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Part VI
HIV, Multiple Minority Status, and Stigma

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01 **Chapter 14**

02 **Why Tell? Serostatus Disclosure and HIV Stigma**
 03 **among HIV Seropositive Asians and Pacific**
 04 **Islander Men who have Sex with Men in**
 05 **New York City**
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 10 **Ezer Kang and Bruce D. Rapkin**
 11

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

AQ1

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

35 This chapter focuses on our findings from a cross-sectional study initiated
 36 to further our understanding of the relationship between five dimensions of
 37 HIV stigma and factors related to decisions about serostatus disclosure among
 38 HIV-seropositive A&PIs receiving services at community organizations in New
 39 York City (NYC). It is important to note that although the aggregate term
 40 "A&PI" is referenced in this study, the authors acknowledge significant
 41
 42

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

06 ***A&PI MSM and HIV: Epidemiological Profile***

09 In the United States, 7,317 cumulative adult AIDS cases were reported among
10 A&PIs through 2004 (CDC, 2005). In NYC, a cumulative of 1,088 (0.8 %) adult
11 cases of AIDS was reported among A&PIs through December 2004 (NYCMH,
12 2006). The majority of A&PIs newly diagnosed with HIV in 2004 were foreign-
13 born, with Asia accounting for 69% of new diagnoses among foreign-born
14 (NYCDOH, 2006). HIV continues to spread nationally and locally at alarm-
15 ingly high rates among MSM of color. In the USA, 72% ($n=2,445$) of
16 estimated A&PI males living with AIDS in 2004 were among MSM, compared
17 with 52% among Hispanic, 57% among American Indian/Alaska Native, and
18 44% among Blacks (CDC, 2006). In NYC, MSM accounted for 80% of new
19 HIV diagnosis among A&PI males. Although the rate of AIDS among A&PIs
20 (4.0 per 100,000 population) was low compared with other racial/ethnic groups
21 in the USA, the estimated number of HIV/AIDS cases has increased among
22 A&PIs between 2000 and 2003 at rates comparable with Whites and Hispanics,
23 and far faster than African Americans, American Indians, and Alaska Natives.

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

36 ***Decision to Disclose Serostatus***

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

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

18 Decisions to disclose one's serostatus can be motivated by a need to release
19 internalized feelings and anxiety over living with a stigmatized illness (Holt
20 et al., 1998). Among Asian undocumented immigrants with HIV/AIDS, for
21 example, living a double life in order to maintain one's serostatus a secret can be
22 physically and emotionally draining and affects how they manage and reorient
23 their lives (Kang et al., 2003). Decisions to disclose one's serostatus can also be
24 influenced by one's sense of duty to protect the well-being of their casual sex
25 partners in order to reinforce protective sexual practices or to encourage
26 partners to get tested for HIV (Gorbach et al., 2004; Serovich & Mosack,
27 2003). In a study of HIV-seropositive African American MSM, one's felt
28 obligation to disclose, coupled with their fear of rejection, discouraged partici-
29 pants from pursuing sexual relationships (Harawa, Williams, Ramamurthhi, &
30 Bingham 2006). Decision to conceal one's serostatus is largely influenced by a
31 perceived fear that others will inadvertently or intentionally breach confidence
32 and disclose their serostatus to others. In a study of 54 A&PIs living with HIV in
33 NYC, Kang, Rapkin, Remien, Mellins, & Oh, (2005) found that fear of inad-
34 vertent serostatus disclosure by others heightened psychological distress. Reser-
35 vations about serostatus disclosure area could also be heightened by a pervasive
36 sense of self-blame for contracting the virus (Derlega, Winstead, Greene,
37 Serovich, & Elwood, 2002). One bears the immense psychological consequences
38 of living with HIV and construes disclosure as a means of garnering support
39 from others—a resource they perceive as undeserving.

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

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

10 The consequences of voluntary serostatus disclosure have been also widely
11 considered in the literature, particularly its influences on health-related quality
12 of life (Chandra, Deepthivarnma, & Thomas, 2003) and mental health out-
13 comes. Although many persons with HIV understandably anticipated the nega-
14 tive impact of disclosing their serostatus, studies indicate surprisingly positive
15 responses. A recent study of 76 HIV-seropositive MSM reported that partici-
16 pants did not report regret about disclosing their illness to family or friends
17 (Serovich, Mason, Bautista, & Toviesi, 2006). Similarly, among a sample of
18 acculturated A&PI gay men, disclosing their serostatus and sexual identity to
19 family members resulted in positive outcomes (Nemoto, et al., 2003).

22 *A&PI and HIV Stigma*

24
25 **AQ3** Scrambler and Hopkins (1990) defined felt stigma as one's fear of being dis-
26 criminated against solely on the grounds of one's perceived unacceptability or
27 inferiority and the feeling of shame associated with having a stigmatized illness.
28 This phenomenon was described by a number of A&PI MSM in the study who
29 were ashamed that they contracted HIV because they felt that they "should
30 know better." They feared being discriminated against by the mainstream A&PI
31 community and shunned by HIV-negative MSM (A&PIs and non-A&PIs)
32 because of their perceived unacceptability. In Courtenay-Quirk, Wolitski,
33 Parsons, & Gomez (2006) cross-sectional study of 205 MSM living with HIV,
34 perceived HIV-related stigma within the gay community were associated
35 depressive markers, maladaptive ways of coping, and serostatus disclosure to
36 potential friends and sexual partners.

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

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

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

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

33 34 35 *Stigma and Serostatus Disclosure* 36

37
38 Numerous studies have considered how HIV stigma influences serostatus dis-
39 closure (Courtenay-Quirk et al., 2006). AIDS-related stigma among A&PIs is a
40 "persistent predicament" that is perpetuated by self-attribution and blame for
41 acquiring HIV, and is recognized as one of the major impediments to serostatus
42 disclosure among A&PIs living with HIV illness, due to pervasive cultural
43 proscriptions against homosexuality and injection drug use within A&PI com-
44 munities. The behavior and personal decisions that result in HIV infection
45 often carry a stigma independent of HIV. In Chin and Kroesen's (1999) study

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

05 Regardless of how the virus was acquired, participants' decision to disclose to
06 whom and when is largely influenced by intrinsic fears of public marginalization.
07 In Yoshioka & Schustack's (2001) qualitative study of 16 HIV-positive Asian
08 men, it was found that serostatus disclosure is further complicated for gay men
09 because of implicit disclosure of one's sexual orientation. Decisions to withhold
10 or delay disclosure within the family network were largely influenced by a desire
11 to protect them from the inherent stigma of HIV and homosexuality. In collec-
12 tivistic cultures, individual decisions are framed within a broader social context,
13 such that HIV stigma extends to one's family and community (Chin & Kroesen,
14 1999). Within the Chinese community, for example, stigma associated with
15 homosexuality is perpetuated by the cultural primacy of preserving the family
16 unit and maintaining social status, perceptions of homosexuality as immoral or
17 abnormal, and social constructs of masculinity (Liu & Choi, 2006). Many A&PIs
18 decide to disclose their serostatus when their health deteriorates—leaving them
19 with an overwhelming sense of obligation to disclose their illness to family
20 members (Yoshioka & Schustack, 2001). In contrast, underlying decisions to
21 disclose one's serostatus to friends are often influenced by a desire to garner
22 emotional support (Choi, Kumekawa, Dang, Kegeles, Hays, & Stall 1999).

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

34 35 36 **Methods**

37 38 *Procedure*

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

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

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

26 *Dependent Variables*

28 *Reasons For and Against Serostatus Disclosure.* The Reasons for Disclosure
29 Questionnaire (Derlega, et al., 2002) included 21 items measuring how
30 much specific reasons accounted for decisions to disclose or not one's HIV
31 serostatus. A principal components analysis with varimax rotation resulted in
32 a five-component solution that accounted for 70% of the total variance
33 (see Appendix A). The five components included three reasons for serostatus
34 disclosure: (1) Duty to inform (e.g., "I felt a sense of duty to tell my friend/
35 family member"); (2) Desire to protect others (e.g., "I didn't want my friend/
36 family member to have to worry about me"); and (3) Supportive relationships
37 (e.g., "My friend/family member would be able to support me"). The two
38 reasons for non-disclosure included (4) Negative self-concept (e.g., "I felt
39 ashamed for being HIV-positive"); and (5) Privacy (e.g., "information regard-
40 ing the diagnosis is my own private information"). Participants were asked to
41 rate the extent to which specific reasons accounted for their decision to disclose
42 or not disclose their HIV serostatus, using a five-point Likert scale ranging from
43 0 (Not at all important) to 5 (Extremely important). The internal consistencies
44 for the subscales were derived from this study (Cronbach $\alpha = 0.63$ – 0.87).
45

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 $\alpha = 0.75-0.92$).

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 various 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

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

08 Results

11 *Description of the Sample*

13 The ages of the 56 participants ranged from 31 to 67 years ($M = 44$ years,
14 $SD = 8.35$)—47 men, 8 women, and 1 unknown gender. The ethnic composition
15 of the sample varied as follows: 37 were Chinese (66%), 4 were Filipino (7%),
16 6 were Southeast Asian (the 12% included Cambodian, Laotian, Malaysian,
17 and Thai), 4 were Japanese (7%), and 5 were mixed-race/other (8%). The
18 majority of participants were born in Asia or the Pacific (94%), and only 8
19 (14%) spoke primarily English. The most common primary language reported
20 was Chinese, with 25% of respondents speaking primarily Mandarin and
21 another 25% speaking primarily Cantonese. Twenty (36%) participants self-
22 identified as homosexual, 30 (54%) as heterosexual, 2 (4%) as bisexual, and
23 4 (7%) declined to respond about their sexual orientation. Twenty-eight (50%)
24 participants were single, never married, and 19 (34%) were married (58% of
25 whom were living with their spouse).

26 There were 31 (55%) legally documented immigrants or US citizens, and
27 25 undocumented (45%) who entered the USA illegally or overstayed their visas.
28 The majority of participants were not born in the USA ($n = 53$, 95%) but had
29 been living in the USA for a mean of 16 years ($SD = 9.75$) and completed a mean
30 of 11 years of school in the USA and/or abroad ($SD = 5.72$). The majority of the
31 participants were unemployed ($n = 23$, 41%) and lived in rental apartments
32 ($n = 43$, 77%). Many received health insurance coverage from the AIDS Drug
33 Assistance Program (ADAP; $n = 30$, 54%) and/or Medicaid ($n = 26$, 46%).

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

40 *Associations Between Stigma and Reasons For or Against* 41 *Disclosure*

42
43
44 Bivariate correlations indicated significant positive correlation between social
45 support reasons for disclosure and demographic variables including years

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

06 Independent sample *t*-tests showed that A&PIs who self-identified as MSM
 07 completed more years of education, lived in the USA longer, and has been
 08 diagnosed with HIV longer than A&PIs who self-identified as heterosexual.
 09 MSM in this cohort also endorsed lower levels of stigma-related social rejection
 10 than Asians who self-identified as heterosexuals ($t(52)=-2.32, p<0.05$). In
 11 addition, self-identified MSM endorsed receiving support as the reason to
 12 disclose their serostatus more frequently than heterosexual participants
 13 ($t(52)=3.86, p<0.001$) (see Table 14.1). Hierarchical regression analyses further
 14 indicated sexual risk practice (MSM/heterosexual), years of education, and
 15 length in the USA accounted for 32% of the variance in serostatus disclosure
 16 to receive support (Adjusted $R^2 = 0.321, p<0.001$). When simultaneously
 17 entered into the equation sexual risk practice ($t(52)=-2.20, p<0.05$) and years
 18
 19
 20

21 **Table 14.1** Means and standard deviations of predictor and outcomes variables for partici-
 22 pants 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 disclose</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)

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

43 Note: Higher scores indicate stronger indicators of illness stigma and endorsement of reasons
 44 for disclosure or non-disclosure. Four cases of non-reported sexual identity were excluded
 45 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 14.2, 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 14.2 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			
MSM				-0.223	-1.62
	0.055	0.055	0.005		
MSM				-0.202	-1.40
Length of HIV diagnosis				-0.073	-0.502
	0.175	0.123*	0.120*		
MSM				-0.245	-1.78
Length of HIV diagnosis				0.69	0.470
HIV Stigma—Secrecy				0.373	2.65*
	0.245	0.181**	0.070*		
MSM				-0.231	-1.74
Length of HIV diagnosis				0.065	0.456
HIV Stigma—Secrecy				0.381	2.80**
HIV Stigma—Negative Self-Worth				0.265	2.09*
	0.290	0.213**	0.045		
MSM				-0.264	-2.00
Length of HIV diagnosis				0.047	0.338
HIV Stigma—Secrecy				0.370	2.77**
HIV Stigma—Negative Self-Worth				0.240	1.92
HIV Stigma—Social Isolation				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).

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

09 Second, educated A&PI MSM in this study were inclined to disclose their
10 serostatus for purposes of receiving support from others, highlighting the impor-
11 tance of establishing and sustaining supportive relationships, at the risk of possible
12 rejection. Previous cross-sectional studies had found that serostatus disclosure was
13 associated with greater quality of social support from target groups (Zea, et al.,
14 2005; Simoni, Demas, Mason, Drossman, & Davis 2000). It is noteworthy that the
15 source and type of support one hopes to receive as a result of serostatus disclosure
16 are speculative from the current findings. Previous studies, however, have high-
17 lighted various support networks available to and utilized by MSM. Friendships
18 with other gay men, for example, helped to mitigate the effects of homophobia
19 among A&PI MSM (Wilson & Yoshikawa, 2004), and interaction with other
20 HIV-seropositive A&PIs alleviated feelings of isolation (Chin et al., 2006).

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

32 Although previous studies have consistently highlighted the importance of
33 social networks and providing a venue for A&PI MSM to safely garner support,
34 further work is needed to assist A&PI MSM solicit specific forms of support.
35 AQ4 Taylor et al., (2004), for example, highlighted Asians and Asian American's
36 proclivity to underutilize social support for coping because of fear that impos-
37 ing one's problems on others will undermine group harmony, overly burden
38 others, resulting in critical judgment by others. Moreover, cultural scripts sway
39 individuals to bear the responsibility of personal decisions rather than to place
40 that burden on others. It is noteworthy that findings from this study are based
41 on a convenience sample of HIV-seropositive A&PIs who are engaged in
42 services at a community-based organization that provides an array of peer-
43 oriented supportive programs. As such, the importance of social support net-
44 works may be understated or overstated, given that the sample is biased
45 towards those receiving support.

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

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

40 *Study Limitations and Future Directions*

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

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

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

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

39
40
41 **Acknowledgment** This research was supported by the Office of AIDS Research, National
42 Institute of Mental Health, and the HIV Center for Clinical and Behavioral Studies at the
43 New York State Psychiatric Institute and Columbia University (P50/P30 MH43520; Principal
44 Investigator: Anke A. Ehrhardt, Ph.D.) The authors thank the Asian and Pacific Islander
45 Coalition on HIV/AIDS, Inc. and Chinese American Planning Council, Inc., for supporting
this study and tirelessly advocating for the needs of A&PIs.

01 **Appendix A**

02

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

04

05 I didn't want to have to carry this information about me all by myself.

06

06 I felt obligated to tell my friend/family member.

07

07 This person had the right to know what is happening to me.

08

08 I felt a sense of duty to tell my friend/family member.

09

09 I wanted to make sure that my friend knew how serious this disease is.

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

11

12 I felt bad about myself.

13

13 I didn't know how to start telling my friend/family member about the diagnosis.

14

14 I was concerned that my friend/family member wouldn't understand what I
15 was going through.

16

16 I didn't want my friend/family member to worry about me.

17

17 I didn't want my friend/family member to have to make sacrifices for me.

18 **Factor 3: Supportive Relationship (Four Items)^c**

19

20 I wanted to prepare my friend/family member for what might happen to me.

21

21 I trusted my friend/family member.

22

22 My friend would be able to provide support.

23

23 My friend would provide me with assistance.

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

25

26 I had difficulty accepting that I was HIV-positive.

27

27 I felt ashamed about being HIV-positive.

28 **Factor 5: Privacy (Two Items)^e**

29

30 My friend/family member might tell other people.

31

31 Information about the diagnosis is my own private information.

32

32 **Excluded Items**

33

34 I didn't want to risk any health problems for my friend/family member; I

35

35 wanted to see how my friend would react when I told them the information; I

36

36 I didn't feel my friend/family member would be supportive.

37

38

39

40

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

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

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

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

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

01 **Appendix B**

02

03 ***Social Impact Scale***

04

05

06 **Factor 1: Social Rejection (Seven Items)^f**

07

I feel that I have been treated with less respect than usual by others.

08

I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I make.

09

I feel others avoid me because of my illness.

10

Some family members have rejected me because of my illness.

11

I feel some friends have rejected me because of my illness.

12

I encounter embarrassing situations as a result of my illness.

13

Due to my illness others seem to feel awkward and tense when they are around me.

14

15

16

17 **Factor 2: Financial Insecurity (Three Items)^g**

18

I have experienced financial hardship that has affected how I feel about myself.

19

My job security has been affected by my illness.

20

I have experienced financial hardship that has affected my relationship with others.

21

22

23 **Factor 3: Secrecy (Three Items)^h**

24

I do not feel I can be open with others about my illness.

25

I fear someone telling others about my illness without my permission.

26

I feel I need to keep my illness a secret.

27

28 **Factor 4: Self-Blame (Two Items)ⁱ**

29

I feel others think I am to blame for my illness.

30

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

31

32 **Factor 5: Social Isolation (Two Items)^j**

33

I feel lonely more often than usual.

34

Due to my illness, I have a sense of being unequal in my relationship with others.

35

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

AQ8

37

Due to my illness, I sometimes feel useless.

38

Changes in my appearance have affected my social relationships.

39

40

41

42

43

44

45

^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 = 7.28ⁱ 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

01 My employer/co-workers have discriminated against me because of my ill-
 02 ness; Some people act as though I am less competent than usual; I fell set apart
 03 from others who are well; I have a greater need than usual for reassurance
 04 that others care about me; I feel less competent than I did before my illness.
 05
 06
 07

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Chapter 14

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AQ1	195	26	"Marks, et al., 1999" has been changed to "Marks, et al., 1992" in order to match with reference list. Is this OK?
AQ2	197	20	"Holt et al., 1993" has been changed to "Holt et al., 1998" in order to match with References. Is this OK?
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