. Stigma theory explores

identification of an individual's notion of belonging within a group. This theory helps social workers to contextualize experience in an effort to better understand behavior as a group member, particularly as related to HIV status within a collectivist ethnic group. This allows for tailoring of interventions in an effort to develop and implement culturally relevant services to client populations. Group belongingness and the threat of social stigma, both actual and imagined, can be powerful forces which cause individual action to maintain group status even to the personal detriment of the individual.

To acknowledge group identification as it affects group behavior, there has been a movement of "multiculturalism" in public mental health programs. The result is a bifurcation of ethnic identity into distinct categories of "white" and "People of Color" (POC). Ethnic and racial groups within the POC category are further separated into distinct categories, and interventions have been developed accordingly. To account for multiple ethnic identities, an additional "biracial" or "multiracial" category was incorporated. The multicultural movement effect is threefold: 1) this reinforces the concept that only one identity is prominent when addressing one's need for social support; 2) identities are mutually exclusive, (i.e. being either "white" or "multiracial") and 3) one's primary identity decidedly relates to one's ethnic or racial group membership, particularly for People of Color.

By contrast, the concept of intersectionality recognizes that one's multiple identities are at work at all times, where ethnic identity may be prominent in one setting but not in another. For example, the (white) public mental health system may see one's status as Chinese American being most important in terms of developing interventions, while the individual's identity as a woman may be most salient to her when seeking mental health services. The arena for much of the service provided to PLWHA is that of public health. The creation and implementation of

public health interventions that address the mental health of PLWHA in the A&PI communities may be most effective with self-identification of one's salient identity/identities. By addressing the HIV/AIDS stigma present in A&PI communities, social workers may better understand how disclosure of HIV-related depression impacts A&PI individuals. In addition, the interaction of multiple identities as they relate to oppression and behavior also affect how social workers clinically address HIV/AIDS clients. These intersections such as gender, sexual orientation, method of seroconversion, (or contracting HIV/AIDS), age, socioeconomics (SES), ethnic identification, documentation status and nationality, all affect the type of care needed by A&PI individuals that are HIV positive. The field of social work must hold open the idea that a dynamic and flexible suite of strategies and interventional approaches is the ideal approach.

In order to create such strategies and provide appropriate mental health services for PLWHA in the A&PI community, culturally sensitive investigation with disaggregated ethnic data, (separation into Chinese, Vietnamese, Filipino, etc. and immigrant vs. 2nd or 3rd generation, etc.) is necessary to examine the complex relationship between disclosure and nondisclosure of HIV status and depressive symptoms. The present paper then will explore the phenomenon of depression in HIV positive Asian and Pacific Islander women through the lenses of stigma theory and intersectionality to explore the diverse experiences of these women and inform the development of culturally appropriate mental health interventions.

### **Potential Biases**

Potential bias is acknowledged as I am a bisexual, HIV negative, able-bodied, white, European American, cisgender (my gender assigned at birth matches my gender identification), female of lower middle class upbringing, working as a clinician in an HIV/AIDS mental health clinic. I am of the generation that grew up with HIV/AIDS being discovered when I was

prepubescent, and sexual topics were comfortably discussed in my family of origin. I have little knowledge of IVDU beyond a basic academic overview and have only a cursory understanding of that particular culture. My examination of the racial and ethnic cultural factors comes from a dominant group member perspective rather than as a target group member and will necessarily "color" my point of view. In addition, I reside in the San Francisco Bay Area and have a personal relationship with many people affected by the local policy and public agency politics. As complete objectivity is impossible, the reader is asked to be mindful of my attempt at culturally informed subjectivity in my examination of the issues.

### **Strengths and Limitations**

Limitations of this approach acknowledge that the present proposal focuses on A&PI communities and intentionally excludes other racial groups. HIV/AIDS affects greater numbers of African American and Latino/a populations and the present focus on A&PI individuals is not intended to suggest A&PI communities require more attention than these populations.

Exploration is certainly warranted into the potential application of stigma and intersectionality in the development of programmatic level mental health interventions to serve these other ethnic groups.

Further the designation of Asian & Pacific Islander is an overbroad category that is problematized by the geographic grouping of a hugely diverse collection of cultures. There are many cultural similarities between these ethnic groups; however, collapsing these various ethnicities into one homogenous or even two categories paints too broad a brush. This leads to invisibility of certain groups and skews the diagnosis, detection and treatment of particular conditions in other groups (Srinivasan & Guillermo, 2000). It is important to note the differences in generational factors and immigrant versus acculturated differences even among generations of

the same ethnicity. For example, Srinivasan & Guillermo (2000) point out that varied social histories of various groups such as the Hmong who were refugees in Laos, Thailand and China before settling in California may have little in common with other A&PI communities.

Collapsing this group in the greater umbrella term of A&PI fails to account for the particular mental health, social service, immigration, and language needs of this population.

Another limitation resides in the narrowing of the definition of intersectionality which is a broad and presently-expanding theory of study. A complete analysis of this theory to incorporate poststructuralist thought is beyond the scope of the present work. Likewise, many theories of group membership including social networking theory help explain individual behavior to maintain group status. Stigma theory is but one approach with particular relevance to both collectivist ethnic groups and PLWHA.

An important strength of this theoretical frame is the identification of individual needs which must be examined in light of intersectional ever-changing modes of privilege and oppression. Applied in public health settings in this manner to all ethnic and racial groups, more culturally appropriate interventions can be created to serve these heavily affected populations.

In a widening of the discussion of how macro level systems of institutionalized privilege and oppression impact Asian & Pacific Islander PLWHA on the micro level with regard to HIV status disclosure and depression, it is anticipated that public health systems may be revitalized, increasing efficacy of existing services and the development of new services to fill gaps in current programs that serve these communities.

Another strength is that the proposed theoretical exploration will bring much needed attention to the intersectional identities of PLWHA that have membership in an A&PI ethnic groups consistent with the Smith College School of Social Work commitment to antiracism. It is

the intention of this theoretical approach to generate discussion at the programmatic level of public mental health to aid social workers in their pursuit of culturally appropriate and theoretically informed practice.

## **CHAPTER III**

### **Phenomenon**

#### **Introduction**

When individuals are diagnosed as HIV positive and treated for the disease, their lives necessarily focus on a personal identity that now encompasses a highly-stigmatized, chronic illness. Due to the transmission methods of HIV/AIDS and its ongoing stigma associated with homosexuality and intravenous drug use (IVDU), this identity as a person with HIV/AIDS, (regardless of sexual orientation or use/nonuse of IV drugs), requires a decision-making process of if, and to whom, one should disclose HIV status. Patients newly diagnosed with HIV/AIDS are generally encouraged to seek individual and/or group counseling services in part due to the risk for depression that frequently accompanies chronic illness; this is the model developed and effectively utilized with the American, white, gay male population in the 1980s as they comprised the vast majority of those diagnosed with HIV/AIDS.

Choosing not to disclose HIV seropositive status in part due to shame and risk of stigma (DeAlmeida, 2007; Zhang, Lin, & Fu, 2011) is correlated with emotional isolation, additional risk behaviors such as not taking precautions against spreading the virus and medication nonadherence (Li et al., 2010; Stirratt, et al., 2006), and the development of depression (Nyamathi et al, 2011; Vyavaharkar, 2009). Issues of shame affecting HIV status disclosure are particularly important in collectivist A&PI cultures (DeAlmeida, 2007) where what happens to

one individual reflects on all family members, and possibly the individual's community. Disclosure of HIV status within these cultures can have a very different outcome than disclosure in a culture and community based on individualism, (i.e., in "white, American culture). While access to public mental health counseling to aid in the decision-making process of disclosure has become de rigueur as part of HIV/AIDS prevention programs due to the protocols established by the Centers for Disease Control and World Health Organization (Taraphdar, Dasgupta & Saha, 2007), such prevention tools were developed in the 1980s and early 1990s when the known affected population was predominately gay, white, American men. Simply making these counseling services available to newly HIV positive individuals in the various affected populations without taking the patient's cultural identity into account is inadequate.

In many ethnic groups and cultures, HIV/AIDS aside, psychological counseling and mental health support is not trusted and is heavily stigmatized. While there is much diversity under the A&PI umbrella term, individuals in A&PI ethnic communities are often reluctant to seek mental health services for fear of family stigma in the larger community (Iwamasa, 2003). With HIV/AIDS being a heavily stigmatized disease and mental health care being so stigmatized in A&PI populations, seropositive status disclosure must be approached with extreme cultural sensitivity to be effective in assisting individuals coping with their diagnosis.

One question not yet fully answered in the literature is how ethnic differences within the A&PI community affect depression and outcomes of HIV serostatus disclosure. A second question is how do ethnic differences further affect or act upon the various intersecting subcultures of sexual orientation, age, immigrant vs. native status, etc. of A&PI individuals who are HIV positive when dealing with disclosure? To explore possible answers to these questions the following sections will first present an overview of A&PI cultural commonalities to



contextualize the subsequent analysis of available data. Next statistics regarding HIV in A&PI communities will be outlined. From there the relationships between HIV stigma, depression, and disclosure vs. nondisclosure of serostatus will be addressed. Finally, the literature covering HIV stigma, depression, and disclosure specific to the A&PI women will be reviewed.

### **Cultural characteristics of A&PI populations relevant to mental health and HIV/AIDS**

There are over 47 ethnic groups represented under the umbrella term “A/PI” (Iwamasa, 2003). While there are many differences between these cultures, a few prominent cultural similarities exist. These similarities are worthy of understanding and exploration to help interpret current literature and to guide future ethnically diverse research involving A&PI HIV positive individuals.

Iwamasa (2003) reports that American A/PI individuals tend to have prevalence rates of mental illness (i.e. depression) that are similar to white Americans however psychopathology, ethnicity, generational level, extent of acculturation and cultural background have an impact on the symptomatology and behavioral manifestation of psychological distress (i.e., lower rates of IV drug use than whites) among American A&PI individuals. Immigrants with a history of oppression and/or violence (i.e., experiencing war while in their home country) appear to have increased psychological distress compared to A&PI individuals born and raised in the United States (Iwamasa, 2003).

Many ethnic groups within the A&PI umbrella focus on the importance of family as central to their understanding of psychological phenomena. This understanding includes a sense of collectivism where psychological experiences are associated with the family as a whole. This deters affected individuals from seeking help for mental health issues to avoid familial shame and stigma. This idea of shared identification and shame moves beyond mental health

identification and extends to the behaviors of individuals within a family system: what one family member does, good or bad, will reflect upon the other members of the family.

In many Asian and Pacific Islander ethnic groups the concept of "saving face" is employed regarding highly sensitive topics including HIV/AIDS (Asian Pacific Islander Wellness Center, n.d.). "Saving face" refers to the maintenance of one's social standing, reputation, social influence, dignity and honor (Rodgers, 2012). Sensitive topics that can cause one to lose social standing or can mar one's reputation are taboo in order to maintain dignity in the family and community. As a result, topics such as sex practices, drug use and HIV/AIDS are not discussed; doing so could cause one to "lose face" or to lose social standing and significance, an issue of extreme importance in A&PI cultures. The silence around topics such as sex and drugs often means a lack of awareness about one's HIV status. This lack of awareness and/or avoidance of discussion can in turn lead to individuals transmitting HIV/AIDS to others unknowingly.

While there are several similarities between A&PI ethnic groups, there are also many differences between cultures and ethnic groups. Treatment programs that are sensitive to the various needs of the many ethnic groups within this Asian & Pacific Islander grouping are essential and must be evaluated by clinical staff for overall appropriateness to the ethnic groups served, especially in public health settings where HIV support often occurs. Much work remains to be done to explore the differences in these specific ethnic groups and to tailor HIV/AIDS support services appropriately however there is movement at the national level to address this issue.

A brief released by the Asian Pacific Islander Health and Wellness Center (2012) reports that the Office of Minority Health (OMH) now intends to provide tightly targeted, specific health

information and epidemiological studies for Asian American, Native Hawaiian and Pacific Islander communities. However, the current information available from the (OMH) focuses on the similarities between these groups, and how these groups may differ as a whole from Blacks or Latino communities rather than examining the intragroup differences of Japanese Americans and Indian American for example. While independent groups of researchers may look at populations of particular communities, (i.e., a number of studies have been conducted regarding HIV mental health outcomes and interventions in South India,) national and international governmental agencies have more funding to conduct large-scale studies with cross-cultural data. A movement towards so-called "granular" data (Asian Pacific Islander Health and Wellness Center, 2012) would provide more robust and applicable outcomes.

To develop a clear picture of how HIV/AIDS affects A&PI communities, it is necessary to understand prevalence and details of transmission. A summation of the current epidemiological HIV/AIDS data available on Asian and Pacific Islander populations in the United States is provided below.

### **HIV/AIDS in Asian & Pacific Islanders**

In 2010, the (CDC) reported statistics about transmission routes for the A&PI community. As cited by the U.S. Department of Health & Human Services Office of Minority Health (OMH) in 2012, Native Hawaiians and other Pacific Islanders in the U.S. were 2.6 times as likely to be diagnosed with HIV in a sample of men, women and children. In males over the age of 13, 84% reported a transmission route of male to male sexual contact (MSM) while 82% of females over the age of 13 reported transmission through heterosexual contact (OMH, 2012). IV drug use (IVDU) resulted in 16% of the transmission for women while IVDU was 3% for men; when combined for men the transmission routes of MSM with IVDU was 7% (OMH,

2012). Heterosexual contact accounted for 5% of transmissions in men (OMH, 2012). A review of these statistics suggests that the largest concern of transmission is with MSM and *heterosexual women*. It is likely that the MSM group also has female partners resulting in transmission to heterosexual women. Because of the stigma regarding MSM and homosexuality in many although not all A&PI cultures, this statistic may reflect a large number of married men passing HIV/AIDS to their spouses and not knowing of or not disclosing their HIV status to their partners. Nondisclosure of status is further complicated as estimates are that 1 in 3 HIV positive A&PI individuals do not know they are infected (Asian Pacific Islander Wellness Center, n.d.) due to low testing rates.

Statistics were also reported for Asians by the CDC in 2010. As updated by the OMH (2012) for Asian Americans, rates of HIV/AIDS have increased over the last few years while the numbers for whites have declined. Compared to whites, Asian American are 20% more likely to contract HIV/AIDS (OMH, 2012). Transmission routes for Asian males are similar to Native Hawaiian and other Pacific Islander individuals reporting 82% of MSM transmission (OMH, 2012). Asian women have a heterosexual transmission route accounting for 87% of cases (OMH, 2012). IVDU transmission is 9% in Asian women and 4% in Asian men while male heterosexual contact accounts for 9% (OMH, 2012). MSM and IVDU in combination account for 4% of cases in Asian men (OMH, 2012). Generally when comparing Asians to Native Hawaiians and other Pacific Islanders the transmission routes are quite similar. This suggests that psychoeducation programs developed for these communities as a result of the research will focus on similar themes of awareness and behavioral modification.

In general, women who engage in vaginal intercourse are more susceptible to HIV/AIDS; the virus passes more easily to women in this type of partnered sex (The Body.com, 2008). In

cultures where "saving face" is a central social construct and sex is not openly discussed, women may be less likely to ask their partners about sexual practices and behaviors that place them at a risk. They may also be less likely to request condom use from their partners. Clearly this is an important issue since roughly 80% of A&PI HIV positive women were exposed to HIV through heterosexual contact (Asian & Pacific Islander Wellness Center, n.d.). The risk for domestic violence and general personal safety concerns resulting from HIV seropositive status disclosure must not be underestimated. This is especially true in a collectivist culture due to the risk of shame brought upon one's family members and partner.

The majority of HIV/AIDS mental health research and intervention literature that examines A&PI communities often groups ethnicities together when reporting findings (Chae & Yoshikawa, 2008; Kang, Rapkin & DeAlmeida, 2006; Scott, Gilliam & Braxton, 2004). While an overall percentage breakdown by ethnicity in the populations studied is often listed (i.e. 63% Chinese, 32% Japanese, 4% Filipino and 1% Vietnamese), outcomes and behaviors are not regularly differentiated by ethnic group. This reduction of individual identity to one main A&PI grouping misses the mark when creating behavioral interventions designed to help these various populations. This designation of Asian & Pacific Islander as an ethnic identifier, while not an arbitrary category, may oversimplify behavioral health activity and mental health outcomes causing misleading results and ineffective interventions. For example, a recent study by Toleran et al. (2012) of substance use in San Francisco Bay Area A&PI men found statistically significant behavioral differences between the Chinese, Filipino and Vietnamese ethnic groups supporting the need for disaggregation of ethnic group data. Toleran et al. (2012) shows how unique group behavior is lost when subsumed under the sole category of Asian & Pacific Islander. Further, as there is a correlation between substance use and HIV/AIDS risk behaviors,

this study suggests that ethnic group break down is highly relevant to the study of interventions related to HIV/AIDS.

As the present paper aims to examine the experiences of HIV seropositive A&PI *women*, the literature was further examined with regard to gender. A meta-analysis looking specifically at research conducted on HIV interventions for women found that women of different ethnicities were regularly combined thus obscuring the complexity of the results (Mize, Robinson, Bockting, & Scheltema, 2002). Clearly, an intersectional approach would provide much needed culturally sensitive data for ethnicity and gender from which to create efficacious HIV/AIDS mental health interventions. With this in mind, the following section explores the intersections of relevant variables discussed in the present study. Since little research has been done examining Asian & Pacific Islanders and HIV, research conducted on other populations is also included.

### **HIV/AIDS and depression**

Depression is not surprisingly linked to the diagnosis of HIV/AIDS. It is important to keep in mind that receiving this diagnosis is still a devastating experience for many even though effective treatments are available. The stigma of HIV/AIDS alone can lead to depression (Groves, Golub, Parsons, Brennan, & Karpiak, 2010; Haller & Miles, 2003; Leserman, 1999). In addition, receiving *any* chronic illness diagnosis disrupts a person's life, especially with regard to health, employment, livelihood and intimate relationships. Simply put, chronic illness places any individual at risk for depression (Greydanus, Patel & Pratt, 2010; Liew, 2012).

The diagnosis of HIV/AIDS in particular often results in fears about loss of health, of partners, of family and friends, of employment, and even housing. In short, the diagnosis often impacts a person in many if not all aspects of his or her life. Gore-Felton, Koopman & Spiegel (2006) found that one's quality of life was the single most important predictor of depression in a

quantitative study of ethnically-diverse, HIV positive, male and female participants in the metropolitan U.S. In addition, Haller and Miles earlier research in 2003 found that overall quality of life measures in HIV positive patients were highly correlated with patient's suicidality. Expression of suicidality was negatively correlated with high quality of life measures. The strongest correlation related specifically to family and friendships as well as engagement in activity in their quantitative study. The results suggest that HIV positive individuals experiencing positive association with interpersonal relationships may have less depression and suicidal ideation. This is an important factor when considering A&PI cultures that generally place a high value on family and community.

Unfortunately depression is underdiagnosed and undertreated in individuals who are HIV positive (Eller et al. 2010; Ownby, Jacobs, Waldrop-Valverde & Gould, 2010). In a literature review of the prevalence of treatment for depression in patients diagnosed with HIV, Ownby, Jacobs, Waldrop-Valverde & Gould (2010) found that secondary depression is under diagnosed in primary care settings because depressive symptoms overlap with HIV infection symptoms such as fatigue, weight loss and sleep disturbance. Further, even when depression is diagnosed in HIV positive individuals it remains undertreated despite the range of interventions available. In A&PI communities, individuals may seek assistance from medical rather than mental health professionals for somatic experiences of depression such as fatigue or insomnia (Iwamasa, 2003). This becomes significant in the lives of patients with HIV as Haller and Miles (2003) note that long-term depression with any chronic illness can affect one's quality of life.

One study suggests treatment of depression could be important as lack of treatment could potentially lead to a shorter lifespan from depression alone. Leserman et al. (1999) found a correlation between depression and rapidity of disease progression in a longitudinal, quantitative

study of 96 African American and white gay male PLWHA. The literature supports the idea that depression is prevalent in individuals who are HIV positive which affects quality of life (Gonzalez, Solomon, Zvolensky, & Miller, 2009; Haller & Miles, 2003). Gore-Felton, Koopman, and Spiegel (2006) suggested that future studies should focus on improving quality of life and increasing one's adaptive coping strategies associated with living with HIV/AIDS, as quality of life was the most important predictor of depression in PLWHA.

The literature also suggests that as HIV-infected persons live longer lives, their use of mental health services increases (Mkanta, Mejia & Duncan, 2010; Moynihan, 1996). Mkanta, Mejia and Duncan (2010) found increased use of mental health services over time in over 1900 HIV positive African American and more than 1600 white male veterans specifically treated for adjustment disorders, depression and anxiety. In a study that focused on HIV in women, disease progression was correlated with increased depression, noting higher prevalence of depression diagnoses in women overall when controlled for sociodemographics, substance use and clinical aspects in over 750 seropositive women in the Northeastern U.S. (Ickovics, 2001). The Ickovics study (2001) indicated that HIV positive women with chronic depressive symptoms were twice as likely to die as those who were not depressed or those having minimal depressive symptoms. In addition, CD4 cell count decline was found in women with chronic depression regardless of treatment. One problem of this study is that demographic breakdown was reported as Black, white, and "Hispanic or other" women without further racial or ethnic designation of results. The literature suggests adequate risk assessment of mental health concerns should be conducted with attention to variance in racial and gender differences to effectively address the impact of mental health on treatment outcomes on disease progression and mortality.



One limitation of some of the studies is their small sample size of around 100 people (Gore-Felton, Koopman & Spiegel, 2006; Gonzalez, Solomon, Zvolensky, & Miller, 2009; Moynihan, 1996). Other studies looked at only men (Groves, Golub, Parsons, Brennan & Karpiak, 2009; Kang, Rapkin & DeAlmeida, 2006; Leserman, 1999; Mkanta, Mejia & Duncan, 2010). Another issue with some of the studies resides in their operationalization of particular quality of life measures assessed through: 1) the MOS HIV scale developed for gay and bisexual men (Gore-Felton, Koopman & Spiegel, 2006), and 2) a Likert-type scale self-report of daily routine, work, health, leisure/social time, sex life, family life/friendships; and “overall” quality of life (Haller & Miles, 2003), the importance of which are culturally-defined.

While the quality of life aspects listed are likely important to A&PI women in measuring their quality of life and depression/suicidality risk after an HIV diagnosis, it is unclear just how important these aspects are. For example, family and social role may be far more important than leisure time in the lives of these women. Generally, these studies did not include Asian & Pacific Islander populations beyond a few male individuals. The present study argues that the use of intersectionality in examination of quality of life issues, depression and suicidality will provide a more inclusive picture of A&PI women's mental health experiences post HIV diagnosis.

Clearly there is a link between HIV/AIDS and depression regardless of how it affects quality of life, longevity, diagnosis and access to mental health care, etc. in different ethnic groups, age groups, and genders. While there are many possible correlates of depression in HIV positive individuals, one factor making this chronic illness different from others which is linked to depression is stigma. This depression/stigma link will now be examined in the available literature on HIV positive individuals.

## **HIV/AIDS-related stigma and depression**

The presence of untreated depression is of concern in PLWHA particularly because of the negative effect on the immune system and related poorer disease outcomes (Ownby et al., 2010). Many of the studies (Charles et al., 2012; Chandra, Deepthivarma & Manjula, 2003; Chin & Kroesen, 1999) regarding the link between depression and HIV positive status employ stigma theory to explain this correlation. Clark, Lindner, Armistead and Austin (2003) examine HIV/AIDS in this context and explain Erving Goffman's original stigma theory as a reaction to the perceived stigma of HIV/AIDS. This causes a publically "discredited" (Goffman's term) or stigmatized identity to emerge as a PLWHA. This results in psychological harm to the individual in the form of mental stress and/or depression. Clark et al. (2003) also uses Herek's definition of AIDS-related stigma which is "prejudice, discounting, discrediting and discrimination" towards an individual or community affected by AIDS (p.59). Research on HIV/AIDS-related, perceived and actual, stigma indicates a correlation of this stigma to depression in HIV positive adults (Groves, Golub, Parsons, Brennan & Karpiak, 2010).

In a longitudinal, qualitative study of 98 HIV positive and 146 HIV negative inner-city African American women, Clark, Linder, Armistead and Austin (2003) found that as perceived stigma increased, psychological functioning and serostatus disclosure, or telling others of one's HIV status, decreased. The researchers recommended caution against generalization beyond the sample demographic of African American mothers, but did urge public health educators to target AIDS-related stigma campaigns at the family level. The study was also limited to poor, inner-city women whose experiences may not reflect A&PI women's experiences, the target population of the present study. On the strengths side, African American families like A&PI families can be

viewed as collectivist. Therefore, these findings may have implications for HIV positive A&PI women.

One study which focused on another collectivist population, migrant Latina women, evaluated their HIV knowledge and attitudes. The quantitative study of 32 Latina women found that these women were unlikely to carry condoms and lower their HIV risk because they feared negative social perceptions such as promiscuity (Organista, Organista, & Soloff, 1998.) Similar to the findings on African American women, *disclosure* of HIV positive status could also be hampered by the fear of negative social perceptions. Additional research in this area is needed to determine if similar behaviors and attitudes regarding stigma can be generalized to A&PI migrant women.

This body of literature raises the issue of HIV/AIDS-related stigma and depression, and indicates a potential correlation to HIV serostatus disclosure. The next section looks more closely at this issue of serostatus disclosure vs. nondisclosure related to HIV stigma and depressive symptoms.

### **HIV-related stigma, depression and serostatus disclosure vs. nondisclosure**

The issue of HIV serostatus disclosure is prominent in HIV/AIDS prevention and treatment. Literature that deals with mental health as it relates to HIV/AIDS has shown differences in rates of depression around issues of disclosure of one's HIV serostatus. Some studies suggest that disclosure of HIV status can protect against depression through social support, while other findings indicate increased depression related to negative reactions from serostatus disclosure and HIV/AIDS-related stigma (Chin & Kroesen, 1999; Kang, Rapkin, & DeAlmeida, 2006; Comer, Henker, Kemeny, & Wyatt, 2000; Steward, et al., 2011). These results are found both across and within ethnic groups.

In a 2000 longitudinal mixed-methods study by Comer, Henker, Kemeny, and Wyatt of 176 Latina, African American and European American women, the researchers examined two models of serostatus disclosure through a program offered by UCLA. The first model predicts improved levels of mental health with increased HIV status disclosure. The second model based on HIV-related stigma predicts poorer mental health with increased illness disclosure. Mental health was operationalized through depression, reported pain levels and experience of distress. The researchers found no relationship between HIV status disclosure and depressive symptoms in the African American and European American women, but Latina women who disclosed their HIV positive status showed a modest relationship to depressed mood, health-related psychological distress and reported pain. As a result, the findings showed no support for the viewpoint that serostatus disclosure improves one's mental health.

One limitation of this study is that disclosure was not clearly defined. Also, disclosure and mental health indices were measured at the same time despite the longitudinal nature of the study. As a result, no causal relationship could be determined. While ethnic background and acculturation may play a role in the finding, cultural issues were not studied directly and cannot be assumed to be a primary reason for the findings. Comer, Henker, Kemeny, and Wyatt (2000) also point out that the Latina women differed from the African American and European American women in terms of lower education levels, documentation status, primary language, and markedly lower income levels. Lastly, no women of Asian & Pacific Islander descent were studied. The researchers do recommend future research on disclosure with a more comprehensive look at cultural variables. While there are more questions about HIV status disclosure that require additional research to better understand mental health outcomes, "We are now more certain that, in the case of HIV/AIDS, disclosure rates and mental health tend to be

inversely related" (Comer, Henker, Kemeny, and Wyatt, 2000). The researchers only found this inverse relationship in Latina women making their conclusion overbroad. Still, the findings challenge the accepted protocol of HIV positive serostatus disclosure due to negative mental health outcomes in some populations. Because of the demographic differences between the Latina women and the African American/European American outside of ethnicity such as SES level and primary language, an intersectional analysis in future studies is necessary to examine this phenomenon further.

Clark, Linder, Armistead and Austin (2003) also found an interaction between disclosure and stigma where disclosure tempered the relationship between perceived stigma and psychological functioning. Participants who disclosed their HIV serostatus to a larger number of people also scored higher on perceived stigma and lower on psychological functioning which included a rating for depression. Participants who did not disclose or told only a few people showed no significant relationship between perceived stigma and psychological functioning including depression. The study did not indicate the direction of this correlation between stigma and disclosure, and found no change in rates of perceived stigma over time.

According to the literature, disclosure vs. nondisclosure of HIV positive serostatus appears to have mixed results with regard to one's mental health and depressive symptoms. If applied specifically to the Asian and Pacific Islander ethnic groups, will these findings remain mixed? The next session analyzes studies of disclosure and depression as related to HIV stigma in A&PI HIV positive individuals.

### **HIV/AIDS-related stigma, depression, and disclosure/non-disclosure in A&PI communities: A look at intersecting identities**

In a general review of the available literature, research findings on depression in HIV positive patients mainly come from studies of the white male population (Hayes, Turner &

Coates, 1992). This suggests that the social aspects of gender, sexuality, and ethnicity, in this model are largely ignored outside of the white male population. While there are ethnicity-specific studies regarding depression and HIV positive status within the African American (Clark, Lindner, Armistead & Austin, 2003; Sublette, 2008; Vyavaharkar, 2009; Wohl et al., 2012) and Latino communities (Reisen, Zia, Bianchi & Poppen, 2011; Ubiem, 2010; Wohl et al., 2012), there are very few studies involving Asian Pacific Islanders (Kang, Rapkin, & DeAlmeida, 2006). Further, research shows that *stigma* is linked to depression in HIV positive adults (Groves et al., 2010) however Asian/Pacific Islander (A&PI) communities are grossly underrepresented in HIV positive literature. This may in part be due to underreporting and nondisclosure of HIV positive status because of stigma in Asian cultures (Yoshioka & Schustack, 2001).

While much research has shown that nondisclosure of HIV positive serostatus is correlated with HIV-related stigma (Chae & Yoshikawa, 2008; Chin & Kroesen, 1999; Li, Lee, Wen, Lin, Wan & Jiraphongsa, 2010; Nemoto, 2003; Vyavaharkar, 2009), and HIV stigma has been correlated with depression (Charles et al., 2012; Chandra, Deepthivarma & Manjula, 2003; Chin & Kroesen, 1999; Groves, Golub, Parsons, Brennan, & Karpiak, 2010), the possible correlation (positive or negative) between HIV status disclosure and depression has not been fully explored. This is especially true in the A&PI female populations.

Generally there is a dearth of information regarding disclosure of HIV status and correlation with depressive symptoms specific to A&PI women outside of India. When these two factors are discussed for the A&PI communities, the focus is generally on the relationship to behavioral HIV risk factors that lead to seroconversion (Chng et al., 2003; DeAlmeida, 2007; Li et al., 2010). What little literature is available focuses on specific ethnicities within the A&PI

community and shows mixed results. As acknowledged, the mixed findings suggest that HIV positive serostatus disclosure can be both correlated with depression (Chin & Kroesen, 1999) or have no relationship to depression (Nyamathi et al., 2011; Steward et al., 2011). Due to the locale in which the studies were conducted (Southern India vs. U.S.) it is unclear what affect immigrant or native status has on the results. It is also unclear how an individualist ideology as found in the U.S. may affect immigrant populations, especially those that come from collectivist cultures. In addition, the attitudes regarding HIV/AIDS stigma in India and U.S. must also be taken into consideration.

A study frequently cited in the literature about A&PI HIV positive women is Chin and Kroesen's 1999 mixed-design examination of HIV/AIDS status disclosure as related to cultural stigma. The original sample of HIV positive women in a 5-year longitudinal study was used to extract and report only the data on A&PI women. This is the earliest study on this population but only included nine participants as 6 of the 15 A&PI women from the original study refused to participate in the qualitative research. All of the women seroconverted through heterosexual contact. While all of the women reported disclosing their status to someone important to them in their family network, generally they reported distancing themselves from friends and acquaintances after learning their serostatus. Fears of stigma, discrimination, and burdensomeness guided their choices of disclosure.

Chin and Kroesen (1999) also found that women who were unmarried and contracted HIV through sex spoke about concerns of stigma and shame whereas married women did not. They also stated that exposure to HIV through a blood transfusion also did not provoke concerns about stigma. Women who perceived their family to be "more Asian" and thus "less Western" were less likely to disclose their status to their parents. The researchers suggested that the

collectivist attitudes of Asian cultures further inhibit disclosure so as to protect family members from shame and/or stigma. While this was a small study, it did examine women of Chinese, Cambodian, and Vietnamese descent—a highly diverse group. Due to the qualitative nature of the study, more detail and variation in the data was captured posing ideas for future research. The researchers stated that the stigma mentioned by the subjects in this study came from taboos prevalent in Asian cultures. As a result, Chin and Kroesen (1999) hypothesized that the stigma concerns of HIV disclosure may be stronger in A&PI cultures than in other ethnic and racial groups.

Chin and Kroesen (1999) did find that disclosure of HIV positive status could lead to social support and reduce stress in A&PI women which provides support for the idea that disclosure can be helpful. However, there was some variation over time due to stigma. Disclosure was found to both exacerbate and ameliorate stress in A&PI women (Chin & Kroesen, 1999). The researchers acknowledged that while participants had increased social support with disclosure, disclosure of seropositive status also brought on new stressors due to some negative reactions based on HIV stigma and ignorance about the disease. Based on these findings the researchers recommended that disclosure be encouraged only to those family and friends that were likely to be supportive. Basic HIV education was also recommended for family members to increase the likelihood of support and reduce the experience of felt stigma and stress.

Steward et al. (2011) quantitatively studied HIV stigma in a group of 198 South Indian women to assess the effect that disclosure avoidance had on rates of depression. The researchers found that while various forms of stigma may limit disclosure of one's serostatus, nondisclosure did not lead to symptoms of depression. With nondisclosure over one year both symptoms of depression and feelings of internalized stigma reduced. This again supports the idea that



disclosure may not lead to mental health or buffer depression symptoms. This is an important finding as many public mental health HIV programs encourage and support the use of disclosure in the acceptance and coping of their HIV diagnosis.

The Steward et al. (2011) study was limited to one small segment of the A&PI community in Southern India. Data was collected through the author's previously designed stigma scales measuring enacted stigma (experienced), vicarious stigma (witnessed), felt normative stigma (subjective community prevalence of HIV/AIDS stigma), and internalized stigma (deserving of discrimination of others). Results may not be generalizable as a result, but the study supports the idea that disclosure of HIV status is not always a means or requirement for buffering against depression. One hypothesis regarding these findings is that PLWHA that are outside of heavily affected communities such as gay men and IV drug users may find disclosure alienating rather than supportive (Steward et al. 2011). This understanding that addressing multiple intersecting identity factors provides a broader picture of one's HIV/AIDS mental health support needs post seroconversion.

Even within the limited literature on A&PI HIV positive women, there have been some mixed results showing status disclosure to be both protective and detrimental to mental health (Chin & Kroesen, 1999; Nyamathi et al., 2011; Steward et al., 2011). Chin and Kroesen's 1999 study sampled different A&PI ethnic groups finding that stigma, both real and anticipated or perceived, hindered HIV serostatus disclosure. In addition, these women tended to isolate themselves from friends and family due to stigma, shame, and fears of burdensomeness on others. The results suggest risk of developing depression in women who have not disclosed their status, in part due to isolation and concerns about keeping a secret. This study was conducted in the metropolitan U.S. with women representing various demographics. The Nyamathi et al. 2011

study which examined 68 women in rural Southern India found HIV stigma-related disclosure avoidance was negatively correlated with rates of depression. Finally, the Steward et al. (2011) study suggested no impact on rates of depression with nondisclosure of HIV serostatus. Considering that all three of these studies examine the experiences Asian & Pacific Islander women, what might explain the differences in these findings?

One possible reason for this complicated relationship of HIV/AIDS-related depression and serostatus disclosure not yet explored in the available studies may be due to the pan-grouping of A&PI communities often found in the research (Chae & Yoshikawa, 2008; Chin & Kroesen, 1999; DeAlmeida, 2007; Kang, Rapkin & DeAlmeida, 2006; Scott, Gilliam & Braxton, 2004), governmental demographics (Centers for Disease Control, 2010; United States Department of Health & Human Services Office of Minority Health 2012), and public health literature; (Asian and Pacific Islander Wellness Center, n.d.; Iwamasa, 2003) to date. If these studies were to categorize ethnic data (i.e., Indian, Vietnamese, Thai, etc.), as suggested by intersectionality, a deeper understanding of HIV stigma, serostatus disclosure, and the effects on mental health could emerge.

Just as generalization to A&PI communities can be nonspecific and thus unclear regarding results, highly specified studies may be limited in their applicability to larger A&PI ethnic and culture groups. To illustrate, there are several studies examining HIV stigma, depression and serostatus disclosure in Southern India (Chandra, Deepthivarma, & Manjula, 2003; Charles et al., 2012; Nyamathi et al. 2011; Steward et al., 2011), these findings may only relate to the rural Southern Indian population studied. It is unclear what affect their marginal socioeconomic status and unknown educational attainment/exposure, had on the data as the population was highly specific being confined to one homogenous community. Also, HIV/AIDS

is still highly stigmatized in India which may affect the results regarding depression and disclosure. As intersectionality states, multiple forms of identity *intersect* but are not simply added or subtracted. Constructs of identity are interwoven and affect one another creating personal experience. The discrimination, stigma, disclosure avoidance and experience of depression may be unique to this segment of A&PI women.

### **Summary**

In general, regardless of ethnic background, gender, socioeconomic status (SES) depression is an important concern for PLWHA. This is true because symptoms of the disease such as insomnia, weight loss, and fatigue can mimic depression, and therefore depression is often left untreated (Ownby, Jacobs, Waldrop-Valverde & Gould, 2010). Since depression can accelerate the disease process and can lead to reduced medication adherence, increased risk behavior, and increased substance abuse, proper diagnosis and treatment is essential for PLWHA (Ownby et al., 2010). As mentioned earlier, disclosure of HIV/AIDS status has been linked to both increases and decreases in rates of depression in the literature, particularly in broad ethnic category of A&PI individuals (Chin & Kroesen; Kang, Rapkin, & DeAlmeida, 2006; Comer, Henker, Kemeny, & Wyatt, 2000; Steward, et al., 2011)

Deciding to disclose/not disclose one's HIV/AIDS positive status is an important component to the psychological care and support of someone newly diagnosed with HIV/AIDS. Disclosure to select people can help the person find emotional support within their inner circle, while alerting sexual partners to their need for testing. Sharing one's status can also buffer against depression as disclosure allows for access to HIV-related services and social support from other HIV positive individuals. Psychoeducation and motivational interviewing protocols, techniques utilized by mental health clinicians to help clients understand and better manage their

psychological symptoms, are often used when making recommendations regarding disclosure of HIV status. Disclosure however must acknowledge cultural attitudes toward stigma such as a positive diagnosis of HIV/AIDS and collectivism vs. individualism in a culture to enable provision for culturally competent HIV care and support programs within the field of social work.

A review of the literature regarding the link between depression and serostatus disclosure reveals a paucity of information regarding the experience of A&PI women who test positive for HIV. Of the few studies that exist, extremely small sample sizes are utilized (Chin & Kroesen, 1999) and homogeneous ethnic groups are studied without further demographic breakdown such as SES, educational level, age, and sexual orientation (Chandra, Deepthivarma, & Manjula, 2003; Charles et al., 2012; Nyamathi et al, 2011; Steward et al., 2011).

While A&PI individuals are grossly underrepresented in the studies, it is important to understand that this population may be difficult to access due to the stigma and sense of shame associated with HIV positive status. Despite the potential challenge in accessing the population, more cross-cultural and intersectional research is needed to determine generalizability of existing studies to A&PI respondents with regard to rates of depression in the HIV positive community. In addition, a focus on different segments of the A&PI community of PLWHA should be employed to provide much needed culturally competent mental health care that perceives and supports the intersecting identities of individuals within the A&PI community who are affected by HIV/AIDS.

The present paper will now discuss stigma theory to explore the link between depression and HIV seropositive status disclosure vs. nondisclosure experienced by Asian/Pacific Islander women living with HIV/AIDS, a group whose incidence rate is rising.

## CHAPTER IV

### Stigma Theory

**stig•ma** \ˈstɪg-mə\ *n, pl stig•ma•ta* \stɪg-ˈmä-tə, ˈstɪg-mə-tə\ *or stigmas* [L] **1**: a mark of disgrace or discredit **2**: *stigmata pl*: bodily marks resembling the wounds of the crucified Jesus **3**: the upper part of the pistil of a flower that receives the pollen in fertilization -- **stig•mat•ic** \stɪg-ˈma-tɪk\ *adj*, (Merriam-Webster, 2004).

#### Introduction

A stigma was originally a physical mark used by the Greeks to indicate one's marred moral status. Stigmas in the original meaning of the word created a socially bound marker which determined one's social standing and general (mis)treatment (Goffman, 1963). Later the term evolved to refer to the stigma status itself rather than the physical mark born on the body (Goffman, 1963; Weiss, Ramakrishna, & Somma, 2004).

Because of the epidemiological origin of HIV/AIDS initially being associated with homosexuality and later IV drug use, the disease has been stigmatized. Many of the earlier studies in the HIV/AIDS literature have used stigma theory to understand the psychological issues at play in those diagnosed as HIV positive. While the stigma surrounding HIV/AIDS has lessened some, this stigma persists. This may in part be because HIV/AIDS stigma exists in all three categories of stigmatized individuals identified by Goffman: 1) deviation from societal

norms or tribal stigma; 2) changes in physical appearance or physical stigma; and 3) alterations in the self-concept of identity or characterological stigma (Brady, 2006).

This chapter will provide an overview of stigma theory as conceptualized by Erving Goffman in 1963. The background and history of stigma theory and its theorist, Erving Goffman, will be explained. Next, the key principles of the theory will be examined. Finally a critique of stigma theory will be presented explicating its limitations as it relates to A&PI HIV positive women.

### **Goffman in context**

Erving Goffman, a Canadian-born sociologist, held various university posts in Canada and then the U.S., during his prolific career. Goffman's main contribution was the study and analysis of human interaction or dramaturgy (Sannicolas, 1997). Dramaturgical analysis is the study of the performance of social interactionism. Sannicolas (1997) noted that Goffman did not consider himself to be a theorist, tending to borrow from other theories and incorporating this into his method of observation. Goffman's skill was to understand and interpret meaning from his observation and analysis of human interaction (Sannicolas, 1997). There was much debate among scholars regarding his contributions, being lauded by some and highly criticized by others (Williams, 1986). His work was not heavily regarded in academic journals initially, but Williams (1986) notes he was appreciated in esteemed sources of popular media, (i.e. The New York Review of Books, and Time Magazine). Williams goes on to point out that some in academia saw him as politically conservative while others saw him as radical or even apolitical.

His concept of dramaturgical analysis included not only actors engaging in an interaction, but also an observer (Crocker, & Major, 1988; Sannicolas, 1997; Williams, 1986). As Williams (1986) states this has led some critics to see his approach as appearance-based rather than reality-

based, reducing human interaction to an act or production. One key element in all of Goffman's writings is that of an external self and an internal self. In his essay on stigma for example, Goffman discusses the concept of a false self which is created by the stigmatized person to interact with the "normals" (1963). The "false self" functions as an actor in social relationships with those who do not share the person's stigma, and thus is produced out of necessity through social engagement. Goffman's explanation for this seems to be that human beings are ever changing with regard to emotion and endurance, but must not reveal these ever-changing states to others in the social sphere (as cited in Williams, 1986). There is an expectation of normative behavior and social custom which must be followed and causes the emergence of the internal vs. external selves.

### **History of stigma theory development**

Goffman created and developed his treatise on stigma in the late 1950s and early 1960s. There was a great emphasis on the idea of cultural normalcy vs. cultural deviance in the U.S. at that time. He was a professor at U.C. Berkeley, a campus known for its intellectual vitality, and forward-thinking political stance, when his essay, *Stigma: Notes on the Management of Spoiled Identity*, was published. The main concept of his theory focuses on the behavior of the stigmatized individual in reaction to social acceptance. Social acceptance or rejection based upon character, physical ability, or group identification can be real, perceived or anticipated (Goffman, 1963). While he had difficulty collapsing all stigmatized groups into one category of deviance, he found value in their commonality. Weiss, Ramakrishna and Somma (2006) point out that Goffman did recommend studying difference between target groups; they emphasize the importance of this in application of the stigma literature to various health issues in various environments.

Stigma in many cases became an issue of disclosure vs. nondisclosure of the stigmatized identity. Thus, the bearer of a stigma, as determined by the society in which one functions, affects the behavior of the stigmatized, either through nondisclosure and/or through reaction to the treatment by others. Disclosure in Goffman's view would result in lack of social acceptance necessitating that the stigmatized create a false self to adapt and cope. The assumption made by Goffman is that of an order of normative and non-normative groups exists, with stigma enacted by the "normals" onto the non-normative groups. An example of this may be seen in treatment of wheelchair users (non-normative) by the ambulatory ("normals"). Here, those who are able to walk unaided may see others who require ambulatory assistance as "handicapped" or "disabled". More recent scholarship by Kusow (2004) problematizes this assumption stating that the stigma arrow may in fact be bidirectional. That is to say that the traditionally stigmatized groups may actually stigmatize the normative groups as well (Kusow, 2004). Despite this assertion the theory is still applicable, especially when applied in a "Keeping Up with the Joneses" value system. We will now turn to an overview of the main elements of stigma theory. This is especially relevant to the A&PI HIV positive women living in this culture.

### **Key principles of Goffman's stigma theory**

Stigma theory is predicated on the notion of social relationships. A stigma is relationally determined as the attribute such does not contain inherent stigma. Goffman (1963) states that the same symbol such as physical scarring can indicate status in some social relationships while inviting stigma in others. He defines a stigma as a quality that is "deeply discrediting" of one's social identity based upon the expectations of how one should act in that particular ascribed social role. As a result Goffman does point out that stigma is really a relationship between attributes and stereotypes.



**Stigma and social identity:** Relationships determine who is considered socially "normal" in their identity, and who is not. Those who are considered abnormal or defective in some manner are stigmatized by the greater societal group. All individuals fall within the in-group or the out-group designation of a particular normative versus stigmatized identity. This theory assesses all stigmas as lessening one's value unaltered by other elements of one's biography. The theory suggests an idealized concept of perfection held by society that can be marred by a number of factors. Goffman gives the example of only one type of person in the U.S. which is free of stigma, listing the valued gender, socioeconomic, educational, sexual orientation, religious, etc. cultural norms of the time. The list of required attributes necessary to qualify as without stigma is so lengthy and describes so few people that "the issue becomes not whether a person has experience with a stigma of his own, because he has, but rather how many varieties he has had his own experience with" (Goffman, 1963, p. 129).

Goffman (1963) states that individuals are defined by the status of the designation of "normals," while those who deviate from the norm in one of three ways are stigmatized. These three areas of stigma are based on characterological, physical, or tribal identities. Goffman's categories of stigma are based on 1) moral and ethical features of one's behavior, 2) physical deformity (congenital or acquired), and 3) group identity, often inherited such as race or ethnicity. Regardless of the type of stigma one possesses, the social shunning and exclusionary or rejecting treatment from "the normal" is the same.<sup>1</sup> Goffman identifies one's "virtual social identity" as what is expected from one's social role while one's "actual social identity" is what is actually possessed by the bearer. Stigma then depends upon how one is read and understood in terms of social role and cultural expectations. Further, since these assumptions and

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<sup>1</sup> While some stigmas may be greater than others, Goffman does not go into this issue.

categorizations placed upon the stigmatized may not be correct, they can result in uneasiness for both parties (Goffman, 1963). Goffman suggests that as a result of the frequency with which stigmatized individuals must handle these situations, they are more likely to become adept at managing them.

***The own and the wise:*** There are the "sympathizing others" who befriend and support those possessing a stigma (Goffman, 1963). This group includes those who also possess the stigma and have experience with how to manage it, especially with regard to the outside world. The "wise" are "normals" whose acceptance and treatment of the stigmatized is no different than "normals" although they are aware of the stigma. Goffman states that these persons may have special, intimate knowledge of the stigmatized group making them sympathetic to the stigmatized person's plight. This could be someone in the role of a caregiver for example. Other examples include a therapist, a special education instructor, or a family member of the stigmatized individual.

***Moral career:*** Goffman (1963) identifies phases in which all stigmatized individuals go through as they form their perception of self and identity. He identifies this as the "moral career" consisting of an identification of the stigma itself as perceived by "normals", followed by the stigmatized person's realization that they possess this stigma. He identifies patterns of socialization relating to: 1) inborn stigma with both phases occurring simultaneously such as an orphan learning that most children have parents at the same time the child learns he/she has no parents; 2) a stigmatized individual raised with a protective shell of a family or community for some length of time such as a blind child going to a series of schools for the blind and transferring to a standard high school; 3) socialization of a stigma occurring late in life such as when developing an acquired disability like limb amputation in late adulthood; or 4) those who

are socialized about their stigma in an alien community who must learn of their stigma as their true and real identity such as a blind writer, initially stigmatized for being blind and later encountering those in his career who stigmatize him for being a writer while being blind. Regardless of which pattern the "moral career" follows, the development of identification with one's stigma and others who share it is a formative time fraught with ambivalence about the self and others.

**Information control and personal identity:** Goffman (1963) discussed the role of the stigmatized person as one of information control, what we might now identify as disclosure of the stigma. He explains there are those who cannot hide their stigma such as with an absent limb. These stigmatized individuals are described as the "discredited"—their stigma is on display at all times, and social interactions with "normals" can only be managed. Over time with increased social exposure, the normative group may come to overlook, ignore, or normalize the stigma through the "tension management" of the stigmatized. By contrast the "discreditable" stigmatized individuals have some ability to keep their stigma hidden. They must practice "information control" and decide when and to whom to disclose their stigma. Attempts to "cover" or "pass" as normal with physical "disidentifiers", such as a glove to mask the appearance of absent digits on the hand, may protect the discreditable, however, they may be fearful of accidental exposure of their stigma should they choose to hide it. An example of accidental exposure could occur when a male-to-female transgender individual currently presenting in both genders at different times is seen with traces of finger nail polish while presenting in the male gender at work after a previous social event presenting in the female gender. "Personal identity" then is set of facts about a person that makes them unique from all others, but is also constructed by the other using aspects of social identity.

**Group alignment and ego identity:** Goffman (1963) makes a distinction between personal identity which can be affected by others, and ego identity which is a subjective experience. He then explains that social identity is the element that allows for stigmatization to develop while personal identity is responsible for information control or disclosure/non-disclosure of one's stigma. Individuals possessing a stigma experience ambivalence of identification with others that share the stigma or an attempt at "disidentifying." In this state of identity vacillation, Goffman observed that the individual will seek advice from "professionals" with experience in stigma management, generally from their own personal experience who share the same stigma the stigma. He uses the term "professionals" to indicate one who has more experience "disidentifying" with the stigma who has essentially become an "expert" at concealment of the stigma. This guidance from the "professional" or "expert" aids the stigmatized individual in understanding societal expectations assigned to her stigma-dictated social role to aid in navigation of social interactions. One might call it "learning the ropes" of her new identity. For example, a person who has undergone gender transition and prefers to disidentify from their prior gender assignment history can advise one who is new to transition about how to update medical, social security, driver's license and other identity documentation to reveal only their present post-transition gender identity.

***In group alignments:*** Goffman (1963) explains that while stigmatized individuals are subject to expectations of the "normals", he also identifies the stigmatized as part of a group. Sociologically, group dynamics indicate that personal identity is defined by group membership. Thus, if the stigmatized accepts the group membership and becomes fully and completely identified with it, her desire to remove the effect of the stigma through belongingness may be counteracted as she now has a politicized identity. Rather than becoming more normative, by

embracing the stigma and becoming more rejecting and separatist, the stigmatized person develops a life "even more different from the normal life initially denied him" (Goffman, 1963, p. 114). Examples of this include movements such as feminism, Black Power, and gay pride.

***Out-group alignments:*** The alternative to separatism is to accept oneself as a valid human being who may be excluded from some facet of social life. The individual possessing the stigma should neither flaunt nor attempt to hide the stigma. This approach suggests that stigmatized individuals should see "normals" as innocent in their occasional slights, and should offer "sympathetic re-education" of the full humanity of the stigmatized. This further suggests that the person possessing the stigma is advised to "take the high road" or perhaps use humor to ease any tension felt by the normative person in an interaction. Goffman (1963) points out however that the extension of this out-group alignment leads to a determination of mental health/illness dependent upon one's acceptance of social exclusion and need to provide comfort for the normative population.

***The politics of identity:*** A stigmatized individual receives mixed messages about her identity. On the one hand she is part of humankind and therefore retains group membership. She is also told she is in some way different than most members of the group and that this difference cannot be denied or ignored. Since social relationships are responsible for this determination of sameness/differentness, one's ego identity is held hostage by these conflicting concepts and the expectations of the stakeholders of "normals" and other stigmatized "professionals".

***The self and its others:*** Goffman (1963) addressed the response of the stigmatized person to their social world. He states that unlike other norms, the intent to follow them to the best of one's ability is not enough. A designation of "normal" is proffered based upon the success to conform to social expectations rather than attempt to do so. Goffman also identifies

the deviant and normal individuals as part of the same identity whole. He identifies the human ability to either be released from a stigma or to develop one, and to recover psychologically and cope with either shift. This ability he attributes to being parts of the same whole. It is in this part of the theory that Goffman identifies the stigmatized and the normal identity as perspectives rather than actual groups of people. Here he hints at one feature of intersectionality stating that each identity can play both roles, albeit one more frequently than the other, at different times and in different situations. In the same way that intersectionality acknowledges the shifting power dynamics of intersecting identity features in different settings, (a white woman experiences less oppression than Black woman but more oppression than a white man,) Goffman acknowledges that identity features are not essentially "normal" or stigmatized but fluid and changeable.

The lifelong attributes of a particular individual may cause him to be typecast; he may have to play the stigmatized role in almost all of his social situations, making it natural to refer to him in opposition to normal. However, his particular stigmatizing attributes do not determine the nature of the two roles, normal and stigmatized, merely the frequency of his playing a particular one of them. And since interaction roles are involved, not concrete individuals, it should come as no surprise that in many cases he who is stigmatized in one regard nicely exhibits all the normal prejudices held toward those who are stigmatized in another regard (Goffman, 1963, p. 138).

Finally, he also suggests that stigma has a role in social order and social control such as the stigma placed upon those who are incarcerated.

**Deviations and deviance:** Goffman (1963) closes his treatise with the idea that so-called deviants are more different than they are similar. He distinguishes between "disaffiliates" who reject the general social order perhaps on political grounds refusing to accept the social status

connected to basic societal institutions (i.e., protesting for gay marriage), and general "deviance" as a type of behavior displayed by the denial of the social order, (i.e. "the urban unrepentant poor", sex workers, drug addicts, criminals, jazz musicians, etc.). This denial is in contrast to those who reject the social norms with a willingness to push against them.

### **Critique of stigma theory**

Stigma theory is one way to conceptualize behavior in individuals living with a social stigma. HIV/AIDS is one such stigmatized identity. Generally those who seroconverted and received treatment since the advent of protease inhibitors do not show visible signs of HIV/AIDS-related illness. As discussed here, the "discreditable", or those who can choose to withhold or disclose their stigmatized identity are often defined by ambivalence especially during the early stages of the "moral career". This ambivalence about disclosure of stigma, necessitating some acceptance of a stigmatized identity, leaves one open to isolation, rejection, intimacy issues, and other concerns. This places the individual at risk for depression in part due to the uncertainty and potential risk to her social role such as with family. However, HIV/AIDS stigma may not be the only issue of identity and stigma that is of concern to a particular individual. There are advantages and disadvantages to this behavioral conceptualization in A&PI HIV positive women. Multiple identities are at work and influence her decision to disclose and her circumstances leading to development of depression.

**Advantages of the use of stigma theory with HIV positive A&PI women:** One advantage of this theory is the identification of ambivalence at the time of the "moral career" pattern is developing. This time of uncertainty regardless of how one might come to understand and associate with their HIV status can help provide a framework to understand the potential for developing or buffering against symptoms of depression. Based upon the particular

circumstances of diagnosis, and how the seroconversion occurred, the individual's willingness to associate with others like her will be affected. This will also affect how ready she is to identify with this stigmatized identity as an HIV positive woman. Feelings of fear, isolation, rejection, etc. during this ambivalent phase leave an opening for depression to develop. Choosing when and how to disclose one's status through this framework can be viewed as protective through information control techniques identified by Goffman (1963).

**Limitations to use of stigma theory with HIV positive A&PI women:** One limitation of stigma theory is that it predicts that stigmatized individuals will have low self-esteem. This is not necessarily the case. Crocker and Major (1989) suggested that those possessing stigma can buffer themselves from low self-esteem. They hypothesize that this protects and bolsters self-esteem in three ways: 1) stigma may be seen as simply prejudice by the stigmatized; 2) comparing themselves to desired others in their group; and 3) assigning value to traits possessed by their group based upon success and failure by those stigmatized others (Crocker & Major, 1989). Lack of disclosure may in fact be protective of self-esteem in newly HIV positive A&PI women.

Next, Goffman's presentation of stigma theory focuses on one particular facet of a person's identity. The theory discusses individuals with identity stigma related to religion or ethnicity, as well as aspects such as mental illness, criminality, and disability. Goffman uses multiple case study examples to explain his theory. In each example, the stigmatized person is identified by their stigma, suggesting only one facet of identity. He does not examine cases of multiple stigmatized identities such as a blind Jewish woman who ambulates in a wheelchair. The theory is silent in explaining how more than one stigmatized identity might affect this concept of a false self or external social identity to emerge. In addition, the theory does not



explain how external stigma from the "normals", not accepted or perceived by the stigmatized, is addressed. This theory was published in the early 1960s and was no doubt developed over the preceding years. As a result the theory is antiquated with regard to the present social temperature. Assimilation and conformity were near absolutes at that time, while concepts of diversity among groups and within one individual were not accepted. U.S. society was arguably more homogenous at that time, at least on the surface. The theory must be expanded to make it applicable to current societal norms.

As Weiss, Ramakrishna, and Somma (2006) assert, Goffman's theory if applied to health policy is 1) antiquated, 2) over broad and 3) unable to adequately account for cross-cultural issues. While Goffman hints at the idea that we each have multiple identities potentially affected by stigma at different points in our lives, his conception is limited. The movement toward diversity, multicultural identities and expansion of normative identity in the U.S. since 1963 requires a more complex theory be used to understand how we identify with, utilize and choose to disclose/not disclose stigmatized identities. In the next chapter a discussion of intersectionality will explore the complexity of normative and stigmatized identities interacting to produce our internal and external social identification.

## **Summary**

Stigma theory as explained by Erving Goffman is helpful in understanding the various forms of stigma afflicting those living with HIV/AIDS. While Goffman (1963) describes three types of stigmatized identities including characterological, physical and tribal, HIV/AIDS complicates this notion as it incorporates all three types of stigma (Brady, 2006). HIV/AIDS can contain characterological stigma due to methods of transmission (anal sex, IV drug use), tribal stigma due to being a member of gay community that embraces sex without condoms, and

physical stigma due to potential physical markers such as facial wasting. The complexity of HIV/AIDS identity is further problematized by the multiple identities possessed by Asian & Pacific Islander women who become HIV positive. Age, sexual orientation, relationship status, ethnicity, educational background, documentation status and other factors all come together to complicate the notion of stigma. Stigmatized identities are oppressed identities. Intersectionality will next be explored to examine the interplay of multiple facets of identity affect issues of stigma, depression, and disclosure of HIV positive status.

## CHAPTER V

### Intersectionality Theory

#### Introduction

While stigma theory has been instrumental to the empirical research on HIV/AIDS status disclosure, intersectionality theory deepens our understanding of racial, ethnic gender, and sexuality variances in depression of PLWHA. This chapter will provide an overview of intersectionality theory as first named by Kimberlé Crenshaw in 1989. The theoretical conceptualization of intersectionality is rooted in Black Feminist theory. It was further developed through antidiscrimination theory, critical race theory, and identity politics. While Crenshaw is frequently recognized as creating the theory of intersectionality, it is important to note that many of the ideas she puts forth were present in feminist writings from The Combahee River Collective in 1977 (Intersectionalities, n.d.) and Gloria Anzaldúa's concept of the "borderlands" in 1987. The earlier writings brought about the birth of identity politics through the experiences of Women of Color. Crenshaw explicated these ideas and took identity politics a step further through the use of a metaphor for which intersectionality is named (Intersectionalities, n.d.).

The term intersectionality refers to intersecting crossroads of social structures experienced by the individual as a member of social categories or groups. One's identity and experience of oppression (or power) can be felt in the intersection of these crossroads. The origin of the theory began with a focus on the interaction of race, primarily Black identity and white

identity, and the gender binary experiences of women and men. Factors of identity which are created and produced at the macro level intersect and interact at the micro level of experience to form identities that are not additive, but interactive in terms of power and oppression (Bowleg, 2012; Collins, 2000; Crenshaw, 1989, 1991). For example, Black experience plus female experience does not equal Black female experience because Black experience is defined by the dominant Black *male* experience while femaleness is defined by the dominant *white* female experience.

As we move through the world, our perceived identities and our actual identities shift and change in terms of our power and access. An identity that is powerful in one setting (white mother of two caring for her children), can change to powerless in another setting, (white mother of two in line applying for food stamps). Since it was first introduced and named by Crenshaw in 1989, intersectionality has been expanded to analyze all forms of identity including race, ethnicity, sexual orientation, the gender array, disability, class, family role, employment status, mental and medical health/illness identity, etc. (Collins, 2000). In this expanded view, the theory asserts that we each possess multiple factors of identity that change day-to-day, moment-to-moment, in terms of significance, priority and dominance/subordination. It is in this context of intersecting identities that the interplay of HIV/AIDS status disclosure, and depression, will be examined in Asian and Pacific Islander women.

First, Crenshaw's biographical information will be presented followed by a brief history of Black feminist theory and the generation of intersectionality theory. Next, the key principles of the theory will be examined through the framework described by Crenshaw highlighting her examples of Black female oppression which challenge the status quo. Then, the evolution of two

main viewpoints from the theory will then be considered, social constructionism<sup>2</sup> and poststructuralism,<sup>3</sup> arguing that social constructionism is the approach from which we must methodologically operate in empirical research and in evidence based practice. Finally a critique of intersectionality theory will be presented explicating its advantages and limitations as it relates to mental health treatment in A&PI HIV positive women.

### **Kimberlé Crenshaw: Pioneer in Black feminist legal theory and critical race theory**

Kimberlé Crenshaw, a professor of law at UCLA School of Law since 1986 and Columbia Law School since 1995, has published widely in preeminent law journals and led numerous workshops regarding gender, race, affirmative action, domestic violence, human rights, and racial inequality (African American Policy Forum, 2013). Her groundbreaking work regarding Black feminist legal theory and intersectionality in journal publications, lectures and workshops has been internationally influential. For example, her theory was drafted in language for an equality clause in the South African Constitution, and she was a main contributor in organizational efforts and presentations for the United Nations International World Conference on Racism. She is an expert in critical race theory. She received her B.A. from Cornell in 1981, her J.D. from Harvard Law in 1984, and her L.L.M. from the University of Wisconsin in 1985 (Crenshaw, 2010). She is a cofounder of the African American Policy Forum (AAPF), an

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<sup>2</sup> Sociological and philosophical perspective that states social constructs such as gender or race are socially constructed and defined rather than containing any essential qualities.

<sup>3</sup> A philosophical perspective which decenters the author's argument and analyzes how social concepts such as "male" or "Black" are constructed and produced through one's individual lens, without a socially defined consensus.

informational collective and policy institute composed of American legal and educational scholars concerning race and gender equality (AAPF, 2013).

Crenshaw first introduced the concept of intersectionality in her 1989 paper which argued that Black women were marginalized and even erased from discourse involving "Blacks and women" (Crenshaw, 1989). It is from this work and her follow up paper in 1991, *Mapping the Margins*, that intersectionality was conceptualized in the early years of Black feminist ideology and discourse. Crenshaw's use of the traffic intersection metaphor resulted in the term intersectionality (Bello, 2008).

### **Black feminist theory and the origin of intersectionality**

The Black feminist movement began in 1973 in response to the racism Black women experienced in the feminist movement, and the sexism experienced in the Black Liberation Movement of the 1960s, with the founding of the National Black Feminist Organization (MIT Alternative News Collective, 1995). Black women found that their experience was not represented in either movement despite being counted as members of both communities. Black Feminism evolved to represent the unique experience of racism, sexism and classism experienced by Black women in the United States, and to address the issue of invisibility providing social and political representation for Black women. The following year in 1974, The Combahee River Women's Collective was founded to take a more radical approach and specifically address the needs of Black lesbians as different from white women, Black heterosexual (and perhaps bisexual) women and Black men (MIT Alternative News Collective, 1995).

Concurrently, feminist ideology had been writing about the experiences of women, but from the perspective of middle class white women. Black women were only invited to join

panels or express opinions that were specifically focused on race or women's issues in developing nations (MIT Alternative News Collective, 1995). In the fight against the sexist ideology as a struggle for women's power, inside and outside of the home, white women's experience however was attributed to *all* women. Black women had long worked outside the home and were seen as naturally promiscuous, while the white female stereotype represented in feminist literature was of the chaste housewife; Black women were simply not represented in feminist literature and discourse (Arifuddin, 2011; Crenshaw, 1989; MIT Alternative News Collective, 1995). The language used to describe women's identities demonstrated the inherent racism and classism experienced societally by Black women: a white mother was simply "housewife" or a "working mother" and a Black mother was either a "welfare mother" if unemployed or a "single mother" if working.

Black Liberation embraced patriarchal ideology of power for all men over all women's bodies. Black women were expected to support the reclamation of Black male power rather than the liberation of the entire Black community (Arifuddin, 2011; MIT Alternative News Collective, 1995). Black women who identified the racism present in feminism and the sexism in the Black Liberation movement were viewed as divisive, as working to undermine the work done by both movements rather than put aside their own needs and join forces. This however suggests that identities are separate pieces, distinct building blocks that make up a person's internal and external experience. Thus, these women could be Black in one space of their lives and women in another space but not Black women in either space. Good.

Crenshaw (1989) makes the case that one's identity experience is found in the intersection of racial and gender discrimination rather than operating on a single axis (AAPF, 2009). She goes on to explain that denying the interaction of these aspects of identity serves as not only

discriminatory but the full erasure of experience (Crenshaw, 1989). Thus women of any racial status experience gender oppression but not of the same quality or magnitude, just as Blacks and all People of Color experience some element of racial oppression however these experiences are of varying degrees and types.

### **Key principles of intersectionality as explicated by Kimberlé Crenshaw**

Traditional theoretical constructs of social justice and injustice have conceptualized the experience of oppression as active in one particular dimension of identity. One may be oppressed based upon race, ethnicity, gender, sexual orientation, class, etc. and may seek reparation for a single mode of discrimination as defined by the dominant group's experience. Thus, racial oppression is defined by *male* racial oppression, while gender based oppression is identified through the experience of *white* cisgender, congruence between gender identity and gender assignment, females. However, concepts of social advocacy have been unable to acknowledge more than one type of oppression based upon the ideology that such a claim is simply additive. Generally, advocacy groups address and one particular construct such as gender or sexual orientation, advancing a political agenda for a chosen aspect of identity. Intersectionality states that elements of identification, including but not limited to race, gender and class interact to create experiences that are not merely the sum of their parts. Blackness and whiteness, for example, come together with elements of gender, nationality, sexuality, etc. to form rich forms of experience. Being a white woman from South Africa is quite different from being a white woman from the southern United States, although both are members of the dominant culture in countries with histories of slavery, colonization.

Crenshaw uses case law to explain the impact of single identity analysis applied to issues of discrimination (1989; 1991). In order to meet the changing demands of social justice,



intersectionality theory calls for an updated means of analysis leading to new legal and social interventions as well as advocacy (AAPF, 2009) such as with fair immigration law and criminal justice system policies. The following concepts are expressed in Crenshaw's work.

**Multiple identities:** All individuals belong to multiple categories of identity including race, gender, class, and sexuality. These identities are based on differences with one category (i.e. whiteness) being dominant while other categories are subordinate (i.e. Blackness). An example of these multiple identities is found in the ADDRESSING Framework categories developed by Hayes (2008) which include age, disability, religious or spiritual affiliation, ethnicity, race, class, sexual orientation, indigenous heritage, gender, and national origin.

***The traffic intersection metaphor:*** The discrimination experienced by the intersection of race and gender are explained by Crenshaw (1989) as similar to someone injured at a traffic intersection; injury can come from multiple directions at the same time. Further, injury from more than one "vehicle" of systemic oppression compounds the problem, confusing the primary and secondary culprits. Much like being hit by two different motor vehicles in an intersection, the situation demands repair of the immediate harm (via 911) regardless of fault. Following this metaphor, delay of medical treatment until fault and responsibility was determined would be inhumane at best. The patient is treated regardless of who harmed her or how her medical care will be paid for. In the legal realm of discrimination however, the case law Crenshaw cited did exactly that—determined which injury was the appropriate one to receive treatment based upon determination of fault, or denied "treatment" to the plaintiffs stating fault could not be determined although harm was done.

***Who stays in the basement; who breaks through the ceiling:*** Crenshaw (1989) explains how the more classes of oppression that mutually exist, the further down in the basement one is.

She states that oppression is analogous to a basement of bodies where the oppressed are kept. Those without oppression, "the unburdened," are upstairs moving freely, (i.e., rich, straight abled-bodied white men.) The oppressed are beneath sorted by multiple forms of discrimination. Those at the top peeking through the basement's ceiling are those that "but for" their color (Black men) or their gender (white women) they would be above. Crenshaw uses this analogy to show how systemic oppression encourages identification with the unburdened (white men) to escape the oppressive basement (1989). Both the feminist movement and the Black Liberation movement "stood on the shoulders" of Black women keeping them "in the basement" while using their numbers to show support and strength in their respective movements.

**Privilege and social access:** Categories of identity can be socially privileged or disadvantaged in terms of social, legal, and financial access. This is especially important when these categories interact with access to goods and services such as housing, employment, and healthcare (AAPF, 2009).

**Differing individual experiences within groups:** Not all members of any given identity experience the identity in the same way. This aspect acknowledges that all women will not experience their femaleness in the same way. For example, a transgender woman and a cisgender woman have very different gender experiences.

**Power and privilege offsets:** Individuals can concurrently be members of both disadvantaged and privileged groups. While one may experience power and privilege as a member of one group, that power may be offset or even eradicated by the disadvantage of another category. A white male who is a homeowner carries daily privilege while a white man who is homeless may have little power to affect change or access to housing, canceling out the privilege afforded by his race and gender when socioeconomic status (SES) is at play.

**Categorical overlap:** Categories of identity are not discrete, essential, mutually exclusive groupings and thus are not merely additive terms of privilege or disadvantage. A Black woman experiencing oppression due to both her gender and racial/ethnic identity cannot be defined in terms of simply sexism plus racism. Her experience as a Black woman is more complicated than the sum of these two forms of discrimination. These factors of her identity overlap and interlock to inform her experience particularly with regard to oppression. As explained above, Black identity is defined by dominant Black *male* experience while female identity is defined by dominant *white* female experience.

**Where, when, and how we move in the world:** All identity categories are socially located, and time and space dependent. In the United States, various ethnic groups have been assimilated into the grouping of "whiteness" over time. During the various waves of immigration, these groups were decidedly racialized and discriminated against upon their initial arrival into the country. Some examples include Italian, Irish, and Jewish immigrants who were once seen as racially inferior but are now generally accepted as part of the white dominant culture and afforded privilege. At the same time, a "white" Jewish person would still be discriminated against today by a white supremacist. In yet another example, a biracial individual may be viewed by others as "Black" in one setting and "white" in another, regardless of self-identification, or may view themselves as part of one group or another at any given time.

**Social location as a determinant for access/power:** Any particular categorical identity can be either disadvantaged or privilege depending upon the individual's social location. A teenage student may be subordinate to her caregivers at home, but experience independence and dominance/leadership as an athletic team captain and/or a manager in a part-time job.

**Categories construct, deconstruct and reconstruct each other:** Identity is created by

social structures and ideologies, while individuals further define, refine and impact these categories either by congruence or incongruence with the categorical definition. Socialization prepares individuals for an expectation of the norm of a particular identity such as masculinity. The degree to which one conforms or alters this construct in performance of this gender role impacts the general construct of masculinity. Individual impact can help account for the change in the expectations of masculinity over time and across cultures. As Collins (2000) explains in her seminal work regarding Black feminist theory, "systems of race, social class, gender, sexuality, ethnicity, nation, and age form mutually constructing features of social organization, which shape Black women's experiences and, in turn, are shaped by Black women."

### **Critique of intersectionality**

**Advantages to use of intersectionality with HIV positive A&PI women:** The use of intersectionality has benefits to clinical research and practice. Nash (2008) believes that intersectionality has problematized race and gender binaries making room for more complex discussion of identity. Use of this framework acknowledges that gender, sexuality, ethnicity, nationality, culture, etc. are inextricably wound together and cannot be separated if we are to understand the experiences and the behaviors and needs of this A& PI or any other population. Taking this a step further, use of McCall's (2005) intracategorical methodological analysis which will be explained further in the next chapter) suggests that study within A&PI groupings of HIV positive women will reveal intragroup difference that would otherwise be missed by the homogenization of this ethnic category.

Speaking directly about feminist perspectives in HIV/AIDS work, Bredström (2006) critiques the work that has been done as limited to intersectional analysis on gender and sexuality while taking an essentialist, cursory, and additive approach to factors of race, class, SES, and

education. She points out that in doing so, assumptions made erase experience and commit the same errors made by essentialist viewpoints. Applied to A&PI women the lack of substantial research on this population effectively results in an erasure of this HIV positive population despite statistics indicating increased prevalence. Empirical focus on this group of women would likely impact prevalence and incidence rates either by uncovering and treating a greater problem or bringing attention to a problem before it becomes of epidemic proportion.

Nash (2008) finally points to the centralization inherent in the theory, making previously marginalized groups the focus of the discussion and research. As A&PI women in the U.S. are not a homogenous group ethnically or culturally yet have been treated as such, and have been largely ignored in the literature on HIV/AIDS despite growing numbers, this approach to research in both qualitative and quantitative studies will allow for greater understanding of the needs of these women especially with regard to mental health concerns. This theory also shifts the focus of the research toward a greater emphasis on the selection of and justification for the choice of study subjects.

Finally intersectionality allows for the possibility that HIV/AIDS is *not* the main issue for some populations, or that it takes a backseat to other more pressing and contributory problems like poverty. Previous HIV/AIDS research by Gurung, Taylor, Kemeny and Myers (2004) found that among African American, Latina, and European American HIV positive women living with multiple burdens invoked by their low SES, HIV/AIDS was not their biggest concern. The pliability of intersectionality allows for an exploratory rather than deterministic approach.

**Limitations of the use of intersectionality with HIV positive A&PI women:** Criticism levied against intersectionality theory states it offers no true method for analysis, while also being imprecise in its definition and application (Nash, 2008; Phoenix & Pattynama, 2006).

Nash (2008) questions whether intersectionality accurately describes lived experience and encourages further examination of critical analysis. I argue that intersectionality is an improved paradigm that allows for more in depth investigation of current problems in need of empirical study, while holding open the possibility that future findings may lead researchers to the need for an alternative framework. This will be discussed further in the discussion section next chapter.

Methodologically speaking this theory is still in its infancy and offers no straightforward approach for researchers thus limiting its applicability and use as a theoretical paradigm. In addition, the theory is intended to complicate and problematize traditional modes of thinking about categorization upon which empirical methods are built which in turn makes research more difficult. Data collection and observation of behavior begin with selection of groupings based upon gender, sexuality, race, etc., and according to the theory, experience occurs at the intersection of these groupings. Perhaps as Nash (2008) suggests, human experience is more complicated and murky. One might imagine experience more like a series of interstate highways with various intersections of which we move in and out. Using traditional categories to understand experience may lead researchers to examine the "wrong intersection" and thus again miss critical information necessary to examine full experience. In this sense, when looking at research itself intersectionality is not an advantage over other methodological frameworks.

### **Summary**

Intersectionality is an improvement upon the use of stigma theory as a conceptualization for HIV/AIDS in the A&PI female experience. Rather than focusing on stigma alone as a guiding force for how and why A&PI women perceive and manage their HIV/AIDS diagnoses, intersectionality allows for a richer picture of the lives of these women, taking into account their nationality, ethnic background, education, documentation status, and other important factors.

This understanding is necessary for the development of evidence based practice to provide mental health support to the growing and likely underreported A&PI HIV/AIDS incidence and prevalence rates.

The theory of intersectionality, named by Kimberlé Crenshaw in 1989 is rooted in Black feminism, and developed through identity politics, antidiscrimination policy and critical race theory. Crenshaw's used a traffic intersection metaphor and basement/ceiling analogy to describe identity, particularly the experience of oppression. She put forth several concepts that were expanded through interdisciplinary scholarship. The key principles to the theory of intersectionality include: 1) the existence of multiple socially constructed identities which intersect and form a unique identity and experience different than the sum of parts; 2) privilege and social access is group identity dependent; 3) the existence of differing individual experiences within groups; 4) privilege due to one status can be effectively "canceled" by the disadvantage conferred by another identity, 5) macro level categories of identity overlap and form a micro level of experience, 6) identity is time and space dependent, 7) one's social location determines access and power; and 8) macro and micro identities interact to construct, deconstruct and reconstruct each other.

Intersectionality has the advantage of breaking through the binary assumptions of experience and centralizes marginalized populations, of which HIV positive A&PI women are a part. It also provides a language to speak about the complexity of human experience, placing some focus on just who and why we study, rather than simply *what* we study in the assessment of phenomena. At the same time, intersectionality is limited by its complexity in terms of research. However, this doesn't mean it's not more accurate than a binary approach. The theory breaks the mold of scientific inquiry embracing the ideology that human experience cannot be

understood through categorical math. As a result, it has been criticized for its imprecision and lack of clarity in methodological approaches. This same argument can be used to critique most quantitative research. Quantitative methodology oversimplifies data and eliminates outliers for the sake of simple statistical analysis. The intent of an intersectional theoretical approach is to include these outliers and provide a more representative and accurate interpretation of research data.

The multiple facets of identity which affect issues of stigma, depression, and disclosure of HIV positive A&PI women should be examined with a movement towards acceptance of complexity. Crenshaw advocates for embracing the intersections of social classifications to find a more rich and complex understanding of human experience in terms of power, access, and oppression. An intersectional framework for change recommends action in methodological analysis such as through use of complex multiple regression statistics, through legal and social interventions, and through political advocacy. Increasing use of this theoretical framework in empirical research can affect change in each of these areas for HIV positive women of Asian and Pacific Islander descent.



## **CHAPTER VI**

### **Discussion**

#### **Introduction**

Receiving an HIV/AIDS diagnosis, as with any chronic illness, is a stressful and life-altering event regardless of one's ethnic background, gender, or SES, placing the individual at risk for developing depression and other mental health symptoms (Ownby, Jacobs, Waldrop-Valverde, & Gould, 2010). Depression is an important concern for PLWHA since lack of treatment for depression has been shown to accelerate disease process (Leserman et al., 2002) and mortality rates, particularly in women (Ickovics et al., 2011). When first diagnosed, deciding to disclose or not disclose one's HIV/AIDS seropositive status is an important decision influenced by many variables including concerns about social stigma. It is often at this juncture that clinical social workers come into contact with HIV positive clients. Culturally responsive support and guidance is critical to help the newly diagnosed person sort through the issues and potential impact of disclosure in multiple relationships, (i.e., with a partner, family members, employers, and others).

Unfortunately, little research has been done on mental health effects of HIV status disclosure in A&PI communities despite increasing HIV/AIDS prevalence rates. Clinical social workers that serve A&PI HIV positive women have few empirical resources to draw from on how best to help these clients adjust to the disease. The limited research available shows

HIV/AIDS serostatus disclosure linked to both increases and decreases in rates of depression in the A&PI community (Chin & Kroesen; Comer, Henker, Kemeny, & Wyatt, 2000; Kang, Rapkin, & DeAlmeida, 2006; Steward, et al., 2011). The small body of existing literature predominately 1) utilizes stigma theory to understand A&PI women's experience post HIV/AIDS diagnosis, and 2) either blurs ethnic and cultural difference into the greater A&PI term or looks at small homogeneous populations, i.e. HIV positive women in rural Southern India which cannot be generalized beyond the group studied (Charles, 2012; Nyamathi et al, 2011; Nyamathi, 2012; Steward et al, 2011). While stigma theory is useful, I argue that a better theoretical construct is available to sort through the mixed findings and to encourage more robust analysis of demographic differences in the data. I also argue for an intersectional approach in clinical social work when treating A&PI HIV positive women in public mental health settings.

This chapter discusses stigma theory as a single axis of identity, providing much needed but limited understanding of psychological effects of HIV serostatus disclosure in A&PI women. Further exploration of intersectionality in empirical and clinical application will then be discussed. A summary and synthesis of the theories will follow with implications for practice and research. Finally strengths and weaknesses of an intersectional approach will be addressed.

### **Analysis of stigma theory and intersectionality theory in A&PI HIV positive women**

A&PI communities have been overlooked when stigma and depression related to HIV/AIDS have been studied in ethnic minorities. This is notable since this community is increasingly impacted by HIV/AIDS. As of 2001 Asian American/Pacific Islander MSM had the second highest proportion (72%) of diagnosed AIDS cases within their community compared to American MSM in other racial and ethnic groups (Chng, Wong, Park, Edberg & Lai, 2003). The available research regarding HIV in A&PI individuals connects HIV stigma with depression, and

HIV stigma with disclosure vs. nondisclosure of serostatus. Stigma theory can be helpful to understand the potential correlation of serostatus disclosure and depression, but it does not shed light on the mixed findings. Another theory is needed to deepen our understanding of this complex issue.

**Stigma theory as single-axis paradigm:** Stigma theory is a useful albeit limiting framework to understand how A&PI women manage the stressful social, cultural, and emotional consequences of an HIV/AIDS diagnosis. HIV/AIDS stigma is a very important issue to consider; however, the danger in this theory is the potential for reductionist thinking with regard to identity. Goffman's (1963) treatise states that the stigmatized person becomes defined by their stigma and then adapts to it. The stigmatized person does not incorporate it or transcend their stigma and remains stuck with the stigma as their primary hallmark of identity, i.e. being defined by HIV positive status before gender, age, ethnicity, or SES. The research conducted by Steward et al. (2011) shows that as time goes on HIV stigma lessens and no longer affects rates of depression, which return to baseline one year after the initial diagnosis. These findings counter Goffman's (1963) stigma theory that HIV/AIDS remains the primary identity marker in one's life. The study supports the idea that HIV/AIDS becomes merely one additional identity factor but no longer dominates the individual's experience.

Stigma theory also focuses on the experience of the individual through the lens of accepted social norms rather than questioning or refuting the construct of stigma. Goffman (1963) does not acknowledge multiple identities of stigma or oppression, i.e., a nonambulatory, HIV positive Filipina woman will likely experience multiple forms of stigma. How will she adapt and cope? Will one stigma be primary? Is the stigma additive making her more oppressed

than someone with only one or two of these stigmatized identity markers? The theory is silent on how she will adapt to these multiple stigmatized identity characteristics.

While the HIV/AIDS illness becomes a part of the individual's identity, it does not erase or necessarily supersede all of the other intersections and facets of selfhood. Asian & Pacific Islander women who become HIV positive will filter their diagnosis through their age, sexual orientation, relationship status, ethnicity, educational background, documentation status and other factors. Some of these identities, such as being poor, are stigmatized identities resulting in the experience of oppression. As women of color, oppression can take many forms. By seeing A&PI women primarily in terms of their HIV/AIDS disease, other factors of their identity may not be addressed fully.

Gurung, Taylor, Kemeny, and Myers (2004) found that chronic burden factors such as low SES, racism, and partner-relational problems are more predictive of depression in women over time than HIV positive serostatus. The researchers sampled 350 HIV positive and HIV negative African American, European American and Latina women over a 6 month period using interviews and questionnaires to assess the effect of psychosocial supports and coping with chronic burden. This study did not include women of Asian and Pacific Islander descent but the findings from other women of color dealing with multiple chronic burdens are notable. This mixed methods study supports the idea that HIV may not always be one's biggest problem. The intersectional model picks up where stigma theory leaves off.

**Intersectionality as a theoretical framework for empirical research:** Intersectionality acknowledges the multiple facets of identity that fluidly intersect and create one's experience of power and oppression in the world. Use of this theory in research can: 1) expand our knowledge base regarding the mental health support needs of HIV positive A&PI women, and 2) urge

examination of more granular analysis of ethnic and demographic data to explain the mixed findings in the existing literature. Ideally, such research methods will allow for development of tightly targeted mental health intervention for A&PI women affected by HIV/AIDS.

Intersectionality locates experience at the crossroads of shifting levels of power and oppression produced by multiple facets of identity (i.e., race, gender, ethnic group, etc.), but does not provide a means for empirical application. How might clinical social work researchers utilize intersectionality to guide future research, particularly with HIV positive A&PI women? Adaptation of Crenshaw's model of intersectionality for policy and social change is a place to begin.

Applying the concept of intersectionality to future research on HIV positive women of color allows for primary issues of concerns to emerge from these women's lives. One way intersectionality can be applied is through acknowledgement of ethnic intragroup variation and qualitative information gathering to complicate research findings rather than oversimplify human experience. Mixed methods designs are also helpful as qualitative data can support or refute the quantitative data that is obtained.

Leslie McCall (2005) discusses the difficulty in empirical application of intersectionality. She locates the challenge inherent in the two main divergent viewpoints of social constructionism and post structuralism. McCall proposes a hybrid category, intracategorical analysis, to integrate these divergent intersectional camps for use in empirical research and data analysis. McCall (2005) suggests three ways of deploying intersectional methodology in empirical research: 1) intercategorical analysis akin to social constructionism, 2) antecategorical analysis utilizing deconstruction, or 3) intracategorical methods which have traditionally been grouped with post structuralism and categorical deconstruction. McCall (2005) explains that this

third approach of intracategorical complexity makes use of categorical designations such as ethnicity and gender but does so critically, strategically choosing which categories will be utilized through the appearance of these constructs in the data. She states that the use of narrative and qualitative studies allows categories to emerge from the data (McCall, 2005) rather than utilizing an a priori construction of relevant categories in a given population. For example, when collecting data on Filipinas, researchers may assume homogeneity in spiritual practice as Christianity is the official religion of the Philippines (Africa, 2013). In designing an outreach program to HIV positive Filipinas, religion and spiritual connection may be a commonality while the practice of Christianity may be more variable. A qualitative approach with inquiry about religiosity of respondents allows the researchers to determine if their sample is spiritually homogenous or heterogeneous. Variable relevance can then guide category development in data analysis. Intersectional difference can be incorporated or dismissed based upon the outcome of the qualitative inquiry. Implementation of McCall's (2005) framework could include preliminary ethnographic research in the population(s) of interest to guide creation of further qualitative and quantitative measures.

Post structuralism approaches argue as Audre Lorde stated that "the master's tools will never dismantle the master's house," and thus categories established by a dominant group to describe a subordinate group allow for minimal if any change. McCall's (2005) intracategorical complexity is an attempt to bridge this gap and allow critical scholarship to emerge, through data-guided deconstruction of traditional identity groupings in empirical research. Ethnic matching of researcher and participant, especially in qualitative data collection and analysis, is another way to address this issue.

**Intersectionality in practice through clinical implementation:** Clinically, stressing the importance of HIV-related mental health support if it is not warranted by the client's circumstances could lead to inappropriate or culturally nonresponsive care. For example, an HIV seropositive undocumented Chinese American woman may focus on a lack of healthcare for her ill child rather than on the loss of her romantic relationship due to her HIV diagnosis. In the therapeutic dyad, a therapist approaching this patient from the direction of stigma may see the client as in denial of her own medical diagnosis. Based upon the Gurung, Taylor, Kemeny and Myers (2004) findings of chronic burden being more predictive of depression than HIV status, a focus on this client's experience of stigma and partner loss, rather than her distress over her child, could lead to an irreparable empathic rupture and early termination of therapy. Envisioning stigma as an axis of identity affecting A&PI HIV positive women acknowledges its importance in serostatus disclosure issues and psychological symptoms but makes room for other issues or axes affecting the client's presentation.

In a different example of intersectional clinical approaches, we can examine the routing of clients to relevant agency services through appropriate data collection. Entrance surveys and exploratory interviewing in public mental health settings is one such way clients' experience can be understood rather than merely categorized. Employing a stance of "any door is the right door" to access services allows providers to place clients' interests first.

Clinical social workers providing services to HIV positive clients often steer clients to support groups. Limiting a client's access to an HIV positive group or an ethnically matched support group may be helpful for some clients but not others. Due to shame and "saving face" common in A&PI communities (Rodgers, 2012), clients may be less likely to attend an ethnically targeted support group, particularly for HIV. An intersectional frame allows the client to decide

her most important need. Similar to the intersectional model suggested for empirical research, complete data gathering of a client's needs in order to provide appropriate care and referrals is necessary. While such methods can be dependent upon funding, (i.e., agency dollars limited to particular services for HIV positive clients), it is incumbent upon clinical social workers to lobby financial stakeholders for service provisions based on client's actual needs rather than assumed needs.

**Synthesis of stigma theory as an intersectional axis:** Stigma theory in HIV research has been critical to understand how this chronic illness differs from other chronic illnesses such as cancer. For example, the issue of disclosure vs. nondisclosure of HIV serostatus can scarcely be understood without a stigma framework. Without the fear of stigma, disclosing one's HIV status would not pose a risk for depression and mental health concerns. That said stigma theory is only one part of the picture. Intersectional approaches to data collection and analysis deepen this understanding and capture a more accurate picture of experience. Rather than disregard stigma theory however, stigma can be seen as one axis of experience that intersects with other layers of identity. The various facets of identity often occur along a continuum and/or an axis. This follows Crenshaw's concept of intersecting "traffic" highways of identity with human experience taking place at the crossroads (1989; 1991). HIV stigma is one more road which intersects with the experience of being an A&PI HIV positive woman in the United States.

### **Summary**

Clinical practitioners have moved towards utilization of evidenced based practice in treatment with their clients. For clients that report a presenting problem for which there is little research, clinicians must draw from existing literature which may or may not apply to their clients. Predominantly the literature on HIV/AIDS in women involves African American and



Latina women. HIV/AIDS research on A&PI ethnic groups is limited at best with the majority of the studies being about the experience of MSM. The information on the mental health needs of A&PI women with HIV/AIDS is extremely limited and is often focused on women outside of the United States. Several of the studies were completed in India, are qualitative, and utilize very small sample sizes. Even within this limited set of studies there are discrepancies about the need for, and effect of, HIV serostatus disclosure as well as the role stigma plays in the emotional lives of these women.

Often when POC are incorporated into white studies regarding HIV and depression the overall demographics are mentioned as percentages of the participants of the various ethnicities represented, but the findings are not broken down by specific races or ethnic groups. The assertion on the part of the researchers appears to be that there are no significant differences between and/or within ethnic groups. Socioeconomic class structure and access to healthcare are on the whole significantly different in HIV positive POC compared to whites which can affect rates of mental health and depression. Therefore, it is necessary to break down findings related to ethnic demographics to determine if rates of depression show significant cross-racial differences such as African Americans vs. Chinese Americans. Increased rates of depression may be related to lack of access to care or other issues such as poverty, sexism and racism which further complicate the diagnosis and treatment of depression in HIV positive clients. In addition, POC may have lower rates of depression due to other factors that serve to insulate them such as spirituality and familial interdependence. This omission of attention to ethnic similarity and difference can result in gaps in empirical knowledge which then result in health disparities or culturally ineffective/inappropriate care.

HIV status disclosure is an important mental health issue due to actual or anticipated stigma, emotional distress, increased risk for domestic violence, and potential transmission to family members/partners. It is important to consider that HIV may be only one of several layers of stress affecting a client. Intersectional approaches to empirical research and clinical work provide a construct to examine the multiple aspects of identity, stigma, and oppression that create the client's symptomatology.

**Implications for social work research and practice:** HIV status disclosure is a never-ending process with each new relationship, employer and intimate partner. An HIV-positive person must make the decision to disclose or not disclose over and over again. While similarities exist between ethnic groups, there are many other intragroup differences that may affect behavior such as citizen vs. immigrant status in the United States and strength of identification with ethnicity compared to identification with another social group, i.e. the LGBTQ community. These intragroup identity factors can have an effect on how one views or copes with an HIV/AIDS diagnosis, especially regarding serostatus disclosure. Disaggregation of demographic information, ethnic data, and social group membership is necessary since HIV status disclosure is a central issue both when newly diagnosed and throughout the life of people living with HIV/AIDS.

Differences in group identification can result in behavior differences not accounted for in the literature; however, clinical social workers are ethically bound to rely upon theory and research to inform practice (NASW, 2008). Development of efficacious mental health interventions for particular communities, (in this case A&PI ethnic groups living with HIV/AIDS,) comes from the understanding of the "person-in-environment" perspective. As a result, a movement in social work towards recognition of the various intersections of one's

individual identities has taken place in the last few decades. This approach acknowledges that how one shows up in the world is best conceptualized as a series of interwoven identities which carry privilege or oppression, and which can be active or inactive at any given time. Further, privilege in one setting may be oppressive in another setting. Ethnic background/culture is only one of the many identities intersecting with other identities, (gender, class, family role, etc.); together these identity aspects determine how others see us and how we see ourselves. To begin, an initial examination of the cultural health-related similarities in A&PI communities can provide a framework to then examine intragroup differences.

A recent study of Pacific Islander (PI) communities in southern California demonstrated how intragroup differences can effect creation of culturally relevant HIV programs. Takahashi et al. (2011) found a correlation between reports of domestic violence and frequency of HIV testing. The study examined two different PI ethnic groups and found differences in testing behavior in the 179 participant sample. Ethnicity and intimate partner violence were the best predictors of HIV testing behavior in Chamorro individuals. Also, individuals who requested the survey in Chamorro were less likely to have an HIV test than respondents who took the English version. Samoan individuals were more likely to have had an HIV test but were also more likely to have experienced domestic violence. Further analysis did not indicate a correlation between HIV testing and the experience of domestic violence. The researchers suggest that there may be ethnic differences in the likelihood of reporting domestic violence, and that linking HIV testing to domestic violence screening may be more effective in Chamorro communities than in Samoan populations (Takahashi et al, 2011). The findings show how two ethnically and geographically similar communities can reveal different results in their need for HIV testing. Studies that collapse data into one A&PI grouping miss these differences.

**Strengths and weaknesses of an intersectional paradigm:** I argue that intersectionality is an improved paradigm that allows for more in depth investigation of current problems in need of empirical study, while holding open the possibility that future findings may lead researchers to the need for an alternative framework. While application suggested by McCall (2005) provides little instruction for execution in research and is therefore a weakness, it is a theoretical starting point. One strength of this approach is that it questions the status quo in pursuit of more accurate and representative data. This is precisely what unbiased scientific inquiry sets out to do, particularly in the field of clinical social work. Further, it is the field of public mental health that predominately serves the multiply oppressed and stigmatized populations. Adapting social justice case law and critical theory constructs to empirical research paradigms is an act of social justice as called for in the NASW Code of Ethics (2008).

Bowleg (2012) explains that the concept of social justice, or egalitarianism through application of law and provision for equally accessible services to all persons, is a perfect match for the public health system. She points out that most scholarship and policy omits this concept of interlocking layers of privilege and oppression acting at the micro level which replicate and reflect the sexism, racism, classism operating at the macro level (Bowleg, 2012). As most of the care given to PLWHA comes through public health systems, this perspective is extremely relevant to providing culturally conscious and effective mental health support to A&PI women affected by HIV/AIDS.

Conversely, Nash (2008) problematizes the applicability of intersectionality as an empirical paradigm highlights what she calls "theoretical, political, and methodological murkiness" in the theory. She challenges the empirical application of this theory claiming a lack of methodological definition, ambiguity in the meaning of the term intersectionality, and

questions empirical validity. She also points to the use of black women as the seemingly only example to which the theory is applied. In answer to Nash's challenge, McCall's (2005) intracategorical analysis provides a methodological approach which is necessarily murky. In fact, one argument for intersectionality is its ability to more fully hold the complexity of human experience by including outliers rather than dispensing with them to "tighten up" the data sets.

Bredström (2006) , like Nash, acknowledges the challenge of using intersectionality in feminist HIV/AIDS policy development and research as she sees that *existing* intersectional policy discourse still gives gender and race primacy when discussing the intersections of identity that make up experience. She critiques the work of the most prolific feminist HIV/AIDS theorists affecting policy and explains how their perspectives continue to contextualize oppression through the centralization of race and gender. This perspective leaves no room for the experience of the stigmatized and oppressed to speak for themselves through the data, imposing yet another layer of oppression onto already oppressed bodies. "For feminist HIV/AIDS research this implies that an exclusive focus on gender and sexuality needs to be replaced by an intersectional approach" (Bredström, 2006). Her critique implies that leading feminists in HIV policy creation give lip service to intersectionality but do not fully deploy the principles laid out by Kimberlé Crenshaw, Patricia Hill Collins and others.

## **Conclusion**

Social workers must hold the richness and complexity of human identity and intragroup belonging to better understand and meet the needs of the various populations they serve. This is particularly important in the arena of public health where identity is often viewed as separate, parallel "silos" of multicultural experience without an understanding of how these identities interact and act upon one another. Public health awareness programs, campaigns and

interventions tend to target specific cultural groups and their behaviors. These cultural groups may be identified by gender, ethnicity, sexual orientation, age, geographic region and so on. While these designations are important in reaching target populations, identifying one particular cultural aspect of a community may not be enough. For example, female monolingual undocumented Mexican migrant workers are not likely to relate to public and mental health information in the same way that female bilingual Mestiza American clerical workers do. Focusing on only one or two segments of cultural identity is likely insufficient when providing public and mental health support/outreach to specific populations. In this example, seeing these two groups as simply "Latina" women without evaluating their other identity differences could lead to development of an outreach program that is unsuccessful at reaching the entire intended audience.

Due to the paucity of information available, more research is clearly needed. A&PI women living in the U.S. with HIV/AIDS are growing in number (CDC, 2012; Sundaram, 2011). HIV prevalence may be grossly underestimated in this community due to many women self-identifying as multiracial or multiethnic and being categorized as "other" in HIV/AIDS statistics. An intersectional approach, particularly one that approaches these groups with McCall's (2005) intracategorical analysis, would help identify and outline the mental health needs of A&PI HIV positive women. Such literature can allow clinicians a starting point for the treatment of A&PI women with HIV/AIDS enabling provision for culturally appropriate mental health support.

Intersectionality theory acknowledges stigma as a form of oppression. This theory is much more pliable and allows for relevant categories of identity to emerge from the data, including stigma and oppression. The key principles of intersectionality acknowledge the complexity of experience and decentralize the importance of any one identity construct. Use of

this theory in future research can help clarify mixed findings on disclosure vs. nondisclosure and depression in A&PI women's experience post HIV/AIDS diagnosis. Through examination of both intergroup and intragroup ethnic and cultural difference, research built on stigma theory can be incorporated with stigma conceptualized as but one of many aspects of identity affecting the lives of HIV positive Asian and Pacific Islander women. Such research will better aid clinicians in the development of culturally supportive and appropriate evidence-based practice for this diverse population.

## References

- Africa, J. (2013, May 10). *Cultural & clinical considerations in working with Filipino Americans*. Key note speech at Asian Pacific American Mental Health Day Celebration of San Francisco Department of Public Health, Community Behavioral Health Services, San Francisco, CA.
- African American Policy Forum. (2009). *AAPF Intersectionality Primer*. Retrieved from <http://aapf.org/wp-content/uploads/2013/01/59819079-Intersectionality-Primer.pdf>
- African American Policy Forum. (2013). *Cofounders: Kimberlé Crenshaw*. Retrieved from <http://aapf.org/co-founders/>
- Anderson, E. & McCormack, M. (2010). Intersectionality, critical race theory, and American sporting oppression: Examining black and gay male athletes. *Journal of Homosexuality*, 57, 949-967. DOI: 10.1080/00918369.2010.503502
- Arifuddin, R. (2011). The construction of Black Feminism thoughts in *Precious* (2009). Retrieved from <http://www.scribd.com/doc/49570002/The-Construction-of-Black-Feminism-Thought-In-Precious-2009>
- Asian & Pacific Islander American Health Forum and Asian & Pacific Islander Wellness Center (2012). Retrieved on October 20, 2012 from <http://www.apiwellness.org/extras2/2012/Brief%20on%20the%20CDC%20Report%2008.21.12.pdf>
- Asian & Pacific Islander Wellness Center (n.d.). Retrieved October 8, 2012 from <http://www.banyantreeproject.org/>



Asian and Pacific Islander Wellness Center (n.d.). Fact Sheet: Stigma, HIV/AIDS, and Asian & Pacific Islanders. Retrieved October 21, 2012 from

[http://www.banyantreeproject.org/extras/factsheets/btp\\_stigma\\_fs\\_FINAL.pdf](http://www.banyantreeproject.org/extras/factsheets/btp_stigma_fs_FINAL.pdf)

Asian and Pacific Islander Wellness Center (Sept 2012). HIV and Asian & Pacific Islanders: National epidemic. Retrieved May 31, 2013 from

[http://www.banyantreeproject.org/extras/factsheets/USA\\_factsheet\\_REV2012\\_FINAL.pdf](http://www.banyantreeproject.org/extras/factsheets/USA_factsheet_REV2012_FINAL.pdf)

Bello, B. (2008). *Intersectionality: An approach to empower women at the crossroads*.

Unpublished paper, Università Statale Milano, Milan, Italy. Retrieved from

[http://www.salto-youth.net/downloads/toolbox\\_tool\\_download-file-](http://www.salto-youth.net/downloads/toolbox_tool_download-file-642/Barbara_Bello.doc)

[642/Barbara\\_Bello.doc](http://www.salto-youth.net/downloads/toolbox_tool_download-file-642/Barbara_Bello.doc)

Bowleg, L. (2012). The problem with the phrase women and minorities: Intersectionality- an important theoretical framework for public health. *American Journal of Public Health, 102*(7), 1267-1273. DOI:10.2105/AJPH.2012.300750

Brady, C. (2006). *The intersecting liminalities of illness and immigration: A theoretical study of the experiences of HIV-Positive Latino Immigrants*. (Unpublished master's thesis). Smith College School of Social Work, Northampton, MA.

Bredström, A. (2006). Intersectionality: A challenge for feminist HIV/AIDS research? *European Journal of Women's Studies, 13*(3), 229-243. DOI: 10.1177/1350506806065754

Centers for Disease Control. (2010). HIV/AIDS among Asian and Pacific Islanders. Retrieved October 8, 2012 from <http://www.cdc.gov/hiv/resources/factsheets/API.htm>

Centers for Disease Control. (2012). Health disparities in HIV/AIDS, viral hepatitis, STDs and TB: Native Hawaiians and other Pacific Islanders. Retrieved on July 18, 2012 from <http://www.cdc.gov/nchstp/healthdisparities/Hawaiians.html>

- Chae, D. H. & Yoshikawa, H. (2008). Perceived group devaluation, depression, and HIV-risk behavior among Asian gay men. *Health Psychology, 27*(2), 140-148.
- Chandra, P.S., Deepthivarma, S., Manjula, V., (2003). Disclosure of HIV infection in South India: Patterns, reasons and reactions. *AIDS Care, 15*(2), 207-215.
- Charles, B., Jeyaseelan, L., Pandian, A.K., Sam, A. E., Thenmokhi, M. & Jayaseelan, V. (2012). Association between stigma, depression and quality of life of people living with HIV/AIDS (PLHA) in South India – a community based cross sectional study. *BMC Public Health, 12*:463. DOI:10.1186/1471-2458-12-463.
- Chin, D., & Kroesen, K.W. (1999). Disclosure of HIV infection among Asian/Pacific Islander American women: Cultural stigma and support. *Cultural Diversity and Ethnic Minority Psychology, 5*(3), 222-235.
- Chng, C. L., Wong, F. Y., Park, R. J., Edberg, M. C., & Lai, D. S. (2003). A model for understanding Asian American/Pacific Islander men who have sex with men (MSM) in the United States. *AIDS Education and Prevention, 15*(Supplement A), 21-38.
- Clark, H. J., Lindner, G., Armistead, L. & Austin, B. (2003). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women & Health, 38*(4), 57-71.
- Collins, P. (1998). Intersections of race, class, gender, and nation: Some implications for Black family studies. *Journal of Comparative Family Studies, 29*(1), 27-36.
- Collins, P. (2000). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment* (2nd ed.). New York, NY: Routledge.

- Crenshaw, K. (1989) Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *The University of Chicago Legal Forum*, 139-167.
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43(6), 1241-1299.
- Crenshaw, K. (2010). Curriculum vitae of Kimberlé Crenshaw. Retrieved from <http://www.scribd.com/doc/59619863/Kimberlé-Crenshaw-CV>
- Crocker, J. & Major B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96(4), 608-630.
- DeAlmeida, C. S. (2007). *To tell or not to tell: An exploration of HIV stigma and sociocultural factors related to HIV/AIDS disclosure and nondisclosure among Asian and Pacific Islanders* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses. (Order No. 304703788)
- Eller, E.S., Bunch, E.H., Wantland, D. J., Portillo, C. J., Reynolds, N. R., Nokes, K.M.,... Tsai, Y.F. (2010). Prevalence, correlates, and self-management of HIV-related depressive symptoms. *AIDS Care*, 22(9), 1159-1170.
- Falvo, D. R. (2005). *Medical and psychosocial aspects of chronic illness and disability* (3<sup>rd</sup> ed.). Sudbury, MA: Jones and Bartlett Publishers.
- Frost, D.M., Parsons, J.T., Nanin, J.E. (2007). Stigma, concealment and symptoms of depression as explanations for sexually transmitted infections among gay men. *Journal of Health Psychology*, 12(4), 636-640. DOI: 10.1177/1359105307078170
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon & Schuster.

- Gonzalez, A., Solomon, S. E., Zvolensky, M. J., & Miller, C. T. (2009). The interaction of mindful-based attention and awareness and disengagement coping with HIV/AIDS-related stigma in regard to concurrent anxiety and depressive symptoms among adults with HIV/AIDS. *Journal of Health Psychology, 14*(3), 403-413.  
DOI:10.1177/1359105309102193
- Gore-Felton, C., Koopman, C., Spiegel, D., Vosvick, M., Brondino, M., & Winningham, A. (2006). Effects of quality of life and coping on depression among adults living with HIV/AIDS. *Journal of Health Psychology, 11*(5), 711-729.  
DOI:10.1177/1359105306066626
- Greydanus, D., Patel, D., & Pratt, H. (2010). Suicide risk in adolescents with chronic illness: Implications for primary care and specialty pediatric practice: A review. *Developmental Medicine & Child Neurology, 52*(12), 1083-1087. DOI:10.1111/j.1469-8749.2010.03771.x
- Grov, C., Golub, S. A., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS Care, 22*(5), 630-639. DOI:10.1080/09540120903280901
- Gu, J., Lau, J. F., Chen, H., Chen, X., Liu, C., & Liu, J. (2010). Mental health and interpersonal factors associated with HIV-related risk behaviors among non-institutionalized female injection drug users who are also sex workers in China. *Women & Health, 50*(1), 20-36.  
DOI: 10.1080/03630241003601137
- Gurung, R., Taylor, S., Kemeny, M., & Myers, H. (2004). "HIV is not my biggest problem": The impact of depression in women at risk for AIDS. *Journal of Social and Clinical Psychology, 23*(4), 490-511.

- Hahm, C. H. & Adkins, C. (2009). A model of Asian and Pacific Islander sexual minority acculturation. *Journal of LGBT Youth, 6* (2/3), 155-173.  
DOI:10.1080/19361650903013501.
- Haller, D. L., & Miles, D. R. (2003). Suicidal ideation among psychiatric patients with HIV: Psychiatric morbidity and quality of life. *AIDS and Behavior, 7*(2), 101-108.  
DOI:10.1023/A:1023985906166
- Hays, P. (2008). *Addressing cultural complexities in practice: Assessment, diagnosis, and therapy* (2<sup>nd</sup> ed.). Washington, DC: American Psychological Association.
- Hays, R. B., Turner, H., & Coates, T. J. (1992). Social support, AIDS-related symptoms, and depression among gay men. *Journal of Consulting and Clinical Psychology, 60*(3), 463-469. DOI:10.1037/0022-006X.60.3.463
- Ickovics, J. R., Hamburger, M. E., Vlahov, D., Schoenbaum, E. E., Schuman, P., Boland, R. J., & Moore, J. (2001). Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: Longitudinal analysis from the HIV epidemiology research study. *Journal of the American Medical Association, 285*(11), 1466-1474.  
DOI:10.1001/jama.285.11.1466
- Intersectionalities, (n.d.) (pp. 201-227). Thousand Oaks, CA: Sage Publications. Retrieved from [http://www.sagepub.com/upm-data/26738\\_Chapter8.pdf](http://www.sagepub.com/upm-data/26738_Chapter8.pdf).
- Iwamasa, G.Y. (2003). Recommendations for the treatment of Asian-American/Pacific Islander Populations. In *Psychological Treatment of Ethnic Minority Populations* (pp.8-12) Washington, D.C.: The Association of Black Psychologists.
- Kang, E., Rapkin, B. D., & DeAlmeida, C. (2006). Are psychological consequences of

- stigma enduring or transitory? A longitudinal study of HIV stigma and distress among Asians and Pacific Islanders living with HIV illness. *AIDS Patient Care and STDs*, 20(10), 712-723. DOI:10.1089/apc.2006.20.712
- Kusow, A. (2004). Contesting stigma: On Goffman's assumptions of normative order. *Symbolic Interaction*, 27(2), 179-197.
- Leserman, J., Petitto, J. M., Gu, H., Gaynes, B. N., Barroso, J., Golden, R. N.,...Evans, D.L. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, 61, 397–406.
- Li, L., Lee, S., Wen, Y., Lin, C., Wan, D., & Jiraphongsa, C. (2010). Antiretroviral therapy adherence among patients living with HIV/AIDS in Thailand. *Nursing & Health Sciences*, 12(2), 212-220. DOI:10.1111/j.1442-2018.2010.00521.x
- Liew, H. (2012). Depression and chronic illness: A test of competing hypotheses. *Journal of Health Psychology*, 17(1), 100-109. DOI:10.1177/1359105311409788
- Liu, H., Feng, T., Ha, T., Liu, H., Cai, Y., Liu, X., and Li, J. (2011). Chinese Culture, Homosexuality Stigma, Social Support and Condom Use: A Path Analytic Model. *Stigma Research and Action*, 11(1): 27–35. DOI:10.5463/sra.v1i1.16.
- McCall, L. (2005). The complexity of intersectionality. *Signs*, 30, 1771–1800. DOI:10.1086/426800
- Meyer, D. (2012). An intersectional analysis of lesbian, gay, bisexual, and transgender (LGBT) people's evaluations of anti-queer violence. *Gender & Society*, 26(6), 849-873. DOI:10.1177/0891243212461299

- MIT Alternative News Collective. (1995). But some of us are brave: A history of Black feminism in the United States. *The Thistle*, 9(9.1). Retrieved from <http://www.mit.edu/activities/thistle/v9/9.01/6blackf.html>
- Mize, S. J. S., Robinson, B. E., Bockting, W. O., & Scheltema, K. E. (2002). Meta-analysis of the effectiveness of HIV prevention interventions for women. *AIDS Care*, 14(2), 163-180.
- Mkanta, W. N., Mejia, M. C. & Duncan, P. (2010). Race, outpatient mental health service use, and survival after an AIDS diagnosis in the highly active antiretroviral therapy era. *AIDS Patient Care and STDs*, 24(1), 31-37.
- Mobley, P. Y. (2006). High-risk sexual behaviors among Asian and Pacific Islander adolescents in Hawai'i. (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses. (Order No. 305317679)
- Moynihan, R. T. (1996). Factors affecting the need and use of mental health services by HIV-infected women. (Doctoral Dissertation). Retrieved from ProQuest Dissertations and Theses. (Order No. 304254314)
- National Association of Social Workers, (2008). Code of Ethics Washington, DC: NASW.
- Nemoto, T., Operario, D., Soma, T., Bao, D., Vajrabukka, A., & Crisostomo, V. (2003). HIV risk and prevention among Asian/Pacific Islander men who have sex with men: Listen to our stories. *AIDS Education and Prevention*, 15(Supplement A), 7-20.
- Nyamathi, A., Heravian, A., Zolt-Gilburne, J., Sinha, S., Ganguly, K., Liu, E., & Leake, B. (2011). Correlates of depression among rural women living with AIDS in southern India. *Issues in Mental Health Nursing*, 32(6), 385-391. DOI:10.3109/01612840.2011.577269

- Nyamathi, A., Salem, B. E., Meyer, V., Ganguly, K. K., Sinha, S., & Ramakrishnan, P. (2012). Impact of an Asha intervention on depressive symptoms among rural women living with AIDS in India: Comparison of the Asha-Life and Usual Care program. *AIDS Education and Prevention, 24*(3), 280-293. DOI:10.1521/aeap.2012.24.3.280
- Ownby R., Jacobs, R. Waldrop-Valverde, D. & Gould, F. (2010). Depression care and prevalence in HIV-positive individuals. *Neurobehavioral HIV Medicine, 2*, 73-83. DOI:10.2141/NBHIV.S7296
- Phoenix, A. & Pattynama, P. (2006). Intersectionality. *European Journal of Women's Studies, 13*(3), 187-192. DOI:10.1177/1350506806065751
- Reisen, C. A., Zea, M. C., Bianchi, F. T., & Poppen, P. J. (2011). Characteristics of Latino MSM who have sex in public settings. *AIDS Care, 23*(4), 456-459. DOI:10.1080/09540121.2010.516337
- Sannicolas, N. (1997, October). Erving Goffman, dramaturgy, and on-line relationships. *Cybersociology Magazine, 1*. Retrieved from [http://www.cybersociology.com/files/1\\_2\\_sannicolas.html](http://www.cybersociology.com/files/1_2_sannicolas.html)
- Srinivasan, S. & Guillermo, T. (2000). Toward improved health: Disaggregating Asian American and Native Hawaiian/Pacific Islander Data. *American Journal of Public Health, 90* (11), 1731-1734.
- Steward, W. T., Chandy, S., Singh, G., Panicker, S. T., Osmand, T. A., Heylen, E. & Ekstrand, M. L. (2011). Depression is not an inevitable outcome of disclosure avoidance: HIV stigma and mental health in a cohort of HIV-infected individuals from Southern India. *Psychology, Health & Medicine, 16*(1), 74-85.



- Stigma. (2004). In *The Merriam-Webster Dictionary*, (11th ed.). Springfield MA: Merriam-Webster, Inc.
- Stirratt, M. J., Remien, R. H., Smith, A., Copeland, O. Q., Dolezal, C., & Krieger, D. (2006). The role of HIV serostatus disclosure in antiretroviral medication adherence. *AIDS and Behavior*, 10(5), 483-493. DOI:10.1007/s10461-006-9106-6
- Sublette, N. K. (2008). Predictors of depressive and anxiety symptoms among African American HIV-positive women. (Doctoral Dissertation). Retrieved from ProQuest Dissertations and Theses. (Order No. 304349947)
- Sundaram, V. (2011, May 18). Saving face can't make API women safe. *New American Media*. Retrieved from <http://newamericamedia.org/2011/05/saving-face-cant-make-api-women-safe.php>
- Takahashi, L.M., Kim, A. J., Sablan-Santos, L., Quitugua, L. F., Lepule, J., Maguadog, T...Young, L. (2011). HIV testing behavior among Pacific Islanders in Southern California: Exploring the importance of race/ethnicity, knowledge, and domestic violence. *AIDS Education and Prevention*, 23(1), 54-64.
- Taraphdar, P., Dasgupta, A., & Saha, B. (2007). Disclosure among people living with HIV/AIDS. *Indian Journal of Community Medicine*, 32(4), 280-282.
- Toleran, D. E., Tran, P., Cabangun, B., Lam, J., Battle, R., & Gardiner, P. (2012). Substance use among Chinese, Filipino, and Vietnamese adult men living in San Jose, Daly City, and San Francisco, and its implications on ATOD prevention services. *Journal of Ethnicity in Substance Abuse*, 11(1), 86-99. DOI:10.1080/15332640.2012.652534

- Ubiem, C. S. (2010). The relationship between depression and coping among Black and Latino men living with HIV/AIDS. (Doctoral Dissertation). Retrieved from ProQuest Dissertations and Theses. (Order No. 193292851)
- United States Department of Health & Human Services Office of Minority Health (2012). HIV/AIDS and Asian Americans. Retrieved on August 9, 2012 from <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=7&ID=3062>
- United States Department of Health & Human Services Office of Minority Health (2012). HIV/AIDS and Native Hawaiians/Other Pacific Islanders. Retrieved on August 9, 2012 from <http://minorityhealth.hhs.gov/templates/content.aspx?ID=7602>
- United States Department of Health & Human Services Office of Minority Health, (2012). HIV/AIDS data/statistics. Retrieved October 8, 2012 from <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=3&lvlid=70>
- Vyavaharkar, M. (2009). The relationships between depression and HIV-related stigma, disclosure of HIV-positive status, and social support among African-American women with HIV disease living in the rural Southeastern United States. (Doctoral Dissertation). Retrieved from ProQuest UMI Dissertations. (Order No. 3336703)
- Weiss, M., and Ramakrishna, J. & Somma D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health & Medicine*. 11(3), 277-287.  
DOI:1080/13548500600595053
- William, S. J. (1986). Appraising Goffman. *The British Journal of Sociology*, 37(3), 348-369.
- Wohl, A., Galvan, F. H., Carlos, J., Myers, H. F., Garland, W., Witt, M. D., Cadden, J., Operskalski, E. Jordan, W. & George, S. (2012). A comparison of MSM stigma, HIV

stigma and depression in HIV-positive Latino and African American men who have sex with men (MSM). *AIDS and Behavior*. DOI:10.1007/s10461-012-0385-9

Yoshikawa, H., Wilson, P., Chae, D. H., & Cheng, J. (2004). Do family and friendship networks protect against the influence of discrimination on mental health and HIV risk among Asian and Pacific Islander gay men? *AIDS Education and Prevention*, *16*(1), 84-100. DOI:10.1521/aeap.16.1.84.27719

Yoshioka, M. R., & Schustack, A. (2001). Disclosure of HIV status: Cultural issues of Asian patients. *AIDS Patient Care and STDs*, *15*(2), 77-82.

Zhang, Y., Lin, X., & Fu, Y. (2011). To tell or not to tell: A qualitative study of status and causes of homosexual men's disclosure the HIV-positive and sexual orientation to others. *Chinese Journal of Clinical Psychology*, *19*(5), 628-632. Abstract retrieved from PsycINFO database. (Accession No. 2011-30402-01)