

Chapter Nine

Why Tell? Serostatus Disclosure and HIV Stigma among HIV Seropositive Asians and Pacific Islander Men who have Sex with Men in New York City

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Introduction

Many persons living with HIV wrestle with the dilemma of whether or not to disclose their serostatus. The benefits of being supported by a network of confidants are weighed against the risks of being rejected and ostracized by family and peers. As such, many persons living with HIV/AIDS continually struggle to fulfill competing needs to share information about their illness and to preserve privacy or maintain control over who, what, and when to disclose their serostatus (Derlega, Lovejoy, & Winstead, 1998). The timing of selective serostatus disclosure can be influenced by disease progression (Mansergh, Marks & Simoni, 1995), length of HIV diagnosis (Emlet, 2006), cultural norms (Simoni et al., 1995; Mason, Marks, Simoni, Ruiz, & Richardson, 1995), relational commitment (Perry et al., 1994), and the number of sexual partners (Marks, et al., 1992).

Decisions regarding serostatus disclosure pose a unique challenge for Asian and Pacific Islander (A&PI) men who have sex with men (MSM) largely because of cultural proscriptions against homosexuality and HIV. Lye Chng, Wong, Park, Edberg, & Lai, (2003) highlighted how prescribed social scripts and roles influence relationships and social exchanges among A&PI MSM. Consideration of how personal decisions reflect upon one's family reputation and the value of passing on the family lineage are two notable social scripts that complicate intentional disclosure of HIV or sexual identity among A&PI MSM.

This chapter focuses on our findings from a cross-sectional study initiated to further our understanding of the relationship between five dimensions of HIV stigma and factors related to decisions about serostatus disclosure among HIV-seropositive A&PIs receiving services at community organizations in New York City (NYC). It is important to note that although the aggregate term "A&PI" is referenced in this study, the authors acknowledge significant

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differences in cultural traditions and values, language, dialects, migration history, and acculturation among A&PIs. As such, the implications of findings from this study are limited to specific groups represented in the sample and may not necessarily apply to all APIs.

A&PI MSM and HIV: Epidemiological Profile

In the United States, 7,317 cumulative adult AIDS cases were reported among A&PIs through 2004 (CDC, 2005). In NYC, a cumulative of 1,088 (0.8 %) adult cases of AIDS was reported among A&PIs through December 2004 (NYCMH, 2006). The majority of A&PIs newly diagnosed with HIV in 2004 were foreign-born, with Asia accounting for 69% of new diagnoses among foreign-born (NYCDOH, 2006). HIV continues to spread nationally and locally at alarmingly high rates among MSM of color. In the USA, 72% ($n=2,445$) of estimated A&PI males living with AIDS in 2004 were among MSM, compared with 52% among Hispanic, 57% among American Indian/Alaska Native, and 44% among Blacks (CDC, 2006). In NYC, MSM accounted for 80% of new HIV diagnosis among A&PI males. Although the rate of AIDS among A&PIs (4.0 per 100,000 population) was low compared with other racial/ethnic groups in the USA, the estimated number of HIV/AIDS cases has increased among A&PIs between 2000 and 2003 at rates comparable with Whites and Hispanics, and far faster than African Americans, American Indians, and Alaska Natives.

Despite low HIV/AIDS incidence rates among A&PIs in the USA, numerous studies have highlighted specific trends that warrant concern including higher rate of HIV risk behavior and depressive symptoms among A&PI MSM compared with other racial/ethnic groups (MacFarland, Chen, Weide, Kohn, & Klauser, 2004; Yoshikawa, Wilson, Chae, & Cheng, 2004), lower rates of HIV testing (Wong, Campsmith, Nakamura, Crepaz, & Begley, 2004), perceived invulnerability to a HIV infection (Choi et al., 1995), delay in accessing medical and supportive services (Chin, Kang, Kim, Martinez, & Eckholdt, 2006; Pounds, Conviser, Ashman, & Bourassa, 2002; Eckholdt & Chin, 1997), and difficulties adhering to their antiretroviral regimen (Kang & Rapkin, 2003).

Decision to Disclose Serostatus

Disclosure is a “strategic social behavior” that is influenced by conscious or unconscious motivation to achieve specific social goals (Omarzu, 2000). Individuals’ strategic decisions to disclose can be influenced by a need to fulfill specific personal or interpersonal needs. Sheon and Crosby’s (2004) qualitative study of MSM in San Francisco found that eagerness to disclose their serostatus to casual sexual partners was largely attributed to relinquishing personal responsibility for transmission and engaging in barebacking or unprotected

sex. Serovich's (2001) consequences theory of HIV disclosure contends that the decision to inform others is a process of weighing the costs and benefits of disclosure. Individuals therefore disclose their serostatus if there are substantial emotional, physical, and social benefits from others knowing about their illness, and conversely conceal their serostatus when they anticipate negative social consequences. Previous studies have identified various benefits of serostatus disclosure that include receiving forms of social support and reaffirmation of self-worth (Parsons, VanOra, Missildine, Purcell, & Gomez, 2004). However, these anticipated benefits of serostatus disclosure are weighed against shifting the blame and worry of living with the illness to others and fear of discrimination (Petрак, Doyle, Smith, Skinner, & Hedge 2001). Applications of Serovich's consequence theory of HIV disclosure are largely influenced by gender, sexual identity, social and family networks, and culture. Higher rates of serostatus disclosure, for example, have been found among more acculturated Latino gay or bisexual men (Hays, Turner, & Coates, 1992; Mason et al., 1995), English-speaking Latinas (Simoni, et al., 1995), and documented Asian immigrants (Kang, Rapkin, Springer, & Kim, 2003).

Decisions to disclose one's serostatus can be motivated by a need to release internalized feelings and anxiety over living with a stigmatized illness (Holt et al., 1998). Among Asian undocumented immigrants with HIV/AIDS, for example, living a double life in order to maintain one's serostatus a secret can be physically and emotionally draining and affects how they manage and reorient their lives (Kang et al., 2003). Decisions to disclose one's serostatus can also be influenced by one's sense of duty to protect the well-being of their casual sex partners in order to reinforce protective sexual practices or to encourage partners to get tested for HIV (Gorbach et al., 2004; Serovich & Mosack, 2003). In a study of HIV-seropositive African American MSM, one's felt obligation to disclose, coupled with their fear of rejection, discouraged participants from pursuing sexual relationships (Harawa, Williams, Ramamurthi, & Bingham 2006). Decision to conceal one's serostatus is largely influenced by a perceived fear that others will inadvertently or intentionally breach confidence and disclose their serostatus to others. In a study of 54 A&PIs living with HIV in NYC, Kang, Rapkin, Remien, Mellins, & Oh, (2005) found that fear of inadvertent serostatus disclosure by others heightened psychological distress. Reservations about serostatus disclosure area could also be heightened by a pervasive sense of self-blame for contracting the virus (Derlega, Winstead, Greene, Serovich, & Elwood, 2002). One bears the immense psychological consequences of living with HIV and construes disclosure as a means of garnering support from others—a resource they perceive as undeserving.

Numerous studies have shown that different types of relationships influence how HIV-seropositive persons weigh the costs and benefits of disclosing their diagnosis (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003). Disclosure to sex or injecting drug using partners, for example, is motivated by an intention to protect the well-being of others (Schnell et al., 1992), while one's decision to disclose to family members is largely determined by a personal need for support,

or a desire to alleviate possible relational strains of concealing one's diagnosis (Simoni et al., 1995). In Zea, Reisen, Poppen, Bianchi, & Echeverry, (2005) study of 155 HIV-seropositive gay Latino men in the USA, participants' decision to disclose their serostatus to select members of their social networks (parents, close friends, and primary sexual partners) was motivated by different factors. Emotional closeness, for example, was associated with disclosure to parents and awareness of participants' sexual activity with other men was associated with higher likelihood of disclosure to parents and friends (Zea, Reisen, Poppen, Echeverry, & Bianchi 2004).

The consequences of voluntary serostatus disclosure have been also widely considered in the literature, particularly its influences on health-related quality of life (Chandra, Deepthivarma, & Thomas, 2003) and mental health outcomes. Although many persons with HIV understandably anticipated the negative impact of disclosing their serostatus, studies indicate surprisingly positive responses. A recent study of 76 HIV-seropositive MSM reported that participants did not report regret about disclosing their illness to family or friends (Serovich, Mason, Bautista, & Tovissimi, 2006). Similarly, among a sample of acculturated A&PI gay men, disclosing their serostatus and sexual identity to family members resulted in positive outcomes (Nemoto, et al., 2003).

A&PI and HIV Stigma

Scrambler and Hopkins (1990) defined felt stigma as one's fear of being discriminated against solely on the grounds of one's perceived unacceptability or inferiority and the feeling of shame associated with having a stigmatized illness. This phenomenon was described by a number of A&PI MSM in the study who were ashamed that they contracted HIV because they felt that they "should know better." They feared being discriminated against by the mainstream A&PI community and shunned by HIV-negative MSM (A&PIs and non-A&PIs) because of their perceived unacceptability. In Courtenay-Quirk, Wolitski, Parsons, & Gomez' (2006) cross-sectional study of 205 MSM living with HIV, perceived HIV-related stigma within the gay community were associated depressive markers, maladaptive ways of coping, and serostatus disclosure to potential friends and sexual partners.

Stigma is explained to a large extent by both individual perceptions of HIV/AIDS and the attitudes confronted in one's social network and reference groups. Alonzo & Reynolds (1995: 305) noted that stigma is "intrinsically entwined with the disease course but is uniquely tied to the responses of the broader society, family, peers, strangers, health professionals, and the identity of the individual." Felt stigma is perpetuated by multiple minority status based on ethnicity, sexual identity, and immigration status. Being marginalized for one's HIV serostatus in addition to one's racial/ethnic identity and sexual orientation creates further ambiguity about whether discriminatory events occur as a result of any particular

group membership. As such, gay A&PI men might encounter different forms of racism and anti-immigration and homosexual sentiment across different social milieus. In Wilson and Yoshikawa (2004) study of A & PI gay men, for example, participants reported most frequent race-based discrimination within the White gay community.

AIDS stigmatization has been recognized as one of the major impediments to timely diagnosis of HIV (Eckholdt & Chin, 1997; Wong et al., 2004), utilization of medical care (Kang et al., 2003; Pounds et al., 2002), serostatus disclosure (Chin & Kroesen, 1999; Yoshioka & Schustack, 2001), and medical treatment adherence (Kang & Rapkin, 2003) among A&PIs living with HIV/AIDS. In a precursor to the present study examining 54 HIV-seropositive A&PIs living in the USA, various dimensions of stigma related to negative self-worth and compromised quality of interpersonal relationships were associated with heightened level of psychological distress (Kang et al., 2005). A follow-up to the study found that encounters with HIV-related stigma carry long-term detrimental consequences to one's psychological well-being in two specific areas of functioning. First, A&PIs' perceived or actual rejection by others on account of one's HIV status lowered their self-esteem at follow-up even after controlling for measures of baseline self-esteem and physical symptomatology at follow-up (Kang, Rapkin, & DeAlmeida, 2006). Second, financial insecurity heightened by HIV stigma and fear of inadvertently disclosing one's serostatus contributed to A&PIs' pessimistic view of their future and sense of dread.

It is also important to consider the immediate social context and the meaning the stigmatized ascribes to it. Crocker (1999: 89), for example, argued that the consequences of stigma are not simply "internalized, stable distortions of personality that individuals carry with them." Rather, it varies as a function of collective representations, situational cues, and individual differences. A&PIs' fear of being shunned is largely shaped by firmly held views of HIV within the Asian immigrant community. Collective beliefs of casual contagion and discriminatory attitudes towards homosexuals, intravenous drug users, and undocumented immigrants shape A&PIs' experiences of their illness and trigger fears of being overtly ostracized by others.

Stigma and Serostatus Disclosure

Numerous studies have considered how HIV stigma influences serostatus disclosure (Courtenay-Quirk et al., 2006). AIDS-related stigma among A&PIs is a "persistent predicament" that is perpetuated by self-attribution and blame for acquiring HIV, and is recognized as one of the major impediments to serostatus disclosure among A&PIs living with HIV illness, due to pervasive cultural proscriptions against homosexuality and injection drug use within A&PI communities. The behavior and personal decisions that result in HIV infection often carry a stigma independent of HIV. In Chin and Kroesen's (1999) study

of HIV-seropositive A&PI women, the stigma of pre-marital sex as well as HIV were carefully weighed in decisions to disclose. In a study of 605 Chinese participants in rural China, the intention to disclose one's serostatus was negatively associated with felt stigma (Liu et al, 2006).

Regardless of how the virus was acquired, participants' decision to disclose to whom and when is largely influenced by intrinsic fears of public marginalization. In Yoshioka & Schustack's (2001) qualitative study of 16 HIV-positive Asian men, it was found that serostatus disclosure is further complicated for gay men because of implicit disclosure of one's sexual orientation. Decisions to withhold or delay disclosure within the family network were largely influenced by a desire to protect them from the inherent stigma of HIV and homosexuality. In collectivistic cultures, individual decisions are framed within a broader social context, such that HIV stigma extends to one's family and community (Chin & Kroesen, 1999). Within the Chinese community, for example, stigma associated with homosexuality is perpetuated by the cultural primacy of preserving the family unit and maintaining social status, perceptions of homosexuality as immoral or abnormal, and social constructs of masculinity (Liu & Choi, 2006). Many A&PIs decide to disclose their serostatus when their health deteriorates—leaving them with an overwhelming sense of obligation to disclose their illness to family members (Yoshioka & Schustack, 2001). In contrast, underlying decisions to disclose one's serostatus to friends are often influenced by a desire to garner emotional support (Choi, Kumekawa, Dang, Kegeles, Hays, & Stall 1999).

Fear of social exclusion after disclosure may be attributed to HIV-related stigma, but also to other forms of stigma perpetuated by social biases based on gender (Anderson & Doyal, 2004; Chin & Kroesen, 1999), sexuality (Keogh, Henderson, & Dodds 2004), ethnicity (Körner, 2007), acculturation (Simoni, et al., 1995), and immigration status (Kang et al., 2003). As such, disclosure decisions are often informed by illness stigma compounded by social scripts ascribed to specific groups. In Simoni et al.'s (1995) study of disclosure patterns among HIV-seropositive Spanish-speaking Latinas, findings of low disclosure rates compared with English-speaking Latinas suggested that cultural denunciation of homosexuality based on religious beliefs heighten pre-existing HIV stigma, thereby discouraging serostatus disclosure.

Methods

Procedure

Individual 2–3-hour semi-structured interviews were conducted with a non-random convenience sample of 56 HIV-seropositive A&PIs referred by two AIDS service organizations. Eligible clients were identified and contacted by caseworkers regarding participation in the study. A written informed consent form approved by a university- and research-based institutional review board

was reviewed and signed by all participants prior to each interview. Upon completion of the interview, they were reimbursed for their involvement in the study and asked for consent to be contacted for future studies. A follow-up study was funded 2 years later, during which the research team contacted participants from the baseline study ($n=54$) regarding participation in the current study. Forty-four participants were recruited from the baseline study and 12 were new participants.

Trained bilingual, bachelor-level interviewers and the principal researcher conducted the interviews in English, Cantonese, or Mandarin. Although we recognized the tremendous diversity of racial and ethnic groups among A&PIs, it was beyond the scope of this study to translate the instrument battery into multiple A&PI languages. Interview instruments were therefore translated into Chinese because they were the largest Asian group, representing nearly half of all Asians in NYC (Scott, 2001). The interview battery was translated into written Chinese by: (1) discussing the content equivalence and sensitivity of the instruments to Chinese with bilingual colleagues; (2) translating the instruments into Chinese by one translator; (3) back-translating instruments into English by another independent translator with conceptual, rather than literal, meaning as the goal; (4) holding a meeting with the translator, back-translator, and the principal researcher, who was tri-lingual (English, Cantonese, and Mandarin), to examine and resolve differences that emerged from the back-translation (Chang, Chau, & Holroyd, 1999).

Dependent Variables

Reasons For and Against Serostatus Disclosure. The Reasons for Disclosure Questionnaire (Derlega, et al., 2002) included 21 items measuring how much specific reasons accounted for decisions to disclose or not one's HIV serostatus. A principal components analysis with varimax rotation resulted in a five-component solution that accounted for 70% of the total variance (see Appendix A). The five components included three reasons for serostatus disclosure: (1) Duty to inform (e.g., "I felt a sense of duty to tell my friend/family member"); (2) Desire to protect others (e.g., "I didn't want my friend/family member to have to worry about me"); and (3) Supportive relationships (e.g., "My friend/family member would be able to support me"). The two reasons for non-disclosure included (4) Negative self-concept (e.g., "I felt ashamed for being HIV-positive"); and (5) Privacy (e.g., "information regarding the diagnosis is my own private information"). Participants were asked to rate the extent to which specific reasons accounted for their decision to disclose or not disclose their HIV serostatus, using a five-point Likert scale ranging from 0 (Not at all important) to 5 (Extremely important). The internal consistencies for the subscales were derived from this study (Cronbach $\alpha = 0.63$ – 0.87).

Independent Variables

HIV-Related Stigma. Perception of being stigmatized was measured using a 24-item instrument, Social Impact Scale (Fife & Wright, 2000). A principal components analysis with varimax rotation resulted in a six-component solution that account for 69% of the total variance (see Appendix B). The five components included: (1) Social Rejection; (2) Financial Insecurity; (3) Secrecy; (4) Self-blame; (5) Secrecy; and (6) Negative Self-Worth. Participants were asked to rate the extent to which they agreed with experiences of being stigmatized by selecting responses scored 1 (strongly disagree) to 4 (strongly agree). Total scores ranged from 24 to 96, with a highest score indicating the strongest sense of feeling stigmatized (Cronbach $\alpha = 0.75\text{--}0.92$).

Sociodemographic Information. Sociodemographic variables included age, ethnicity, country of birth, sexual orientation, language preference, education and employment history, housing, marital status, medical insurance coverage, and immigration status.

Medical Information. Participants self-reported CD4 lymphocyte cell count, HIV/RNA viral load, date of and reason for HIV-antibody test, and HIV disclosure information.

Statistical Methods

Prior to conducting the major analyses to determine the relationship between HIV-related stigma factors and reasons for and against disclosure, we examined the bivariate relationships between sociodemographic variables and disclosure. Independent sample *t*-tests were also conducted to compare mean group differences on outcome variables between documented and undocumented participants, and homosexual and heterosexual orientations. In order to obtain an independent measure of each stigma and disclosure factor, exact-weighted scores were obtained based on the principal components solution after varimax rotation. Exact weighted scores effectively isolated variance related to major aspects of stigma onto different summary scales that were constrained to be orthogonal. The five orthogonal stigma variables summarize 69% of the total variance among 19 items, and six orthogonal disclosure variables summarized 70% of the total variance among 18 items. As such, they were included in the regression analyses without concern for multicollinearity.

Hierarchical forward multiple regression analyses were performed to determine main effects of HIV-related stigma factors (Social Rejection, Financial Insecurity, Secrecy, Self-Blame, Social Isolation, and Negative Self-Worth) on reasons for or against disclosure while controlling for demographic confounding variables. Given the small sample size, six sets of forward stepwise regressions were performed separately for each of the reasons for or against disclosure. Only

those independent variables that met criteria for forward stepwise selection were retained at each step. Given the small sample size, the significance level for entry was set at $p < 0.10$. Exact weighted scores were used in these regressions. Thus, all scores were created with a mean of 0, effectively “centering” variables for this multiplicative treatment. Centering of scores reduces multicollinearity effects between components included in the same regression model.

Results

Description of the Sample

The ages of the 56 participants ranged from 31 to 67 years ($M = 44$ years, $SD = 8.35$)—47 men, 8 women, and 1 unknown gender. The ethnic composition of the sample varied as follows: 37 were Chinese (66%), 4 were Filipino (7%), 6 were Southeast Asian (the 12% included Cambodian, Laotian, Malaysian, and Thai), 4 were Japanese (7%), and 5 were mixed-race/other (8%). The majority of participants were born in Asia or the Pacific (94%), and only 8 (14%) spoke primarily English. The most common primary language reported was Chinese, with 25% of respondents speaking primarily Mandarin and another 25% speaking primarily Cantonese. Twenty (36%) participants self-identified as homosexual, 30 (54%) as heterosexual, 2 (4%) as bisexual, and 4 (7%) declined to respond about their sexual orientation. Twenty-eight (50%) participants were single, never married, and 19 (34%) were married (58% of whom were living with their spouse).

There were 31 (55%) legally documented immigrants or US citizens, and 25 undocumented (45%) who entered the USA illegally or overstayed their visas. The majority of participants were not born in the USA ($n = 53$, 95%) but had been living in the USA for a mean of 16 years ($SD = 9.75$) and completed a mean of 11 years of school in the USA and/or abroad ($SD = 5.72$). The majority of the participants were unemployed ($n = 23$, 41%) and lived in rental apartments ($n = 43$, 77%). Many received health insurance coverage from the AIDS Drug Assistance Program (ADAP; $n = 30$, 54%) and/or Medicaid ($n = 26$, 46%).

The mean length of post-HIV/AIDS diagnosis was 7 years ($SD = 4.45$, range = 1–18 years), and the majority of participants self-reported stable immune functioning with 87% reporting undetectable HIV/RNA viral load, and 95% reporting CD4 lymphocyte cell counts greater than 200 cells/mm³.

Associations Between Stigma and Reasons For or Against Disclosure

Bivariate correlations indicated significant positive correlation between social support reasons for disclosure and demographic variables including years

living in the USA ($r = 0.29, p < 0.05$), MSM status ($r = 0.50, p < 0.001$), and years of education completed ($r = 0.47, p < 0.001$). Duty to protect others was positively correlated with stigma-related self-blame ($r = 0.32, p < 0.05$). Non-disclosure due to difficulty accepting HIV serostatus was positively correlated with stigma-related Secrecy ($r = 0.32, p < 0.05$).

Independent sample *t*-tests showed that A&PIs who self-identified as MSM completed more years of education, lived in the USA longer, and has been diagnosed with HIV longer than A&PIs who self-identified as heterosexual. MSM in this cohort also endorsed lower levels of stigma-related social rejection than Asians who self-identified as heterosexuals ($t(52) = -2.32, p < 0.05$). In addition, self-identified MSM endorsed receiving support as the reason to disclose their serostatus more frequently than heterosexual participants ($t(52) = 3.86, p < 0.001$) (see Table 9.1). Hierarchical regression analyses further indicated sexual risk practice (MSM/heterosexual), years of education, and length in the USA accounted for 32% of the variance in serostatus disclosure to receive support (Adjusted $R^2 = 0.321, p < 0.001$). When simultaneously entered into the equation sexual risk practice ($t(52) = -2.20, p < 0.05$) and years

Table 9.1 Means and standard deviations of predictor and outcomes variables for participants who self-identified as MSM or heterosexual

	MSM (n = 22)	Heterosexual (n = 30)
Demographic variables		
Age	44 (8.51)	42 (9.13)
Years of education completed	14 (4.96)	8 (4.84)***
Length of HIV diagnosis	9 (4.25)	6 (4.13)*
Years living in the US	22 (9.63)	11 (5.71)***
Stigma		
Social Rejection	2.26 (0.846)	2.68 (0.476)*
Financial Insecurity	2.56 (0.756)	2.72 (0.618)
Secrecy	2.63 (0.813)	2.74 (0.657)
Self-Blame	2.80 (0.722)	2.74 (0.577)
Social Isolation	2.63 (0.71)	2.60 (0.48)
Negative Self-Worth	2.56 (0.726)	2.74 (0.493)
Reasons for or against disclosure		
<i>Reasons to disclosure</i>		
Duty to inform	2.84 (1.02)	2.56 (0.964)
Duty to protect others	3.00 (1.06)	2.65 (0.792)
Supportive relationship	3.45 (0.816)	2.47 (1.02)***
<i>Reasons to not disclose</i>		
Difficulty accepting HIV serostatus	2.50 (1.32)	2.79 (1.05)
Privacy	3.44 (1.12)	3.26 (0.932)

* $p < .05$ (two-tailed); *** $p < .001$ (two-tailed)

Note: Higher scores indicate stronger indicators of illness stigma and endorsement of reasons for disclosure or non-disclosure. Four cases of non-reported sexual identity were excluded from this analysis.

of education ($t(52) = 2.08, p < 0.05$) significantly predicted serostatus disclosure to receive support.

Hierarchical forward stepwise regression analyses were conducted to determine whether the stigma factors were independently associated with motivating factors for serostatus disclosure, controlling for MSM status and years living with HIV—both were significant variables in the bivariate analyses. As shown in Table 9.2, MSM status and length of HIV diagnosis at Steps 1 and 2, respectively, were not significantly associated with negative self-concept as reason for non-disclosure. Entry of stigma-related Secrecy at Step 3 added significantly to the regression equation (Adjusted $R^2 = 0.123$, with a significant R^2 Change = 0.120, $p < 0.05$). When stigma-related negative self-worth was added at Step 4, the equations remained significant (Adjusted $R^2 = 0.25$, with R^2 Change = 0.070, $p < 0.05$). Overall, stigma-related social isolation did not add significantly to the model. The overall model explained 21% of the variance in not disclosing due to difficulty accepting one's HIV status ($F(5,46) = 3.75, p < 0.01$).

Table 9.2 Hierarchical forward stepwise regression predicting non-disclosure due to difficulty accepting HIV serostatus

	R^2	Adj R^2	$R^2\Delta$	β	t
Step 1	0.050	0.031			
<i>MSM</i>				-0.223	-1.62
	0.055	0.055	0.005		
<i>MSM</i>				-0.202	-1.40
<i>Length of HIV diagnosis</i>				-0.073	-0.502
	0.175	0.123*	0.120*		
<i>MSM</i>				-0.245	-1.78
<i>Length of HIV diagnosis</i>				0.69	0.470
<i>HIV Stigma—Secrecy</i>				0.373	2.65*
	0.245	0.181**	0.070*		
<i>MSM</i>				-0.231	-1.74
<i>Length of HIV diagnosis</i>				0.065	0.456
<i>HIV Stigma—Secrecy</i>				0.381	2.80**
<i>HIV Stigma—Negative Self-Worth</i>				0.265	2.09*
	0.290	0.213**	0.045		
<i>MSM</i>				-0.264	-2.00
<i>Length of HIV diagnosis</i>				0.047	0.338
<i>HIV Stigma—Secrecy</i>				0.370	2.77**
<i>HIV Stigma—Negative Self-Worth</i>				0.240	1.92
<i>HIV Stigma—Social Isolation</i>				0.217	1.71

* $p < 0.05$; ** $p < 0.01$, *** $p < 0.001$

Note: β , standardized regression coefficients

Discussion

The decision to intentionally conceal or disclose one's serostatus is a process of weighing the costs and benefits of revealing or maintaining one's illness a guarded secret within family and peer networks. Determination of the risks and value of disclosure can be influenced by gender, cultural identity, medical condition, or discriminatory attitudes toward persons living with HIV/AIDS (Kang et al., 2003, 2006). This cross-sectional study highlighted specific dimensions of stigma that weighed upon A&PI MSM's decision to disclose their serostatus. Specifically, HIV stigma-related secrecy was associated with non-disclosure due to difficulty accepting one's serostatus, after controlling for sexual risk behavior and length of HIV diagnosis. Moreover, MSM in this study reported less stigma-related social rejection and were more likely to disclose their serostatus based on need for social support, compared with heterosexuals in the study. Based on these findings, several considerations for clinical practice and research are noteworthy.

First, regardless of sexual risk behavior, self-identified A&PI MSM and heterosexuals both held reservations about disclosing their serostatus due to shame and difficulty accepting the reality of their illness. Perceived stigma that heightened fear of public ostracism and rejection swayed A&PIs toward concealing their HIV status. It is noteworthy that the length of HIV diagnosis did not necessarily facilitate acceptance of illness, nor did it mitigate the negative consequences of stigma. Self-imposed shame and passive denial of HIV influenced personal decisions to conceal one's serostatus, even years after learning about their diagnosis (mean length of HIV diagnosis was 7 years). Moreover, as the epidemic approaches its third decade, it is unsettling that perceived and actual HIV stigma continue to significantly influence A&PI's disclosure decisions and relationships. Studies have also suggested that MSM in the USA continue to contend with HIV stigma within gay communities in form of discriminatory attitudes, thereby creating a divide between HIV-seropositive and negative men (Collins, 1998; Courtenay-Quirk et al., 2006).

Both dimensions of HIV stigma and reasons for non-disclosure were related to internalized processes of maintaining secrecy, shame, and denial of illness. This underscores the importance of considering how multiple layers of stigma might heighten the overwhelming task of preserving one's serostatus a secret. Perceptions of marginalization and social rejection could be perpetuated by virtue of one's serostatus, risk behaviors associated with HIV transmission, undocumented immigration status, gender, or sexual orientation. A&PI MSM, for example, further contend with race-based stigma within the gay community that compounds their overall sense of marginalization—specifically perceived stereotypes of A&PIs adopting a submissive or feminized role in sexual relationships (Nemoto et al., 2003). Disentangling the multiple layers of stigmatizing attributes is crucial to informing effective policies and interventions that mitigate the effects of HIV stigma on disclosure and other quality of life outcomes (Reidpath & Chan, 2005).

Previous studies with a similar cohort of A&PIs found that felt stigma and perceived repercussions of public disclosure are shaped by both individual perceptions of HIV/AIDS and the dominant attitudes in one's community (Kang, et al., 2003, 2005). The interplay of individual and social forces that shape illness stigma underscores the importance of challenging A&PIs' misperceptions of HIV transmission and risk behaviors, and discriminatory attitudes towards homosexuality and bisexuality in order to promote greater understanding of the illness and wider acceptance of persons living with HIV.

Second, educated A&PI MSM in this study were inclined to disclose their serostatus for purposes of receiving support from others, highlighting the importance of establishing and sustaining supportive relationships, at the risk of possible rejection. Previous cross-sectional studies had found that serostatus disclosure was associated with greater quality of social support from target groups (Zea, et al., 2005; Simoni, Demas, Mason, Drossman, & Davis 2000). It is noteworthy that the source and type of support one hopes to receive as a result of serostatus disclosure are speculative from the current findings. Previous studies, however, have highlighted various support networks available to and utilized by MSM. Friendships with other gay men, for example, helped to mitigate the effects of homophobia among A&PI MSM (Wilson & Yoshikawa, 2004), and interaction with other HIV-seropositive A&PIs alleviated feelings of isolation (Chin et al., 2006).

However, perceived available social support and received social support are distinct dimensions (Schwarzer, Dunkel-Schetter & Kemeny, 1994; Derlega, Winstead, Oldfield, & Barbee, 2003). Previous studies on Asian American women with breast cancer, for example, highlighted the important distinction between wanting support and acknowledgment of need that will lead to actual solicitation of support (Wellisch et al., 1999; Kagawa-Singer & Wellisch, 1997). Josephson's (1997) study of 163 persons with HIV found that both actual and perceived social were associated with decisions to disclose serostatus. The extent to which A&PI MSM possibly underutilize available forms of support should be considered, particularly if serostatus disclosure is perceived as a relational requisite for soliciting support from others.

Although previous studies have consistently highlighted the importance of social networks and providing a venue for A&PI MSM to safely garner support, further work is needed to assist A&PI MSM solicit specific forms of support. Taylor et al., (2004), for example, highlighted Asians and Asian American's proclivity to underutilize social support for coping because of fear that imposing one's problems on others will undermine group harmony, overly burden others, resulting in critical judgment by others. Moreover, cultural scripts sway individuals to bear the responsibility of personal decisions rather than to place that burden on others. It is noteworthy that findings from this study are based on a convenience sample of HIV-seropositive A&PIs who are engaged in services at a community-based organization that provides an array of peer-oriented supportive programs. As such, the importance of social support networks may be understated or overstated, given that the sample is biased towards those receiving support.

Further studies are needed to clarify specific forms and utility of social support among A&PI MSM when considering their motives for serostatus disclosure. Although social networks can buffer against disruptive life events, the costs and benefits of social support are not equally shared across groups (Kawachi & Berkman, 2001; Smith & Rapkin, 1996). For women with low resources, for example, Belle (1987) found that participation in social networks might be more harmful than helpful because they face greater demands from their support networks. Moreover, particular A&PI groups place value on their ability to cope with problems independently and differentiate between the support received from “in-group” (e.g., family and intimate friends) and “out-group” members (e.g., service providers; Matsudaira, 2003). Some HIV-seropositive A&PIs, for example, garner mutual support from other APIs living with the illness who function as a proxy for family (Eckholdt et al., 1997), while others minimize their contact with other A&PIs in fear that suspicions of their illness will circulate within their community (Yoshikawa et al., 2001). This underscores the importance of clarifying how APIs define and utilize supportive networks and identifying specific aspects of social support that buffer against psychological distress.

Clinical interventions perhaps should move beyond helping A&PI MSM consider whether or not to disclose their serostatus, to begin addressing issues that potentially curtail the benefits of disclosure to specific social networks. What factors possibly interfere with the process of garnering support from targets of disclosure or fulfilling a sense of relational duty and responsibility? Findings from this study suggest that perceived HIV stigma within one’s personal social network (defined by sexual orientation, ethnicity, immigration status, social class, and gender) and internalized shame and non-acceptance of personal serostatus pose significant challenges for A&PI MSM and heterosexual men when considering decisions to disclose. However, serostatus disclosure is not a static event; rather, it is a dynamic process by which A&PIs continue to wrestle with issues that rendered their initial disclosure decision difficult. It cannot be presumed that internalized denial of HIV and isolation, for example, would be immediately resolved following the disclosure event. Interventions that focus on A&PI’s adjustment to post-disclosure should address how these transitory issues unravel in the context of a “new relationship.” Moreover, the uncertainty of whether the potential relational benefits of disclosure may dissipate or be sustained over time warrant longitudinal studies that will clarify our understanding of the impact on disclosure mental health and quality of life indices (Zea, et al., 2004).

Study Limitations and Future Directions

This study has several limitations that could affect its generalizability and interpretation. First, this study did not specify how types of relationships influence disclosure decisions. Previous studies have consistently found that

MSM were more inclined to disclose their serostatus to friends or sexual partners than to family members (Kalichman et al., 2003; Zea et al., 2005). Given that decisions to disclose to various targets are influenced by an appraisal of potential benefits, further studies are needed to specifically examine common and distinctive reasons that inform serostatus disclosure to sex partners, friends, and family among A&PI MSM. Moreover, efforts to clarify the relational consequences of disclosure necessitate examining the content of disclosure. Omarzu (2000), for example, highlighted the importance of considering the dimensions of breadth, duration, and depth in theoretical models of self-disclosure. Given the influence of stigma on disclosure decisions, describing one's HIV diagnosis as a "chronic blood disease" rather than being "HIV-positive" to family members bear different relational consequences.

Second, findings from this study focused on illness-specific stigma without considering the different "layers" of HIV-related stigma that influence serostatus disclosure (Reidpath & Chan, 2005). Perceptions of marginalization and social rejection could be perpetuated by virtue of one's serostatus, risk behaviors associated with HIV transmission, immigration status, or sexual orientation. It is conceivable that A&PI MSM's reluctance to disclose their serostatus is largely influenced by their avoidance of revealing their sexual practices or identity, and less by fear of discrimination on the basis of their HIV illness.

Third, the findings and implications of this study cannot be generalized to the experiences of all Asians and Pacific Islanders living with HIV/AIDS in the USA. The findings are limited to a small convenience sample of HIV-seropositive APIs receiving supportive services from community-based AIDS organizations, 66% of whom were ethnic-Chinese. The majority of A&PIs in this sample were also in medically stable conditions (87% reported undetectable HIV/RNA viral load). These self-selection biases limit the generalizability of the current findings to those similarly situated individuals and may not be relevant to those who are not accessing or utilizing supportive services as well as other A&PI groups with more significant immunocompromise. Notwithstanding these limitations, findings from this study demonstrate that decision-making regarding serostatus disclosure is a complex and multifaceted process that continues to be influenced by HIV stigma—a pernicious social phenomena that perpetuates internalized secrecy, shame, and denial of illness. Efforts to mitigate the influence of stigma on A&PI MSM's disclosure decisions must recognize that HIV stigma encompasses formidable social biases based on sexual orientation, ethnicity, immigration status, and country of origin—that persists even as the epidemic approaches its third decade

Acknowledgment This research was supported by the Office of AIDS Research, National Institute of Mental Health, and the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University (P50/P30 MH43520; Principal Investigator: Anke A. Ehrhardt, Ph.D.) The authors thank the Asian and Pacific Islander Coalition on HIV/AIDS, Inc. and Chinese American Planning Council, Inc., for supporting this study and tirelessly advocating for the needs of A&PIs.

Appendix A

Factor 1: Duty to Inform (Five Items)^a

I didn't want to have to carry this information about me all by myself.
 I felt obligated to tell my friend/family member.
 This person had the right to know what is happening to me.
 I felt a sense of duty to tell my friend/family member.
 I wanted to make sure that my friend knew how serious this disease is.

Factor 2: Duty to Protect Others (Five Items)^b

I felt bad about myself.
 I didn't know how to start telling my friend/family member about the diagnosis.
 I was concerned that my friend/family member wouldn't understand what I was going through.
 I didn't want my friend/family member to worry about me.
 I didn't want my friend/family member to have to make sacrifices for me.

Factor 3: Supportive Relationship (Four Items)^c

I wanted to prepare my friend/family member for what might happen to me.
 I trusted my friend/family member.
 My friend would be able to provide support.
 My friend would provide me with assistance.

Factor 4: Difficulty Accepting HIV serostatus (Two Items)^d

I had difficulty accepting that I was HIV-positive.
 I felt ashamed about being HIV-positive.

Factor 5: Privacy (Two Items)^e

My friend/family member might tell other people.
 Information about the diagnosis is my own private information.

Excluded Items

I didn't want to risk any health problems for my friend/family member; I wanted to see how my friend would react when I told them the information; I didn't feel my friend/family member would be supportive.

^a Five items; $\alpha = 0.833$; eigenvalue = 6.41; percent of the variance explained = 30.53

^b Five items; $\alpha = 0.838$; eigenvalue = 3.61; percent of the variance explained = 17.22

^c Four items; $\alpha = 0.877$; eigenvalue = 1.72; percent of the variance explained = 8.20

^d Two items; $\alpha = 0.841$; eigenvalue = 1.65; percent of the variance explained = 7.85

^e Two items; $\alpha = 0.632$; eigenvalue = 1.21; percent of the variance explained = 5.79

Appendix B

Social Impact Scale

Factor 1: Social Rejection (Seven Items)^f

- I feel that I have been treated with less respect than usual by others.
- I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I make.
- I feel others avoid me because of my illness.
- Some family members have rejected me because of my illness.
- I feel some friends have rejected me because of my illness.
- I encounter embarrassing situations as a result of my illness.
- Due to my illness others seem to feel awkward and tense when they are around me.

Factor 2: Financial Insecurity (Three Items)^g

- I have experienced financial hardship that has affected how I feel about myself.
- My job security has been affected by my illness.
- I have experienced financial hardship that has affected my relationship with others.

Factor 3: Secrecy (Three Items)^h

- I do not feel I can be open with others about my illness.
- I fear someone telling others about my illness without my permission.
- I feel I need to keep my illness a secret.

Factor 4: Self-Blame (Two Items)ⁱ

- I feel others think I am to blame for my illness.
- I feel I am at least partially to blame for my illness.

Factor 5: Social Isolation (Two Items)^j

- I feel lonely more often than usual.
- Due to my illness, I have a sense of being unequal in my relationship with others.

Factor 6: Negative Self-Worth (Two Items)^k

- Due to my illness, I sometimes feel useless.
- Changes in my appearance have affected my social relationships.

^f Seven items; $\alpha = 0.923$; eigenvalue = 10.37; percent of variance explained = 43.22

^g Three items; $\alpha = 0.866$; eigenvalue = 2.20; percent of variance explained = 9.19

^h Three items; $\alpha = 0.869$; eigenvalue = 1.74; percent of variance explained = 7.28

ⁱ Two items; $\alpha = 0.768$; eigenvalue = 1.62; percent of variance explained = 6.76

^j Two items; $\alpha = 0.757$; eigenvalue = 1.28; percent of variance explained = 5.34

^k Two items; $\alpha = 0.774$; eigenvalue = 1.07; percent of variance explained = 4.46

Excluded Items

My employer/co-workers have discriminated against me because of my illness; Some people act as though I am less competent than usual; I feel set apart from others who are well; I have a greater need than usual for reassurance that others care about me; I feel less competent than I did before my illness.

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