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Methods for Understanding the Stigma of AIDS in the United States: A Review and Future Directions

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Abstract

Since AIDS was first diagnosed in the United States in 1982, people with AIDS have been severely stigmatized. In this article, we explore the origin of the AIDS stigma and offer an explanation for why individuals with AIDS are stigmatized. Then, we review studies that exemplify how the stigma of AIDS in the United States is typically investigated. Finally, we outline future research directions for studying the stigma of AIDS. Specifically, we argue that future research should disentangle the stigmas of homosexuality, IV drug use, and the stigma of AIDS; address the implications of the AIDS stigma in the workplace; and consider strategies for remediating the stigma.

Keywords: Acquired Immune Deficiency Syndrome; stigma; United States; research.

Métodos para Entender el Estigma del SIDA en los Estados Unidos: Una Revisión y Direcciones Futuras

Compendio

Desde el primer diagnóstico de SIDA en los Estados Unidos en 1982, las personas con SIDA has sido severamente estigmatizadas. En este artículo exploramos el origen del estigma asociado al SIDA y ofrecemos una explicación de las razones por las cuales se estigmatiza a las personas con SIDA. Entonces, revisamos estudios que ejemplifican cómo el estigma del SIDA ha sido típicamente estudiado en los Estados Unidos. Finalmente, esbozamos futuras direcciones de investigación para el estudio del estigma del SIDA. Específicamente, argumentamos que las futuras investigaciones deben explorar las combinaciones de los estigmas sobre la homosexualidad, el uso de drogas inyectables y el SIDA; abordar las implicaciones del estigma del SIDA en los escenarios de trabajo; y considerar estrategias para reducir el estigma.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; Estados Unidos; investigación.

Since the HIV virus was first diagnosed in the United States in 1982, an estimated 929,985 individuals have been infected with the virus (Centers for Disease Control [CDC], 2004). In 2003 alone there were 43,171 diagnoses of AIDS, including 31,614 men, 11,498 women, and 59 children under the age of 13 (CDC, 2004). It is estimated that 524,060 individuals in the United States have died from the virus (CDC, 2004). Unfortunately, it is difficult to report the full scope of both incidence and deaths due to AIDS. The Center for Disease Control (CDC) estimates an additional 180,000 to 280,000 people have HIV and do not know they have the disease or are hesitant about seeking medical assistance. This hesitancy may be a product of the persistent stigma associated with AIDS in the United States. That is, despite the increasing number of Americans affected by the disease, individuals associated with AIDS are subject to negative stereotypes, social rejection, and discrimination (Crocker, Major, & Steele, 1998). Consequently, the purpose of this chapter is threefold: to review the foundations of the stigma associated with HIV/AIDS, to review the methods that are typically used in U.S. based investigations, and to offer suggestions for future research in this area.

The Nature of Stigma

Goffman (1963) ignited research on the topic of stigmas, and provided a framework for their examination, when he defined a stigma as an attribute that is discrediting and prevents full social acceptance for the stigmatized individual. His early research identified two classes of stigma, the "discredited" stigmas (or those that are known to others) and "discreditable" stigmas (or those that can be concealed).

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Jones et al. (1984) also identified the communicability of stigma as an important dimension along which reactions to stigmatized individuals may vary. More recently Crocker et al. (1998) defined stigma as "devaluation by being the target of negative stereotypes, being rejected socially, being discriminated against, and being economically disadvantaged" (p. 505). For the purpose of this chapter, we concentrate on the three factors that past researchers postulated as definitive for stigma: controllability, concealability, and contagion.

First, controllability is defined by the perception of how much control an individual has over their condition. Weiner, Perry and Magnusson (1988) suggested that the more a stigma is perceived to be controllable, the more negative is its stereotype. The perception that AIDS is a gay-related disease is still prevalent in the United States. Therefore, it is possible that many Americans believe that those individuals who have AIDS had some control over their infection. The second leading cause of AIDS is through the use of IV drugs. Since 1982, intravenous drug (IV) drug use has been blamed for 26.5% of all AIDS cases (CDC, 2004). Given that IV drug use is a chosen behavior (Cooney, 1997), it is easy to see why its link with AIDS strengthens perceptions of AIDS being highly controllable.

Second, a stigma that is concealable (e.g., alcoholism) gives rise to very different considerations than a stigma that is not concealable (e.g., obesity). When an individual's stigma is not obvious to observers, they face the difficult decision of whether to disclose their stigmatized status. The "disclosure dilemma" is often researched from the perspective of gay and lesbian individuals who "come out of the closet" or reveal their sexual orientation (e.g., Griffith & Hebl, 2002; King, Reilly, Hebl, & Griffith, 2005). A similar dilemma might apply to individuals who are in the early stages of HIV, but who have no visible signs of the AIDS disease. Such individuals must decide whether, how, when, and to whom they should reveal their HIV status. However, the final stages of AIDS may be very identifiable to others. Herek (1999) suggested that the nature of the advanced stages of AIDS makes the disease readily apparent to observers, and these visual cues may cause distress to potential interactants. Thus, the progression of the disease creates a stigma that varies along the concealability spectrum and has very divergent consequences.

Third, the stigma of AIDS is affected by the fact that it is a potentially contagious disease (see Herek, 2002). Simply put, many people wish to avoid all contact with those who have HIV or AIDS because they fear being infected. In fact, a study by Rozin, Markwith and McCauley (1994) showed that people were even reluctant to try on sweaters previously worn by individuals with AIDS. Thus, added to the controllability and concealability descriptions of the AIDS stigma, interactants may respond with negative affective and avoidant reactions in an attempt to ostensibly protect themselves from what is largely misperceived as a highly communicable disease. Consistent with this explanation, despite far-reaching advances in its treatment, the majority of Americans continue to believe that the disease is fatal and highly contagious (Herek, 2002).

In defining stigma, it is also important to understand that these three factors- controllability, concealability, and contagion- are negotiated within the social interaction. That is, stigma is a socially constructed phenomenon. We next turn our attention to describing the social constructivist nature of stigma and present a specific look at how it has been negotiated within the context of the U.S. military.

The Social Construction of AIDS

To better comprehend the nature of this stigma, it is necessary to also understand the history of the HIV virus. One method for investigating the historical basis for AIDS stigma is through a social constructionist framework. Social construction refers to the process society uses to give meaning to some type of phenomenon. These meanings may be experienced differently across various cultures (Cooney, 1997). As Rushing (1995) points out, one example of such social construction occurred in the 14th century when the "Black Death" became an epidemic in Europe and Asia. At that time, the world was largely divided along religious lines and medical knowledge was limited. A lack of scientific knowledge, coupled with the dominance of religion and the magnitude of the epidemic, led the survivors to the same interpretation: mankind was being punished by God for its sins (Cooney, 1997). In other words, the plague was attributed to the perceived sinful conduct rather than the poor sanitation conditions and diseased vermin. The Plague came to symbolize sinful conduct and embodied existing religious differences. Rushing (1995) also suggested that, Jewish individuals were primary targets of stigmatization and bore the brunt of the blame for the epidemic.

The social construction of AIDS shares a similar historical evolution. In 1981, 108 cases of a Pneumocystis Carinii (a rare form of pneumonia), and Karposi's Sarcoma (a rare form of cancer) were diagnosed (Shroff, 1991). When those cases were first reported, medical personnel were unable to explain the nature of the illness. When it was discovered that ninety-five percent of the diagnosed individuals were homosexual, it was assumed that some aspect of homosexual behavior was responsible. That assumption lead to the original label of the disease, "Gay Related Infectious Disease" (GRID). Perhaps even more

important to the evolution of the AIDS stigma was the unofficial name given to this new disease, the "Wrath of God Syndrome" (WOGS) (Shroff, 1991).

Both the official name of GRID and the unofficial label of WOGS have had an important impact on the AIDS stigma. The initial construction of AIDS as a gay-related disease led the American public to associate homosexual behavior with a very frightening new disease. The media assisted in the propagation that the disease was in fact a manifestation of homosexual behavior by referring to AIDS as a "gay disease", "gay cancer", or even "gay plague" (see Herek, 1999). It is not surprising that one explanation of the persistence of the moral interpretation of AIDS rested in the fact that the most commonly infected individuals were gay men, an already highly stigmatized group (Rushing, 1995). It was not until 1982, when AIDS began to be diagnosed in heterosexuals at higher rates, that the syndrome was relabeled Acquired Immune Deficiency Syndrome (AIDS) (Rushing 1995; Shroff 1991). However, the framework for AIDS stigma had already taken hold and would persist for years.

Thus, AIDS stigma could be closely aligned with the homosexual population based merely on the fact that the disease first showed up in gay men. In 1988, the Center for Disease Control (CDC) reported that 63% of adults diagnosed with AIDS in the United States were men infected through homosexual behavior (CDC, 1988). The CDC reported that the second most common method of AIDS transmission was through the use of illegal drugs (19%). Since 1988, the avenue by which AIDS is transmitted has changed. As of 2003, only 48% of all AIDS cases since 1981 were attributed to male-male sexual contact. In fact, in 2003 only 41% of all new AIDS cases were attributed exclusively to male-male sexual contact. The next highest group, constituting 31% of all new reported AIDS cases, were individuals who contracted AIDS through heterosexual contact (CDC, 2004). Despite the decreasing incidence of male-male sexual contact as the primary method for HIV acquisition, AIDS stigma is still very much associated with homosexual men. In fact, Pryor, Reeder and McManus (1991) found that people with negative attitudes toward gay men were less likely to want to interact with an AIDS patient than those who had more positive attitudes. One reason for this persistence could be the early work of some conservative religious organizations. At the onset of the AIDS epidemic, political conservatives attacked homosexual behavior and used AIDS as part of their rhetoric (Herek, 1999). For example, in a 1987 column Patrick Buchanan wrote:

> There is one, only one, cause of the AIDS crisis—the willful refusal of homosexuals to cease indulging in the immoral, unnatural, unsanitary, unhealthy, and suicidal practice of anal intercourse, which is the primary means by which the AIDS virus is being spread through the 'gay' community, and, thence, into the needles of IV drug abusers, the transfusions of hemophiliacs, and the bloodstreams of unsuspecting health workers, prostitutes, lovers, wives, and children. (Herek & Capitanio, 1999, p. 1131)

It was not uncommon for articles to espouse such views of AIDS and homosexuality during the first decade of the disease as some conservative groups were eager to attack the "gay lifestyle". AIDS stigma was propagated through the inflammatory rhetoric of special interest groups trying to demoralize the gay rights movement.

Of particular importance in the evolution of AIDS stigma is the spread of the disease to "innocent" individuals. When the disease began to spread to the heterosexual population, the dominant group began to blame those whom society considered deviant, namely homosexuals, drug users, and prostitutes (Cooney, 1997). It is through this social construction that one can truly understand the origin and persistence of the stigma associated with AIDS in the United States.

A Case Study of Social Construction: AIDS and the U.S. Military

One striking example of the social construction of AIDS comes from the United States military. When AIDS was first identified among military members, the initial inclination was to medically disqualify those individuals from serving in the armed forces (Cooney, 1997). While reaction has been modified, as we shall explain there are still policies in place that legally discriminate against individuals with AIDS in the U.S. military. Although some people might prefer that military members with AIDS be expelled from the military, the Department of Defense (DoD) policy has formally stripped many of the moral implications from AIDS and focused solely on the ability to complete duties expected. The DoD encompasses all of the military arms of the United States (Army, Air Force, Navy, Marines and Coast Guard) and is the driving force for creating and implementing policies that affect all DoD employees. There are two facets of the DoD policy that are important in regards to how AIDS has been socially constructed: testing and disposition (ability to perform required job tasks) of those who have AIDS.

The first component of the DoD policy on AIDS concerns testing for AIDS prior to service. According to DoD Directive 6485.1 (Department of Defense [DoD], 1991), which applies to all military branches, all military applicants are screened for exposure to HIV. For those hoping to enlist, this means testing prior to being accepted to serve in the military. Applicants must test positive for the HIV virus on three separate tests to be disqualified from service (DoD,

1991). Those in officer training programs such as the Reserve Officer Training Corps (ROTC) or the service academies who test positive for HIV are also denied appointment and discharged from service (Burrelli,1992). This means that anyone who is HIV positive and currently enrolled in a commissioning program (e.g., U.S. Military Academy or U.S. Air Force Academy) will be disenrolled and prohibited from serving in the military.

Finally, each active duty soldier (officer and enlisted) is tested on a regular basis, approximately once every two years (Burrelli, 1992; DoD, 1991). When an individual on active duty tests positive for HIV, several procedural consequences follow. To begin, the soldier is given a medical examination to determine fitness for duty (i.e., disposition). If an individual is still mentally and physically able to perform their military duties, they are retained in the service until such time that they can no longer accomplish their duties. At that time, they are medically retired and guaranteed continued medical coverage for themselves and their dependents (Towell, 1996). In other words, military personnel are not discharged when they test positive for HIV.

However, active duty personnel that are HIV-infected are placed under certain restrictions. First, they are permitted to serve only within the United States. Many host countries have policies that prohibit the stationing of HIV-infected soldiers within their territories and access to necessary medical treatment overseas may be limited. Second, they are not permitted to perform in combat, largely due to the increased potential for fluid (i.e., blood) transmission (All of you, out, 1996). Third, they are usually given a written order to inform any sexual partner of the fact that they are HIV-positive and to use protective measures, such as condoms, should they engage in sexual intercourse (Miller, 1991).

Despite the generally equitable policies toward active duty HIV positive soldiers, its socially constructed association with homosexuality complicates the actual attitudes and behaviors encountered. Homosexual behavior is expressively forbidden in the military environment (Cooney, 1997). A recent study of HIV infected Army personnel revealed that the risk behaviors that most increased a soldier's chance of becoming infected were same-gender sex and, among heterosexuals, sex with casual or anonymous partners (Levin et al. 1995). The military's HIV screening process can also be understood from the perspective of the social construction of the AIDS stigma. By prohibiting HIV positive individuals from serving, the military guards against introducing homosexuals with AIDS into a predominantly heterosexual population.

Beyond the effects of DoD policies, a soldier identified as being HIV-positive is stigmatized by other soldiers as a function of the socially constructed perceptions of AIDS and its transmission. While efforts are certainly made to protect the identity and status of infected soldiers, the information is not classified and may easily leak out to others. The combination of restriction of assignment, duty time lost for medical appointments, loss of a security clearance, and notification of sexual partners may provide clues to nonstigmatized perceivers. The consequences of societal perceptions of AIDS in the context of the U.S. military highlight the need to promote research and a more accurate understanding of the AIDS stigma. This understanding should be based on findings of past AIDS stigma research carried out in the United States.

Past Research

Fortunately, a sizeable amount of medical research has given people with AIDS a better quality and quantity of life over the past twenty years. However, what is less encouraging is the scarce amount of research concerning the psychological factors associated with AIDS and its stigma. The remainder of this chapter will offer examples of research that has been conducted in the United States regarding the stigma of AIDS. We will also identify what we believe are fruitful areas for future research.

Perceptions of AIDS

Much of the stigma-related research conducted in the United States since AIDS was first discovered has been focused on the perceptions and attitudes toward people with AIDS. Early studies showed that there was widespread fear of the disease and inaccurate information regarding how the disease was contracted and the extent of contagiousness of the disease. There have been many anecdotal stories of how horribly people with AIDS were treated in the 1980's. For instance, Herek and Glunt (1988) reported that such treatment ran the spectrum from a mail carrier refusing to deliver mail to an AIDS Task Force office for fear of catching the disease to a family's house being burned down after three brothers tested positive for the HIV.

Misperceptions surrounding the contagiousness of AIDS fueled much of the early research into AIDS stigma. Sheehan, Lennon and McDevitt (1987) investigated employees' attitudes toward working with a coworker who had AIDS. Employees read short vignettes with endings differing in the type of illness a team member had (either AIDS, cancer, or hepatitis) and the perceived control over each of these diseases (either controllable or not controllable). Thus, the individuals with AIDS either contracted it through homosexual behavior or a blood

transfusion, the individual with cancer either had lung cancer from smoking or pancreatic cancer, and the individual with hepatitis either was a drug user or acquired the disease through a blood transfusion. The results showed that participants indicated less willingness to interact with a coworker with AIDS than coworkers who had cancer or hepatitis. In addition, the controllability perception influenced evaluations of coworkers with cancer and hepatitis but did not affect ratings of the individual with AIDS. It is possible that the overwhelmingly negative reaction to the stigma trumped any factors that might mitigate reactions (e.g., controllability perceptions).

In another study showing the dramatically negative effects of the AIDS stigma, Rozin et al. (1994) investigated the impact of "indirect" contact with other people, including people with AIDS. In their study, participants were given a survey intended to measure participants' willingness to wear a sweater, drive a car, or sleep in a hotel bed that had been previously used by a healthy male, a man with Tuberculosis (TB), a man who had been convicted of murder, a man who had lost a leg in an uncontrollable automobile accident, a man who was homosexual, a man who was homosexual and had AIDS, and a man who had AIDS from a blood transfusion. The results indicated that participants were less willing to wear a sweater, drive a car, and sleep in a hotel bed if the man was homosexual than if the man were not. Furthermore, participants were even less willing to engage in those activities if the man had AIDS (regardless of the source of transmission) (Rozin et al., 1994). This suggests that despite attempts to educate the American public on the transmission of HIV, there still exists a perception that people with AIDS should be feared and that AIDS can be spread not only through direct contact, but also through vicarious contact with inanimate objects.

Unfortunately, these attitudes and beliefs persist today. Such discrimination is evident in more recent events, including the fact that an eight-year-old girl with HIV was unable to find a Girl Scout troop that would allow her to be a member after she disclosed her infection. That act of discrimination occurred in 1998, more than 15 years after the disease was first diagnosed in the United States (HIV positive girl…, 1998). In light of the fact that negative feelings continue to persist regarding AIDS, it is imperative that further research investigates more of the consequences of the AIDS stigma.

Dual-Process Frameworks

Most social psychological research on the incidence and processes involved in stigmatization examine two simultaneous systems. For example, Pryor, Reeder, Yeadon and Hesson-McInnis (2004) proposed that there are two psychological systems involved in people's reactions to stigma. The first system is reflexive, evolutionary in nature, and requires little conscious decision making processes. The second system is reflective and uses cognitive processes to determine the correct response for the situation. Pryor et al.'s model is based on the idea that people control their prejudicial attitudes based on two factors: internal and external motivations (Plant & Divine, 1998). People control their attitudes because of internal factors such as their belief that being prejudiced is wrong. Similarly, there is an external factor for controlling prejudice that includes the belief that other people would not approve of their attitudes. This dual process theory of stigma was applied to understanding reactions to individuals with HIV. That is, Pryor, Reeder and Landau (1999) suggested that people have automatic and controlled reactions to an individual perceived to have HIV. First, people first have an impulsive reaction to a person with HIV such as disgust or fear. Second, people experience a reaction that is more controlled. Although they might feel fear or disgust, they are able to control how their external behavior based on their belief that a measured response is expected. This cognitive portion of the dual process theory is similar to the external motivation that Plant and Devine (1998) suggested. Simply stated, people will control their reaction to a person with AIDS because society requires empathy rather than disgust.

Pryor et al. (2004) expanded their original model by suggesting that the two processes can be labeled as "reflexive" and "rule based." They believe that reflexive systems involve instinctive reactions or spontaneous reactions that have developed through learning and do not possess a cognitive element. Following this rationale, AIDS provokes an instinctive avoidance reaction due to the perceived danger that HIV projects. However, rather than openly show fear when confronted with somebody with AIDS, the rule based process might cause an individual to purposefully act in such a way that conforms to society's rules by actively engaging the person with AIDS rather than avoiding the perceived danger. This element of the model involves a cognitive element of thoughtful reaction and deliberation (Pryor et al., 2004). In an empirical test of this rationale, Pryor et al. (1999) investigated whether rule-based processes could lead to emotional reactions against the stigma of HIV. They hypothesized that pity might be the reaction when an individual is not considered responsible for their stigma. Conversely, anger or irritation might be the reaction when the stigma is considered controllable by the individual inflicted. Specifically, they predicted that participants would display more positive reactions to a

person with an uncontrollable stigma if given time to respond than they would if required to give an immediate response. They found that if given 15 seconds to respond, participants rated having lunch in the company of a little girl with AIDS (an uncontrollable stigma) more positively than those participants who were required to respond immediately. When the researchers asked participants to react to having lunch with somebody with a drug addiction (a controllable stigma) the 15-second delay did not have an effect on participants' reactions. Thus, it seems that the rule-based process may take longer to dictate a response when the stigma is perceived as controllable.

Building from these findings, Pryor et al. (2004) studied the moment-by-moment reaction to the AIDS stigma in a computer simulation paradigm. Participants used a computer to indicate the distance they would like to be from three different people (someone with HIV from a blood transfusion, someone with a criminal past, and an honors student). Consistent with their theory, the researchers predicted that participants would avoid the person with HIV and the person with a criminal past. Conversely, it was expected that participants would be more likely to move their cursor (i.e., feel positively) toward the honor student. Participants also completed a survey after their computer work that measured their attitudes toward homosexuality using the Heterosexual's Attitudes Toward Homosexuality (HATH; Larsen, Reed, & Hoffman, 1980) as well as a questionnaire to measure their motivation to control prejudice (Motivation to Control Prejudice Scale) (MTCP) (Pryor et al., 1999).

The results indicated that participants with negative attitudes toward homosexuality kept a greater distance from the person with AIDS in the first few seconds of their response. In other words, their reflexive response was to avoid the individual with AIDS, while their rule-based response motivated participants to move toward the person with AIDS. Additionally, the results were interpreted to suggest that perceived controllability attenuated initial responses. Although participants' first reaction was not positive toward those with AIDS, after cognitively assessing the situation their behavior was modified. It is possible that they changed their opinion of the individual with HIV as a function of the fact that HIV was contracted from a blood transfusion.

Contact Frameworks

In addition to considering the position of the AIDS stigma within dual-process frameworks, research has also focused on the stigma as a function of direct and vicarious contact. Herek and Capitanio (1997) investigated the relationships between the AIDS stigma and direct contact with people with AIDS (e.g., a friend, family member or acquaintance) as well as vicarious contact (e.g., a public figure through the media who has AIDS). They randomly selected interview participants from the 48 contiguous states using a Computer-Assisted Telephone Interviewing (CATI) system. Survey questions assessed respondents' attitudes regarding coercive policies, perceived blame for persons with AIDS (e.g., "people who got AIDS through sex or drug use have gotten what they deserve"), avoidant behaviors (e.g., having a close relative with AIDS, having a child attend a school where another student has AIDS, working with a male coworker who has AIDS, and discovering that the owner of a neighborhood grocery store had AIDS), and beliefs of how AIDS is acquired (e.g., by drinking glass or use of public toilets). In addition, participants were asked whether they had any direct contact with an individual with AIDS. Vicarious contact was measured using opinion measures on the influence of public figures with AIDS (e.g., Magic Johnson) on their own opinions. Finally, participants' attitudes towards gay men were measured using a 3-item Attitudes Toward Gay Men (ATG) scale (Herek & Capitanio, 1997).

The results of this survey suggest that direct contact does affect the AIDS stigma. Respondents who indicated that they had experienced direct contact with a person with AIDS reported that the contact had influenced their attitudes some (30%) or a great deal (40%) (Herek & Capitanio, 1997). Furthermore, those individuals reported significantly lower stigma scores than the participants without direct contact. Conversely, of respondents who had heard of Magic Johnson's HIV announcement, only half indicated that their attitudes toward individuals with AIDS were influenced some (29.5%) or a great deal (24%). A separate study confirmed that individuals made negative attributions for Magic Johnson's illness, blaming internal and controllable, rather than external and uncontrollable, factors (Graham, Weiner, Giuliano, & Williams, 1993). This indicates that although vicarious contact might reduce the stigma of AIDS, it is through direct contact with people who have AIDS that most negative perceptions of AIDS are dispelled.

Herek and Capitanio (1997) also studied various demographic issues and how they relate to the AIDS stigma. The responses were broken down by race, political ideology and socio-economic status (SES). They found that the Black participants were more likely than members of the rest of the sample to know a person with AIDS, and that their perception of people with AIDS was highly influenced by that contact; 71% reported it affected their attitudes a great deal and another 14% reported that it affected their attitudes

some (Herek & Capitanio, 1997). Similarly, Blacks who had experienced direct contact with an individual with AIDS demonstrated less severe stigmatization than those without contact with regard to their attitudes toward coercive policies, blame, and avoidance.

Perhaps the most disheartening conclusion of these surveys is the amount of support for policies that would ostracize, discriminate, and severely restrict individuals with AIDS. Herek (1999) reported that a "significant minority" of the United States public reports negative feelings towards people with AIDS. Those feelings can have tremendously negative consequences for people with AIDS. Herek, Capitanio, and Widaman (2003) investigated support for HIV surveillance policies as well as how the stigma of AIDS could affect people's willingness to seek medical treatment if they suspect they could have AIDS. In another telephone survey of respondents from the original survey (n = 666) and new, randomly selected respondents (n = 669) participants were interviewed on four separate measures: perceptions of HIV stigma (the researchers asked respondents their opinion on how much people with AIDS had been unfairly persecuted), the social risk and HIV testing (had respondents ever been tested for AIDS and what their perceptions of their treatment would be if they were diagnosed with AIDS), their attitudes toward HIV surveillance procedures (should AIDS reporting be mandatory), and their attitudes toward people with AIDS and other stigmatized groups. The results indicate that the majority of respondents did believe that people with HIV are a continued target of persecution. Consistent with the fact that most individuals reported being concerned about being stigmatized if they should test positive in the future (39% very concerned, 29% somewhat concerned and 15% a little concerned), only 52% of respondents indicated that they had been tested for HIV. This indicates that there is a possibility that the stigma of having AIDS could be an impediment for people being tested. The possibility of facing the stigma of AIDS and the adverse outcome of having AIDS could fuel the continuation of the stigma as well as serve as an impediment toward people seeking treatment for AIDS. A plethora of research has identified that there is a stigma, and further research has identified the cognitive processes involved in the AIDS stigma, but many questions regarding the stigma of AIDS remain unanswered.

Future Directions

There are innumerable directions that AIDS stigma research could take with regard to the research content and methodology. In particular, we suggest that researchers consider the independent and associated effects of the stigmas of AIDS and homosexuality, the workplace implications of the AIDS stigma, the targets of stigma, and strategies for remediation. We also suggest that research continue to utilize experimental and field methodologies, and to incorporate social interaction and behavioral paradigms.

Potential Content of Future Research

Homosexuality and AIDS Stigmas - One particularly important question for future research is the association of the stigma of AIDS and the stigma of homosexuality. Survey research has indicated that there is a strong association between the stigma associated with AIDS and the stigma associated with homosexuality (Bouton et al., 1989). Although there is good evidence to suggest that both stigmas are perceived to be controllable (Graham et al., 1993; Herek, 2000) research is still needed to disentangle the independent effects of AIDS and homosexuality stigmas. In other words, is AIDS stigmatized primarily because the onset of the disease was associated with homosexual activity? Rozin et al. (1994) found that people do not differentiate between individuals who had AIDS from transfusions and those who had AIDS from homosexual contact in relation to perceived interpersonal contagion. In addition, research should consider the associations between sexual activity, another controllable behavior, and the AIDS stigma. Unsafe, promiscuous behavior may increase an individual's likelihood of contracting AIDS. Consistent with gender stereotypes and the social construction of expectations for sexual behavior across genders, these behaviors may be perceived more negatively for women than for men.

In addition to considering these aspects of the perceived controllability of AIDS, future research should also examine the unique dilemmas that are associated with the initial concealability of the disease in its early stages and its visibility later in the disease progression. The initial stages should be tested in comparison to the experiences of gay and lesbian individuals who decide whether or not to make public or disclose their sexual orientation (i.e., "come out of the closet"). A new framework is needed to understand the experiences of individuals with AIDS as it begins to manifest visibly, the potentially changing nature of the stigma, and the best strategies for coping with this progression. It is likely that perceptions of the communicability of the disease will be influenced by its visibility; that is, as visible symptoms emerge, people may fear that the disease is more highly contagious. Thus, it may be particularly important to increase education and awareness efforts regarding later stages of

HIV-AIDS. Future research should examine these yet untested issues.

AIDS at Work - One context in which these questions should be given particular attention is the workplace. The topic of AIDS at work has an enormous amount of potential for future research. Although some research has been dedicated to investigating the effects of being openly gay in the workplace (Ragins & Cornwell, 2001), the topic of being HIV-positive in the workplace has only recently begun to gain attention. In one study, Timmons and Lynch (2004) studied the importance of employment for individuals with AIDS. They conducted four separate focus groups with 29 participants who had AIDS. The results indicated that employment was an important source not only of economic security, but also self-respect, fulfillment, and well-being for people with AIDS (Timmons & Lynch, 2004). The same group of participants identified two employment-related concerns: health benefits and fear of discrimination. Participants were concerned that their jobs would not provide the necessary health benefits that AIDS requires and that their social security benefits would be revoked upon employment. Additionally, participants were very concerned that they would face discrimination when they disclosed their condition at work. In fact, the majority of participants indicated that they would leave their job rather than disclose their condition at work.

One framework that may be helpful for investigations of the stigma of AIDS is a recently proposed multi-level, dual perspective approach to understanding the nature of stigma in the workplace (Hebl, King, & Knight, 2005). This model explores the possibility that stigma in the workplace can be viewed from multiple levels and perspectives. That is, research should investigate the antecedents, consequences, and manifestations of stigmatization at the individual, group, and organizational levels of analysis. In the case of the stigma of AIDS, what organizational actions enhance the AIDS stigma (e.g., refusal to institute benefit plans)? What are the outcomes of stigmatizing individuals with AIDS? Is a workgroup stigmatized as a function of one member's HIV status?

In addition to offering a framework for answering these questions, Hebl et al. (2005) model advocates consideration of the experience of the target of stigmatization. In other words, the authors argue that it isn't enough to simply study why individuals with AIDS are stigmatized in the workplace, or even what consequence that might have on workplace outcomes. It is also necessary to investigate the outcomes of such stigmatization on all three levels of analysis: the individual level (e.g., self-esteem and feelings of worth), the group level (e.g., task cohesion and group performance) and the organizational level (e.g., the traditionally thought of outcomes studied such as workplace violence, attrition and job satisfaction). Many questions can be understood within this framework, and this type of research could provide a wealth of information that has not yet been available.

For example, at the individual level of analysis, one area that is of particular importance would be in the manifestation of discrimination toward individuals with AIDS. Although it is illegal to discriminate against a person with AIDS under the Americans with Disabilities Act, it is possible that people with AIDS are still discriminated against in the workplace. Hebl, Foster, Mannix and Dovidio (2002) developed a taxonomy to distinguish between "formal" and "interpersonal" discrimination. Formal discrimination encompasses behavior that is typically considered illegal (e.g., firing somebody because they have AIDS). Conversely, interpersonal discrimination would describe behavior that is not illegal such as nonverbal behavior. This discrimination could take place in very subtle ways that have not received sufficient research. It is possible that although an organization might not overtly discriminate against anyone with AIDS, their actions and behaviors might inadvertently cause adverse impact. For example, a supervisor might not feel completely comfortable traveling to conferences or conventions with an individual with AIDS. Therefore, the supervisor might select other employees for traveling to conferences, thereby building a relationship that might enhance the perceived promotability of the non-stigmatized individual. Meanwhile, the person with AIDS did not have that interpersonal exposure with the supervisor and may be penalized by being overlooked for a promotion in the future. Subtle instances of discrimination may accumulate over time and create large discrepancies and disadvantages for stigmatized individuals (Valian, 1998).

These subtle forms of discrimination have been documented for openly gay employees. Ragins and Cornwell (2001) found that gay employees who reported being discriminated against received fewer promotions than employees who did not report discrimination at work. Conversely, those employees that reported discrimination did not report a significant difference in compensation from those employees that did not report discrimination. They propose that since compensation is a highly visible method of discrimination and easily documented, that it was used less than the subtle form of promotions and awards. Furthermore, they postulate that promotions are due to selective grooming, mentoring and networking, and that

gay employees report being excluded from such mentoring relationships. Similarly, Hebl and colleagues (Hebl et al., 2002) found that gay and lesbian individuals were hired at similar rates as heterosexual individuals, but received more negative interpersonal treatment. This type of research should be conducted for employees with AIDS to determine how discrimination is manifested toward this stigmatized group.

Targets of Stigma - The influence of the perceived controllability, concealability, and contagion of AIDS should be examined across many populations. However, the individuals targeted by the majority of research in this area is limited. For example, little research has investigated the effects of stigmatization on the group being stigmatized. Most research, to date, regarding the stigma of AIDS has been focused on how individuals with AIDS are stigmatized, and how that stigma has changed over the years. However, the effects of being stigmatized on the targets of the stigma have received very little attention (see Swim & Stangor, 1998). This is another direction that we believe should be investigated more thoroughly. The stigma of AIDS might negatively impact self-esteem, self-efficacy, and ultimately health outcomes. In addition, it would be valuable to investigate how the stigma of AIDS impacts interpersonal relationships and family dynamics. Mason et al. (1995) investigated stigma disclosure and found that Spanish-speaking Latinos were less likely to disclose their condition to significant others (including family members) than English-speaking Latinos and whites. Furthermore, when asked for reasons for withholding disclosure, Latino men were more likely than white men to withhold disclosure of their condition for "other-focused" reasons. In other words, they did not disclose their condition for fear of hurting those close to them (Mason et al., 1995). This points to the importance of considering ethnic differences in the decision to disclose AIDS to family members and the experience of the AIDS stigma.

One of the most neglected aspects of the AIDS stigma involves an often ignored segment of the homosexual population: female-female sexual relationships. Since the HIV epidemic began, research has focused on male-male sex, but has virtually ignored lesbian, bisexual and transgender individuals. While it may be true that male-male sex and heterosexual sex account for the vast majority of AIDS cases, research still should address the stigma attached to HIV for female-female sexual relationships. This oversight has severe consequences, including a failure to include gay women in the education and prevention of AIDS (Morrow, 1995).

Another often-ignored population that should be given more consideration for future research is parents of individuals with HIV-AIDS, as well as parents who have AIDS themselves. Letteney and LaPorte (2004) studied how the stigma of AIDS affects the extent to which mothers with AIDS disclosed their illness. Those participants who felt devalued and discriminated against because of AIDS were significantly more likely to hide their illness from their children. This secrecy could have unintended consequences such as disease transmission, lack of medical treatment, and lack of proper planning for the care of children. More research should address the unique concerns of parents with AIDS and how the stigma affects not only the parents, but also the consequences for surviving partners and children.

Coping Strategies - Although past research has effectively identified and described the stigma of AIDS, there is a lack of research aimed at remediating the stigma of AIDS. In other words, what should be done to combat the stigma of AIDS? Herek and Capitanio (1997) studied how direct and vicarious exposure to a person with AIDS affects attitudes and found that such contact can alleviate the stigma of AIDS. However, it is not feasible to believe such a method could effectively eliminate the stigma. Future research should address the possibility that current methods for educating the public on AIDS might not be as effective as hoped, and even more importantly, what can be done to further eliminate the stigma associated with AIDS.

Several remediation strategies have been tested in social psychological research studies that may direct investigations of the remediation of the stigma of AIDS. For example, Hebl and Skorinko (2005) found that acknowledgment of one's stigma early in an interaction can improve interaction outcomes. However, this study focused on the stigma of disability, which is typically perceived to be uncontrollable. In cases, such as AIDS, where stigmas are perceived to be controllable, different strategies may be more effective. For example, stigmatized group members who provide individuating information about themselves may be able to separate their identity from the stigmatized characteristic. An individual who is HIV positive may inform interaction partners about their hobbies, community service projects, or other activities and information that can help them be perceived to be more than just a person who is HIV positive. In addition to these personal strategies, organizations and government agencies might remediate the stigma of AIDS by instituting protective legislation, policies, or training programs. The relative effectiveness of each of these

strategies in remediating the stigma of AIDS and its consequences should be thoroughly tested in empirical research.

Methods of Future Research

Future research should examine many of the questions discussed previously with a myriad of methodological approaches, including vignette studies, computer simulations, and social interaction paradigms. One method that has been used, but could be expanded on is the use of vignettes to study participant reaction to interacting with a person with AIDS. That type of research strategy could address many of the questions regarding AIDS in the workplace. For example, researchers could use vignettes to establish how participants would feel working in a variety of workplace conditions (i.e., jobs that require strong task cohesion, jobs that require travel, jobs that require personal contact, etc.) with people who have AIDS.

The use of vignettes could also be used to study situations that would be virtually impossible to study using behavioral strategies. For example, suppose researchers are interested in determining how jobs requiring very close personal contact (i.e. a dental hygienist working with a dentist) are affected by an individual who discloses being HIV positive. It might be important to determine if employees are affected by the knowledge that their coworker has AIDS. However, it would be ethically irresponsible to develop an experimental strategy that deceives participants who might fear for their own health. In such cases the use of vignettes could determine if there is a relationship without causing mental anguish.

Another method that should be used more extensively in future research is the use of computer simulations. Pryor et al. (2004) used computer simulation to study the moment-by-moment reactions to individuals who have AIDS. That type of research could be used in a variety of research strategies. For example, researchers could use computer simulations in which participants react to an interactive computer-based scenario. The scenario could involve what a participant might be expected to encounter in everyday life. As the participant changes their behavior in the simulation, the computer program changes the situation. For example, a participant might be requested to interact as part of a simulated group with a specific work related goal. The participant would be required to make decisions on how they would interact with members of the group, including one group member who is identified as having AIDS (either controllable or uncontrollable). The manner in which the participant interacts with members of the group dictates what is achieved.

Finally, we strongly advocate the use of social interaction paradigms in studying the stigma of AIDS, as they will provide some of the richest data for studying the AIDS stigma. What individuals indicate their response would be through the use of vignettes or computer simulations could be vastly different from how individuals actually respond when confronted with a real situation. For example, participants might vary their response to a vignette because they fear they will seem closed minded or mean. However, when faced with a real-life situation, their reaction might be completely different. For example, suppose a participant indicates a willingness to drink out of the same glass as a coworker with AIDS through the use of computer simulation. That participant might be influenced by their expectations of social norms and how they appear to the researcher, and may adjust their response to seem more empathetic or unconcerned. However, it is possible that the same individual would be unwilling to actually drink out of the same glass as a person who has AIDS if placed in a situation where they actually have to make that decision. Rozin et. al. (1994) found that people would be less willing to wear a sweater if somebody who had AIDS had previously worn the sweater, drive a car if the car had previously been driven by somebody with AIDS and sleep in the same hotel bed that had been slept in the previous night by an individual with AIDS, even if these things were clean. The results of their study indicate an unwillingness to have vicarious contact with inanimate objects that had been used by people with AIDS. Future research should study how people will act in what they perceive as a real-life situation. It would be valuable to determine if behavior now is similar to attitudes expressed over ten years ago.

A triangulation of methodologies may be the best approach to maximize internal and external validity and develop a comprehensive understanding of the processes involved in the stigma of AIDS. As an example of such a design consistent with previous stigma research, a researcher could develop a study using an experimental field paradigm to determine how AIDS affects employment selection. Confederate researchers could participate in job interviews in which they either disclose HIV positive status or do not. Interpersonal, subtle behaviors and hiring decisions could be assessed to determine the contemporary manifestation of discrimination toward individuals with HIV/AIDS. Furthermore, research must address the perceptions of the stigmatized group. Experiences of those individuals who are stigmatized should be investigated further. Although

qualitative in nature, such information would be invaluable for determining future research directions.

In summary, there exists enormous potential for studying the stigma of AIDS in work and social contexts in the United States. Much of the stigma of AIDS research has investigated the nature of the stigma, while very little research has addressed the potential impact of the stigma of AIDS on its targets. Future research should consider the impact of the stigma of homosexuality on the AIDS stigma, the dynamics of the stigma of AIDS in organizational contexts, and strategies by which the stigma may be reduced or avoided. By thoroughly integrating behavioral and applied scientific approaches, we may begin to fully understand the problem of the stigma of AIDS and to identify and implement its solution.

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