Stigma Management Among Gay/Bisexual Men with HIV/AIDS

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People with HIV infection are subjected to prejudice, discrimination and hostility related to the stigmatization of AIDS. To manage the stigma of their disease, they mount complex coping strategies. This paper reports results from a qualitative study that examined gay/bisexual men's experiences of living with HIV infection. Unstructured interviews from a diverse sample of 139 men were analyzed to examine how men coped with AIDS-related stigma. We discerned a variety of stigma management strategies that could be arranged along a continuum from reactive to proactive based on the extent to which they implicitly accepted or challenged the social norms and values that underlie the stigmatization of HIV/AIDS. Reactive strategies to cope with stigma involve defensive attempts to avoid or mitigate the impact of stigma, but imply acceptance of the underlying social norms and values that construct the stigma. Examples of reactive strategies include hiding one's HIV status, presenting one's illness as a less stigmatizing one (e.g., cancer), or distancing one's self from more damaging aspects of AIDS-stigma (e.g., attributing infection to blood transfusion). Proactive strategies challenge the validity of the stigma and imply disavowal and resistance of the social norms and values that underlie the stigma. Examples of proactive strategies include engaging in public educational efforts that address misperceptions about HIV transmission and social activism to change the social and political conditions that affect PWA/HIV.

KEY WORDS: stigma; HIV/AIDS; gay/bisexual; coping; proactive; reactive.

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Since its inception, the AIDS epidemic has evoked widespread public fear and condemnation both of the disease and those afflicted by it. The stigmatization of AIDS derives in large part from a dread of the illness as one that is still poorly understood, highly debilitating and usually fatal, as well as a threat to the larger community because of its communicable nature (Alonzo & Reynolds 1995). Also at the root of AIDS stigma is its association with socially disapproved behaviors, especially homosexuality, and illicit drug use (Jones et al. 1984; Alonzo & Reynolds 1995; Crandall & Coleman 1992; Herek & Glunt 1988; Herek & Capitanio 1993). Further, because these behaviors are popularly viewed as voluntary 'life-style choices,' AIDS has been construed as a self-inflicted disease for which the infected individual must assume personal responsibility (Weitz 1990). This construction has legitimized viewing most infected individuals as culpable for their plight and depriving them of the compassion normatively accorded seriously ill individuals (Weiner, Perry, & Magnusson 1988).

Stigmatized persons have been described as experiencing a number of negative sequelae including social exclusion, anxiety, alienation, loss of self-esteem, discrimination, and social disenfranchisement (Allport 1954; Goffman 1963; Rosenberg 1979; Jones et al. 1984; Alonzo & Reynolds 1995; Whiteford & Gonzalez 1995). The anticipated liabilities of being labeled as deviant create sufficient motivation for most potentially discreditable individuals to try to manage (i.e., avoid or minimize) stigmatization.

Goffman's (1963) seminal work on stigma is almost certainly the most important contribution to this field of inquiry to date and has strongly influenced much of the subsequent writing in this field. Yet his writings, and much derivative work, can and has been criticized as heavily biased toward seeing individual responses to stigma as primarily defensive and aimed at reducing or avoiding the private experience of stigmatization (Anspach 1979; Gussow & Tracey 1968). Gussow and Tracey (1968: 317), for example, contend that "Goffman's people are both other- and self-stigmatized and forever doomed" to feeling discredited because ultimately they "concur with the norms and therefore view themselves as failures." Similarly, Anspach (1979) points out that while Goffman (1963: 767-8) sees stigmatized persons as "strategists and con artists" rather than merely passive victims, he nevertheless depicts them as ultimately accepting the prevailing definitions of normals and thus "deriving their identity reactively, in response to the imputations of the wider society." Anspach's (1979: 767) criticism, however, is not limited to Goffman. She writes, "most studies of deviance generated by the labeling perspective portray the deviant as powerless, passive and relatively uninvolved in the labeling process." Fine and Asch (1988) have also noted that much social psychological work on disability has inadvertently fostered stigmatizing views of disabled individuals, includ-

ing that they are victims who cope through self-blame, reinterpretation of their suffering or denial.

More recently, scholars studying AIDS have also confronted the limitations of the traditional perspectives on stigma. Crandall and Coleman's (1992: 172) questionnaire study identified a significant "group of people infected with HIV who do not feel much stigma and do not show the effects of stigmatization." Alonzo and Reynolds (1995: 305) attempt to explain the "differentials in stigma experience," found in the literature on people living with HIV, with reference to "variation in individual social identities and attitudes confronted in one's social networks and reference groups." And Crawford's (1996) "meta-analysis" of AIDS-related stigma suggested that the interactions among numerous moderating variables make it particularly difficult to apply familiar conceptions of stigma processes to AIDS without a much deeper analysis of the many different experiences and social settings of people living with HIV. Thus while classic approaches to stigma establish the framework, they do not address the unique aspects of HIV-related stigma.

Among the most commonly written about defensive strategies are those aimed at regulating the availability of information about the discreditable trait and those that regulate contact with "normals" in an effort to minimize opportunities for enacted stigma. The latter class of strategies, which includes self-segregation, is more commonly applied when the individual's discreditable trait is known or easily discerned. Examples of such defensive strategies include Goffman's (1963) "passing" and "covering," Jones et al.'s (1984) descriptions of "withdrawal" and "concealment," Anspach's (1979) discussions of "dissociation" and "retreatism," and Hughes and Degher's (1993) descriptions of "avoidance." As would be expected, these strategies have been identified as frequently enacted by HIV-infected individuals. Alonzo and Reynolds (1995) described the life of HIV-infected persons as a constant struggle to manage a stigma. Along with the increasing effort these individuals must undertake to conceal their illness as their disease advances, they suffer greater and greater social isolation. Similarly, Weitz (1990: 25) noted that "PWAs avoid or reduce stigma by concealing their illnesses, learning when and to whom they should reveal their illnesses, changing their social networks . . ."

While early sociological writing may have been biased toward emphasizing the passivity of deviants in the face of societal stigmatization, more recent work has emphasized that stigmatized individuals are not passive recipients of stigma and prejudice, but rather may reject prevalent constructions and seek to influence "normals" to do so as well. Gussow and Tracey (1968: 317), for example, discussed attempts by stigmatized groups to develop theories or ideologies "to counter the ones that discredit them"

and “disavow their imputed inferiority or danger.” Weitz (1990) described the use of the same strategy among people with AIDS.

In reviewing the dominant theoretical orientations to stigma, Anspach (1979: 768) contended that “the sociology of deviance must revise its conceptions to account for active attempts on the part of those labeled as deviant to mold their own identities.” As an example, she described how handicapped individuals and former mental patients used political activism to counter the prevailing negative societal beliefs and assumptions about them, and in so doing enhanced their own self-conceptions. Jones et al. (1984: 153) wrote that such collective action by stigmatized groups to repudiate the norms that render them discreditable “may take the form of banding together with fellow targets, . . . withdrawing from one social environment and embracing another, and redefining an attribute of the self that was previously considered to be negative as positive.” Crocker and Major (1989) noted that by uniting, stigmatized individuals may be able to affirm and validate their minority culture and values, and to discredit stigmatizing norms and values of the dominant culture. Active responses to managing stigma often involve attempts to confront stigma in the hope of “breaking through” societal prejudice (c.f., Jones et al. 1984, Crocker & Major 1989) and altering the assumptions by which a condition is treated as discrediting. As an example, with the “Black is Beautiful” campaigns of the 1960s African Americans challenged stigma by reappropriating the discrediting trait as a source of pride. Whittaker (1992), studying “resistance by [HIV] positive people” in Australia, identified similar reappropriation processes as “the inversion of AIDS metaphors.”

Yet for people with a shared illness, especially a stigmatized one, there are impediments to adopting strategies that require collective action. Usually a sick person becomes labeled upon diagnosis and begins to cope with the stigma attached to his or her new condition alone. It is usually only after a considerable period of time, if at all, that he or she may seek a “community” of others with the same illness to help in coping with the stigma. If this occurs at all, the sick person may then become a part of a loosely defined group of similarly afflicted individuals. However, this process is often hindered by the desire to conceal one’s condition in an effort to reduce or avoid stigmatization. Thus, persons with stigmatizing illnesses may remain isolated from one another. For example, Schneider and Conrad (1980) found that regarding epilepsy, where “there is no illness subculture [patients] are separate, alone, and unconnected with others sharing the same problems.” Similarly, Link and colleagues noted that stigmatized mentally ill individuals are not likely to band together in fighting stigma because they typically “avoid collective settings for fear of being associated with a stigmatized group” (Link et al. 1987: 25).

While there has been considerable discussion in the literature on AIDS about the strong stigma associated with the disease, there has been surprising little empirical investigation to date on how infected individuals cope with this problem. In this paper, we describe a variety of stigma management strategies that were discerned from unstructured interviews with 139 HIV-infected gay/bisexual men who provided narrative accounts of their experiences living with HIV infection. In so doing, we explicitly seek to incorporate the full range of responses and to consider both the reactive strategies and the 'fighting back' strategies, which we define as proactive. Finally, we propose a provisional classification scheme for ordering these strategies along a continuum based on the degree to which individuals accepted or rejected the values, norm or assumptions that underpin the stigma.

METHODS

The qualitative study from which the data presented below are drawn was designed to examine gay men's experiences of living with HIV infection as a chronic illness. Specifically, we were interested in the adaptational tasks their HIV-infection posed for them (e.g., developing strategies for maintaining health and preserving functioning, confronting existential/spiritual issues, making treatment decisions under conditions of uncertainty) and the coping strategies they invoked to meet these challenges. The "representative case" sampling method (Shontz 1965) was used in which cases are not chosen at random, but rather are selected because they are judged to be representative examples with respect to the phenomenon under investigation. Through selecting cases with maximal theoretical relevance, the representative case method seeks to learn about a general class of individuals by studying representative members. The emphasis of these methods is not on statistical generalizability, but on the analytical generalization of issues and problems that may provide insight into the study topic.

One-hundred and forty-four men were accrued. These men had been identified through self-referral in response to advertisements, flyers and community outreach efforts. Eligible were HIV-positive gay and bisexual men between the ages of 20-45 who lived in the greater New York metropolitan area and who had not injected drugs within the past two years. Cases were quota sampled to provide approximately equal numbers of African Americans ($N = 46$), Puerto Ricans ($N = 47$), and non-Hispanic whites ($N = 46$). These three ethnic groups were chosen because available epidemiologic data indicated that they accounted for the large majority of AIDS cases in New York City (and therefore also presumably the large

majority of infected cases, although infection is not a reportable condition). Within each ethnic group an approximately equal number of men were sampled who were asymptomatic, were symptomatic but not qualifying for a diagnosis of AIDS, and who had a diagnosis of AIDS. This assured that there was adequate representation of cases across the full range of the disease spectrum since it was felt that this variable might be a significant factor in understanding adaptational patterns. Those with a history of intravenous drug use in the past two years were excluded because we felt such use would complicate the problems of adaptation (e.g., through requiring disclosure of an illegal activity, of managing treatment around current drug use) and distract from the discovery of more usual patterns of adjustment among gay and bisexual men. From among men who met the criteria for eligibility, we selected cases based on theoretical considerations. For example, in the present study, we attempted to include men who were and were not in stable relationships, who had been aware of the infected status for varying periods of time and who varied on how widely they had disclosed their status to others. While we did not impose formal sampling quotas on these criteria because practically it would have created too many cells, we did make deliberate efforts to ensure variability on such factors.

The men had a mean age of 36 years ($SD = 6$). About a third (32%) had 12 or less years of education, 39% had some college education, and 28% had graduated college or received a postgraduate degree. At the time of interview, 33% were employed full- or part-time, and 67% were unemployed (mostly due to disability).

Participants were asked to participate in three research meetings with a mental health clinician, typically spaced about two weeks apart. They completed an extensive battery of standardized measures at the initial meeting. At the second and third meetings a clinician interviewer conducted an unstructured focus interview to elicit respondents' own perspectives on their experiences living with HIV infection. Whereas structured interviews reflect the investigators' frame of reference in choosing the domains of the investigation, the use of unstructured interviews allows discovery of each respondent's perspective by allowing him to define the situation by choosing the topics of his narratives and identifying his own issues, emphases, and categories (Merton, Fiske, & Kendall 1956).

Each unstructured interview lasted approximately two hours and covered a wide variety of issues in the respondent's life. The interview was initiated with a very general question as a stimulus. Respondents were asked to talk about what it has been like living with the knowledge that they are HIV-infected. The interviewer followed the respondent's lead and, when possible, used his material to introduce natural bridges to other topics. For example, "In talking about how you have changed your daily rou-

tines since learning about your infection, you mentioned that you spend more time alone at home now and less time with your friends. Can you tell me more about how your condition has changed your relationship with your friends, as well as your family, or other people?" The interviewer had only a set of topic areas that were assumed to be of theoretical relevance based on a prior review of the literature on illness behavior. Respondents typically addressed most of these issues spontaneously over the four hours of interviewing. However, if they did not, the interviewer introduced the topic again with a general question that allowed the respondent to address the issue in any of a number of ways that seemed relevant to his own experiences. The interviewer used questioning and prompting only to clarify issues raised by the respondent and to encourage elaboration of themes that had been raised in the respondent's narrative. In most cases, the interviewer and respondents were matched on ethnic background to facilitate establishing rapport. Spanish speaking respondents had the option of using Spanish for both the standardized questionnaires and the interview.

The unstructured interviews were audiotaped and transcribed verbatim. From the content analysis of subsets of the interviews, the authors developed a list of search terms to help identify any textual material from the interviews that might bear on feared or experienced stigmatization and attempts to avoid or manage such occurrences. An extensive list was developed which included, for example, the terms stigma, discriminate, fag, shame, contaminated, reject, avoid, disgrace, disapprove, ashamed, discredit, hide. Relevant text was excerpted through ZY-Index, a text-based software program designed to aid in qualitative analysis. From the narrative material we identified the array of stigma management strategies used by study participants across a variety of situations.

RESULTS

The stigma management strategies discerned in the men's narratives can be arranged along a continuum from reactive to proactive. We derived this distinction, in part, from Charles Tilly's studies of social movement activism (Tilly 1978; Tilly, Tilly, & Tilly 1975). He distinguishes different forms of collective action in terms of claims made against the State. Reactive actions address some tangible claim, some desired change in law, or protection against these events. A campaign to lower property taxes, or repeal Jim Crow legislation, or strike down the Colorado gay-discrimination laws, are reactive efforts. Such strategies implicitly or explicitly accept the state's procedures and authority to enact judgements on the matter under question, while challenging particular decisions, events, or applications.

Proactive movements, by contrast, seek greater empowerment. They “assert group claims which have not previously been exercised” (Tilly 1978: 147). Proactive strategies question the legitimacy of state actions and implicitly challenge the authority underlying them. Reactive strategies to cope with stigma involve defensive attempts to avoid or mitigate the impact of stigma, but imply acceptance of the underlying social norms and values that construct the stigma. In reactively coping with stigma, individuals attempt to avoid its impact but they do not challenge it. Proactive strategies involve confronting the stigma. They challenge the validity of the stigma and imply disavowal of the social norms and values underlying the stigma, and represent an effort to redefine them.

Table 1 displays the strategies we identified along the reactive-proactive continuum. We use the categorization proposed—*reactive*, *intermediate*, and *proactive* strategies¹—heuristically in an effort to make the discussion more manageable. While some strategies may be defined as essentially purely proactive or reactive, most involve a mixture of these elements. For example, those who participate in collective efforts to alter societal attitudes about a stigmatized condition usually recognize that their efforts, if successful, will ultimately also reduce the personal stigma they experience. Virtually all of the men relied on a combination of strategies.

A. Reactive Strategies

Using reactive strategies, respondents sought to avoid being discredited by hiding their HIV seropositive status, by disclosing selectively under ‘safe’ conditions, and by creating distinctions between themselves and “other” people living with HIV. Concealing and disclosing strategies were aimed at controlling information about HIV/AIDS within one’s close social network. When disclosing, respondents typically employed a complex set of strategies to control the content and timing of information released about themselves,

Table 1. Stigma Management Strategies Along the Reactive-Proactive Continuum

Reactive	Intermediate	Proactive
I. Concealment	IV. Gradual Disclosure	VIII. Preemptive Disclosure
II. Selective Disclosure	V. Selective Affiliation	IX. Public Education
III. Personal Attributional Style	VI. Discrediting One's Discreditors	X. Social Activism
	VII. Challenging Moral Attributions	

how information about their condition would be presented, and, where possible, how it would be received.

I. Concealment Strategies

Concealment strategies, perhaps the most commonly invoked response to the fear of stigmatization, aim at avoiding being discredited by hiding the discreditable attribute. Men who attempted to conceal their HIV/AIDS status used varied strategies depending on the stage of their HIV disease, whether they had visible signs or symptoms of HIV infection, and the extent to which social withdrawal was possible. In concealing, they attempted to represent themselves as healthy. Or, if visibly ill, they presented themselves as having a less stigmatizing condition.

When possible, before symptoms of HIV appeared, some respondents chose to conceal their HIV status altogether. The strategy, which Goffman (1963) referred to as “passing,” aims at maintaining and protecting normal social relations. The decision to conceal was often painful. Respondents felt that they needed to hide the truth to protect themselves, but still viewed that choice as requiring them to “live a lie,” and “live a double life.” Many men spoke of the strain of excluding family and intimates from the most significant aspects of their lives, cutting themselves off from possible sources of support, and distancing themselves from the communities of other people living with HIV.

One man reported that he had not divulged his HIV infected status to his family because of the “mixed signals” he perceived from them. While on the one hand he felt they would want to support him, he added, “I also have the fear that they would desert me. . . And it’s much easier for me to go through my life not telling them.” Another respondent struggled with the decision of whether or not to disclose his status to his family:

I’m weighing the pros and the cons. The pros are that, you know, [my mother] shouldn’t know because the cons are that she doesn’t accept me for being gay. So if you don’t accept me for being gay then I don’t think you could . . . accept the fact that I’m HIV.

Passing required men to conceal their illness by hiding or disguising symptoms that they thought could evoke AIDS-stigma. Wasting syndrome and Kaposi’s Sarcoma were the two conditions most often mentioned as strongly evocative of AIDS stigma. As one respondent said, “Just by looking at me, you could tell something wasn’t right because of my face.” Passing sometimes involved concealing evidence of the use of medications associated with AIDS (e.g., AZT or Bactrim). To hide their use of such medi-

cation some respondents were even willing to relinquish insurance reimbursement.

I wouldn't even write a check for them, because I think—I think it was because I was trying to change my insurance policy, and I didn't want any record of any, you know, treatment for HIV.

I don't want anybody to see me on medication, either. ... because [if] they see [me, they'd say], 'Oh, this is a gay person. Oh, he's taking medication. Oh, he's got AIDS.' You know. 'Oh, you're losing a lot of weight. Oh, you look sick. Are you alright?' You know, they see, gay, and they immediately associate you with being sick. And it's so ridiculous.

If what the men regarded as telling symptoms could not be concealed, they might withdraw from all but the most essential social encounters in an attempt to completely hide themselves. This response inevitably led to a disruption of normal social encounters and isolation from family, friends and neighbors. One man who described himself as unable to “deal with leaving my house with all these black blotches all over my body, and everybody looking at me as if I'm some ugly duckling” said that he would “seriously consider suicide” rather than live with such marks permanently. A sense of alienation and hopelessness was often associated with this response.

When respondents could not conceal that they were ill (e.g., because of functional limitations), but their symptoms were not unequivocally HIV-related, some chose to conceal or misrepresent the true nature of their illness, usually preferring to report they had cancer. This subterfuge seemed to convey the seriousness of their illness, while avoiding strong censure. Goffman conceptualized such behavior as “covering.”

I tell them it's, it's, it's a bone cancer. And I feel bad lying, but, you know, why should everybody know? I mean, because discrimination is almost—to me, discrimination ranks up there with racism. ... Because you see people going around talking to other people with leukemia. You see them going talking around to people who have one leg, one arm, you know. To them that's horrible. But having HIV or AIDS isn't. So, I tell them it's cancer. Having cancer is normal.

II. Selective Disclosure

In deciding who to tell about their HIV status, respondents considered the strength of the relationship, its ability to withstand a challenge, the potential for support and intimacy, the other's need to know, and the other person's ability to understand the disease. One respondent said that he only disclosed to “those that are HIV themselves,” describing it as “like a death sentence” to tell others. Another simply said “I only tell people that

I have it in common with.” Some could only tell those closest to them, while others were most afraid of hurting those to whom they were closest.

The perception that a gay identity and having AIDS were two negatively viewed statuses led to the expectation of understanding and acceptance from gay or bisexual people who did not have HIV/AIDS. When gay/bisexual people proved intolerant, respondents seem to experience great disappointment, anger and frustration. One man related:

I remember being on a phone once with somebody who had answered an ad that I had in a magazine or I had answered his ad. I don't remember which was which.... And he said, he made the comment that he wouldn't want to get to know anybody who was HIV positive because they might not be around. And I was furious. I, you know, I got—started ranting and raving at him over the phone. Consequently we never got together.

III. Personal Attribution Strategies

Some respondents attempted to defend themselves against stigmatization by attributing the cause of their HIV infection to a more socially acceptable source than homosexual behavior or drug use (e.g., blood transfusion) or by distancing themselves from other infected individuals. In doing so, they did not challenge the stigma or guilt ascribed to infected people, but rather attempted to expand the category of “innocent victims” to include themselves. One man contended:

Well, they—it could be, um, I'm from New Jersey and they say, like 90% of all hemophiliacs in New Jersey have gotten it, so it's in like one batch of blood. But I also got a operation on my elbow, four months prior to that, . . . , so it could have been from that, too. So I really didn't know. And also, I think a lot of it, um, has to do with that it really wasn't my fault.

Other respondents while accepting responsibility for their infection, attempted to distance themselves from infected individuals they felt were viewed most negatively. Thus, respondents asserted that they were not like “most” gay men who were infected in that they had never been promiscuous or gone to bath houses or engaged in anonymous sex. Others offered ignorance as an “excuse” (Scott & Lyman 1968) and defense against blame. They asserted that they were quite certain that they had become infected before much was known about AIDS since they had adopted safer-sex guidelines as soon as they had been identified. One man said:

So I can hold my head up because [i]t really wasn't my fault that I got it, 'cause I didn't know [about the risk from sex] at the time.... I really started taking precautions as soon as I started reading about everything that was going on.

Some men who accepted personal responsibility for their infection tried to reduce the application of stigma against them by openly and vol-

untarily admitting the “error of their ways.” The men we interviewed condemned their own past behavior and seemed to hope that a public confession and display of contrition would soften their discreditors’ negative attitudes toward them. Goffman (1971) termed such actions “apologies.” Weitz (1981) also observed this strategy among the HIV-infected men and women she interviewed. It is an exemplary reactive approach, in that it protects the individual in their personal encounters while internalizing the stigmatizing discourse about HIV.

I’m not too proud of this. I’m not, it’s not the greatest thing in my life. I feel ashamed at times for not being more, more precautionous [sic], but something that I just didn’t think I would get. And I got it, so I deal with it.

B. Intermediate Strategies

Each of the approaches described below is potentially empowering, but they do not provide a fully-formed challenge to the dominant ideology. In other words, each is potentially proactive, but also somewhat reactive. *Gradual disclosure* helps to diminish the stigmatizing attitudes of small numbers of people in private settings, but the lasting influence may be minimal. *Selective affiliation* brings respondents into self-help groups and empowering actions but may also be a form of hiding. *Discrediting the discreditors* usually takes place in isolated encounters and has little impact in a larger social arena. Lastly, *challenging moral attributions* questions the basis for some of the most significant forms of discrediting, but, unlike the activism and education strategies discussed later, it rejects the source of the stigma without substituting something more constructive for it proactively.

IV. Gradual Disclosure

Some men disclosed information about the disease and their own HIV status in a controlled incremental manner that allowed them to “test the waters” (Schneider & Conrad 1980) and, if necessary, adjust the future release of information. For example, in preparation for disclosing their status to others, they might raise the topic of AIDS in a general way in order to have an opportunity to assess both the others people’s attitudes and their knowledge about HIV/AIDS. If when they did so, they encountered negative attitudes, stereotypes or misinformation, they sought to modify these through education and emotional support. In this way, they attempted to create a situation that would permit a more favorable reception to their ultimate disclosure of their own infection.

Ah, my parents sort of—I don't want to say, 'they knew,' but I tried to prepare them. So when I went and took the test, you know, like I sat down with both of them on separate occasions and told them that ah, that I think that I—there's a good possibility that I, you know, have been exposed to AIDS or whatever.... And we went through a whole kind of, I guess, growth process because I had to sort of educate them and still be the person that I always was, without all the stereotypical images of AIDS patients and what not.

Placing themselves in the role of educator and leader may also have enhanced respondents' own sense of worth and allowed for a more favorable presentation of the self.

I sat my father down, my ex-lover down. I said, 'oh I want to watch this program. It's all about HIV positive people.' . . . And they all, we all sat and looked at it. I started to cry a little bit. And then my father said ah, 'oh is that person on the film straight or gay?' I said, 'they're straight.' He said, 'Oh you can get AIDS from being straight?' I said, 'yeah.' So and then that's probably all the comment he—my ex-lover didn't make any comment. And that was all. Just, I'm slowly trying to indoctrinate them, and through that process. That's why I have them watch it. So I guess I'm not ready to actually tell them, but I'm working on it. The first step was to have them watch a program about it.

V. Selective Affiliation Strategies

Many men described a preference for largely restricting their social contacts to "the own and the wise" (Goffman 1963: 19 fn.)—other infected people or those who held favorable attitudes toward infected individuals—among whom they felt accepted and supported. They emphasized the psychological distance between themselves and others who lacked their experience and understanding. As one man commented about dealing with HIV-negative people: "[It is] frustrating, so I keep away, I stay away, I don't talk to them no more ... fuck them, even my family."

Often, the men's affiliative strategies of coping with AIDS-related stigma were borrowed from previous experiences of coping with stigma, especially regarding homosexuality. In many instances, social networks that provided support regarding HIV/AIDS overlapped with those that provided support for respondents' gay identity, ethnic identity or those relating to treatment of addictions (e.g., twelve-step programs). This provided access to resources and opportunities to learn from others facing the same stigmas.

By restricting their social contacts as much as possible to supportive networks, respondents accomplished two tasks. First, they reduced the opportunity for enacted stigma by avoiding potentially troublesome encounters. Equally important, they exposed themselves to supportive encounters which might facilitate the development of alternative ideologies about HIV/AIDS. The communities of HIV-positive people or sympathetic others they joined shared many common constructions of the experience from

which new values and attitudes were derived. This shared value system allowed respondents to adopt a construction of HIV that contrasted with prevalent social stereotypes. Supportive encounters thus reinforced the collective identity of PWA/HIV providing a source of strength and self-enhancement.

VI. Discrediting the Discreditors

Discrediting those who sought to discredit them was another strategy men used for defending themselves against stigmatization. They raised questions about the real motivations of those who condemned or rejected them. For example, they contended that religious leaders were compelled to support negative beliefs towards HIV/AIDS and to view the epidemic as divine retribution in order to uphold church doctrine condemning homosexuality. Medical practitioners who displayed AIDS-phobic attitudes were described as ignorant. In discrediting their detractors, respondents undermined the legitimacy of the stigma.

Many respondents interpreted their experiences of prejudice as evidence of ignorance. They saw themselves as having been educated by their illness experience so that they could now teach others. Respondents often expressed understanding, patience, and even sympathy for the ignorance of others, a position that also allowed them to morally elevate themselves above their intolerant and sometime malicious discreditors. One man whose sister no longer allowed him to hug her daughters because of fear of AIDS said:

And she's trying to keep them distant from me. But I saw it at first as her sort of punishing me for having, for being HIV positive. But, and then I realized it's just due to her ignorance.... It's just has to deal with her being ignorant and just the type of person she is So I just tack it up to sheer ignorance. Ah, and I just pray that she wakes up one day, you know, and realizes that ah, life is too short and that you shouldn't turn your back on anyone.

VII. Challenging Moral Attributions

Respondents were particularly plagued by the public's distinction between the innocent (i.e., blood transfusion recipients, babies) and the guilty (i.e., gay men, drug users) 'victims' of AIDS. Such attitudes were often associated with religious groups. One way in which respondents combated these attitudes was by denying the legitimacy of religious values in HIV/AIDS discourse and advocating a countervailing secular explanation for the epidemic. This achieved two functions. It both helped to normalize HIV by associating it with familiar medical conditions and it emphasized

the humane obligation of society towards the sick. As one respondent said: "This is just a virus, the virus doesn't have a morality." Another concurred: "It's not like God's punishment, no. And it's not a disease that only affects gay people, no. It's not a gay disease. No. It's a disease. It's like lung cancer."

Some men employed a different attributional approach in which they constructed HIV infection as a source of moral enhancement rather than a moral stigma. These men spoke of their diagnosis as having galvanized them to reprioritize their lives and transforming them morally. Several contended that while before their diagnosis they were exploitative of others or narcissistic, they now derived great satisfaction from volunteering their time to help other less fortunate infected individuals. They saw themselves as more mature and socially responsible now, and as having adopted a more authentic, spiritually informed approach to life because of their illness.

One man who described his experience as "torturous" added "I thank God it happened because it forced me to wake up and realize that the things that I had been taught and so many ideas I held near and dear were wrong."

I used to tell people, in actuality it was a blessing. That may seem funny, but when you're living and you don't care, and if you die it's all right. And if you live, it's a blessing. It gave me motivation, a point of reference, something to work from. Okay, I'm HIV positive. Now what am I going to do?

C. Proactive Strategies

Proactive strategies were used by men in an effort to construct and promote alternative views of AIDS that undermine societal stigma. The responses that we identified as most proactive address the meaning, values, beliefs, practices and power imbalances behind the stigma rather than the situations in which stigma might be encountered. Respondents use preemptive disclosure to present a positive framing of the illness to those close to them, ignoring and replacing the negative images found in the popular discourse of AIDS. Public education strategies attempt to do the same for a larger audience, while social activist strategies seek to bring their more positive framing of the disease into the popular discourse.

VIII. Preemptive Disclosure

In the most proactive form of disclosure, some respondents chose to take charge of the timing and manner of their disclosure. Respondents who adopted the preemptive approach disclosed their HIV status widely and

voluntarily. Men used this approach to control the exchange of information and to bring about a discussion of the illness on their own terms.

Preemptive disclosure protected respondents from the risk of being exposed and accused of hiding. By choosing to volunteer this information they hoped to create the impression that it was not shameful and did not need to be concealed. This strategy forced others to confront their own assumptions that the illness should be hidden. Preemptive disclosure protected respondents from unexpected questions about HIV that might be provoked by changes in their appearance for example.

As one respondent who had disclosed his condition on national television explained: "It only gives you strength, because if you hide it's because you're ashamed of something, and I'm not ashamed of having HIV." Others found that hiding their condition was counterproductive. One man said:

The more you talk about it, the less stigmatized you feel. And the more people you tell, the more people are on your side. The more love and understanding and comprehension you get from everyone, and the less ostracized you feel.

IX. Public Education Strategies

By attempting to alter the discourse on AIDS and the prejudices and misperceptions that contribute to the stigmatization of PWA/HIV, respondents acted publicly on behalf of all people living with HIV and AIDS. Proactive strategies could potentially improve conditions for the individual invoking them, but typically only indirectly and in the long term. Most often the immediate effects to the individual would be increased stress, stigma, and discrimination in their private lives, since coming out as a PWA/HIV often carried great personal risk. Still, some chose to disclose their HIV status in order to refute negative social attitudes related to AIDS. Those who chose to do so expressed a sense of social responsibility that prompted them to come out. As one man said, "I could just say nothing or I could do what I believed in, which was to come forward and I did that."

Men cited the ignorance of HIV-negative people as the primary cause of their discrediting attitudes and discriminatory behavior. In confronting stigma, they sought to alter public attitudes by providing information and offering themselves as examples that defied stereotypes about PWA/HIV. They hoped, for example, that their life as functional, capable individuals with HIV would serve as a model to challenge the stereotypical image of PWA/HIV as diseased and disabled. Weitz (1981) similarly observed that some of the HIV-infected individuals she studied attempted to reduce stigma through the use of a kind of "bravado" in which they tried to refute

negative stereotypes and convince others of their continued normalcy by through offering themselves as examples of normal functioning individuals.

In taking active, socially valued roles as HIV educators, for example, they strove to offer a positive image which could supplant the popular negative image associated with being a PWA/HIV. The education that respondents provided commonly centered on risk prevention. The underlying message they sought to convey was that despite the public perception that susceptibility to HIV is virtually limited to marginalized groups, the risk for HIV infection is universal. By universalizing the risk for HIV, men attempted to break through the stigma of PWA/HIV as 'other,' confronting the "we-they" distinction that allowed some uninfected individuals to define themselves as both safe and morally superior to PWA/HIV. Many men expressed a keen awareness of their public roles.

Yeah I've spoken, especially if they tell me they're bisexual or they're . . . straight, and they think that they're okay or that . . . it's not going to happen to them. I spill the beans and just tell them, that's not the way to think, you know.... They learn a little bit, and then they start to, then they talk differently.

Speaking on behalf of all PWA/HIV helped them to make proactive identity claims in opposition to the notion of a "spoiled identity."

Something I've realized about being HIV positive, ... I became more out, more vocal, and more defensive but also willing to help other people to deal with it, as opposed to just, you know 'it's not my problem.' Whereas, you know, people would make homophobic remarks before, you just let them pass, now, I like stop and try to find out, you know, it's like 'OK if, why does it bother you so?' . . . look, people need to be educated. I think for me, being able to be this open, out and honest, is one of the most important things, I think, that has come out of my being HIV positive and diagnosed with AIDS.

X. Social Activism

Social activism was the most proactive strategy identified used to manage stigma. By demanding policy changes and increased funding for HIV-related research, activists protested discrimination. By asserting the right to inclusion in the policies that affected their lives (e.g., FDA approval of experimental treatments), rather than hiding, activists resisted marginalization. Defying stigma, activists asserted the right to define their own identities. While most of the benefits of social activism are long-term, activism also offers immediate gains. In having chosen to participate in social activism, men attached themselves to an empowerment movement. This allowed them to identify with a community of strength and often provided an accepting and supportive social network. But some activists demonstrated an altruistic concern for the gay community that went beyond personal gain.

Of course I'm gonna fight it until the last day, the last breath of mine I'm gonna fight any way I can by writing letters, phoning Senators, phoning Congressmen.

Now I'm even active in voicing help for this for all peoples. Especially in Harlem. . . . No one cares about people, what happens to the people in Harlem.

DISCUSSION

We have provided, we believe, the most extensive discussion to date of strategies used by individuals to manage the stigma of HIV-infection. In addition, we have offered a heuristic scheme for classifying these strategies along a continuum based on the degree to which they challenge or implicitly acquiesce to existing social norms and values which support the discrediting of infected individuals.

In coping with HIV-related stigma, individuals face conflicting needs. To avoid personal liabilities related to stigma, they may need to conceal their illness. However, to maintain a positive sense of self, to preserve their social standing, and to live a full and meaningful life, they may need to challenge societal reactions to their illness. Using reactive strategies, such as concealment, individuals may avoid enacted stigma. However, there may be significant psychological costs associated with the burden of having to always be vigilant about maintaining "the secret". Additionally, such strategies implicitly reinforce the norms by which they are discredited. Prior work on the effectiveness of reactive coping (when compared to no coping) among former mental patients showed it to be ineffective in reducing the negative effects of stigma on mental health and employment problems (Link et al. 1987). Using proactive strategies, such as social protest, stigmatized individuals may expose themselves to greater risks of discrimination and social rejection, but may ultimately help to bring about modified norms and beliefs that could help to improve their social standing.

We found that men often used proactive and reactive strategies in different parts of their social networks. For example, some engaged in public education efforts which required publicly disclosing their HIV-status, yet concealed it from family. Others covered their illness publicly while disclosing to their families. The use of strategies seemed also to be in part related to the how long men had been living with awareness of their infection. Typically, men's initial response to diagnosis and the accompanying threat of stigmatization was to adopt reactive strategies. Movement toward the incorporation of intermediate or proactive strategies often came later as they either achieved greater self-acceptance as an infected person or

felt that they had adequate support to risk more public exposure of their discreditable trait.

Charmaz (1987) has argued that the struggle to define one's identity is the central task facing chronically ill persons. She defined this struggle as "a quest for control and self-esteem." In adjusting to illness, Charmaz (p. 289) noted, "some persons aim for high identity levels, requiring much effort to *overcome* stigmatizing identifications and to live autonomous lives. Others aim for lower identity levels to *avoid* stigmatizing identifications, rather than risk more attention focused on themselves.... [The latter] simply fade into quiet lives, largely anonymous except to those who reside with them" (emphasis in original). Higher identity levels include restoration of premorbid identity or aspiration to "supernormal" identity and functioning, lower identity levels include a "salvaged self," in which individuals "hold little hope of realizing typical adult identities" (p. 287).

The classification scheme of stigma management strategies we propose supports Charmaz's conceptualization. Men who routinely adopted proactive strategies may be seen as striving for higher identity levels by directly confronting threats to maintaining a valued identity by, for example, attempting to promote alternative constructions of HIV or by challenging the values and norms that underpin the stigmatization of the illness. These individuals wished to avoid restrictions on their social activities and interactions (i.e., social control) that those who discredited them would seek to impose. Men who relied on reactive strategies could be said to be willing to accept lower identity levels. They chose to acquiesce to the prevailing norms and values and accept a life in the shadows, out of public scrutiny. Withdrawal into a more protected, but limited, social world was an acceptable solution to the problem of minimizing or avoiding being stigmatized.

It is plausible, as Link et al. (1993) have suggested, that a proactive approach to stigma is superior to reactive strategies because it involves rejection and disavowal of the stigma and replacing it with self-enhancing attitudes and attributions. Research is needed to determine to what extent the strategies we describe help protect individuals from the negative effects of stigma, and what are the costs and benefits of the different strategies. For example, by employing primarily concealing strategies individuals may protect themselves from the negative impact of stigma, but this may lead to poor self-esteem, social isolation, and lack of support. In contrast, engaging in proactive strategies may lead to an increase in exposure to stigma and discrimination, but it may bring about secondary gains including a sense of control over one's life, self-fulfillment that comes from commitment to the cause, an improved sense of self and community, and social support. The costs and the benefits of each of the strategies depend greatly upon

the social conditions under which one seeks to enact them and on the social resources available to the individual making this decision.

A number of limitations of the study should be noted. While we have described the varied stigma management strategies used by HIV-infected individuals, we have not addressed to what extent, if at all, engaging in these strategies promotes or impedes adaptation to the illness in a broader sense. Nor do we know the relative value of one style of coping over another in any given context.

Further, our sample was entirely composed of gay/bisexual men in a concentrated urban setting. It must be recognized that the experiences of gay men dealing with the disease seem unique in that they were an already discredited group with experience in collectively fighting stigma related to their sexuality. AIDS initially affected gay men who were strongly identified with the gay community (Shilts 1987). For them, the gay community has provided the opportunity and means to develop proactive strategies to manage stigma that could be utilized by gay/bisexual men with AIDS. The gay community had ideologies, values, and institutions in place that were ready to confront the newly defined AIDS-related stigma. They had access to resources such as communications networks and community-based organizations which facilitated their mobilization against AIDS-related stigma. As Schneider and Conrad (1980) observed in their study of epileptics, the "link between the closet metaphor and the development of identity is premised . . . on the assumption that in 'coming out' there is indeed something to come out to: that there are some developed or developing social definitions that provide the core of this new, open and proud self."

It remains unclear to what extent the example of gay/bisexual men confronting AIDS-related stigma can serve the self-protective and identity-reconstructive needs of others groups (e.g., women, socioeconomically disadvantaged minorities) facing HIV/AIDS. Future work is necessary to consider the role of proactive coping strategies among resource-poor communities of persons coping with AIDS-related or other stigmas.

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ENDNOTE

1. These categories in many ways parallel Schneider and Conrad's (1980: 214) three subtypes of adjusted epileptics—secret, pragmatic, and quasi-liberated—their typology attempts to characterized broad adaptational styles to living with the disease “as a personal, physical and social object.” While stigma management is clearly the central motivational force in such adaptational choices, their typology nevertheless has a broader conceptual focus than our own.

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