

## AIDS Telling: The Delivery of Bad News of HIV/AIDS

Medical advances have dramatically slowed the progression of HIV infection to AIDS, resulting in more individuals now surviving and living longer with HIV (AIDS.Gov 2008). Currently, over 1 million individuals are living with HIV/AIDS in the U.S. (Centers for Disease Control and Prevention 2008; Schneider, Kajese, and McKenna 2006). Stigma associated with HIV/AIDS has a significant impact on the quality of lives of those infected (Herek, Widaman, Capitanio 2005; Herek 1999; Herek 2004). Stigma attached to this disease means that those infected are devalued and may experience prejudice, discrimination (Valdiserri 2002) as well as shame and blame (Scambler and Paoli 2008). Fear of these negative consequences means that many will engage in strategies or tactics as protective measures (Scambler and Paoli 2008). One recognized protective measure is the control or management of the disclosure of one's status. This allows for the management of the impressions projected to others (Goffman 1963).

The study of the disclosure and receipt of the news of one's positive HIV status continues and extends prior research on the "delivery of bad news". With few exceptions (Beach 2002; Clark and LaBeff 1986; Clark, LaBeff, and Cadle 1993) much of the delivery of bad news literature focuses on how a variety of professionals communicate the news of death (Clark and LaBeff 1982; Leash 1994), or how healthcare practitioners communicate news of impending death or serious illness to patients or clients (Barclay, Blackhall, and Tulsy 2007; Lutfey and Maynard 1998; Ptacek, Leonard, and McKee 2004; Ptacek, Ptacek, and Ellison 2001). According to Maynard (1996), much of this research tends to be anecdotal, emphasizing the need to improve communication skills (see Rosenbaum and Kreiter 2002). Very little research addresses the patient's perspective of being on the receiving end of the delivery of such bad news

(see White and Shriver 2002; Yardley, Davis and Sheldon 2001). Moreover, we found only one study that examined the communication of bad news between family members. This study did not entail the ill person delivering the bad news about her condition, but rather a father delivering the news to his son that his mother had malignant cancer (Beach 2002).

The present study extends prior research by examining the strategies used for telling others of one's own illness (one's HIV or AIDS status). Not only is it important to understand the strategies used to deliver this bad news, but also who one tells and why. Unique to HIV/AIDS as an illness is the potential impact of others knowing (associated stigma, sexual prejudice, discrimination, concerns over fear, risk etc.). Stigma associated with HIV/AIDS has implications for adherence to medical regimens (Chesney & Smith 1999; Schuster, Collins, Cunningham, Morton, Zierler, Wong et al. 2005), engagement in further high-risk sexual activities (Preston, D'Augelli, Kassab, Cain, Schulze & Starks 2004), and general well being.

Advocating for societal and prevention program changes or implementation strategies to alter the interactional experiences of persons living with HIV/AIDS means we must have a more in-depth understanding of how stigma plays out in their lived experiences. Of further importance in comprehending the impact of the stigma attached to this illness is understanding such issues as whether one tells others how the virus was contracted; how the delivery message changes over time; and if there are disclosure differences between those who are newly diagnosed as opposed to those diagnosed longer. Finally, we are interested in how the bad news is received.

### **Theoretical Framework**

The need to manage stigmatizing information is not unique to those who are HIV positive. There are many other groups who possess stigmatizing, and therefore discreditable,

traits that are not readily apparent to others. As numerous as there are groups with discreditable traits, there are theories employed to explain and categorize their experiences. No analysis of those who are HIV positive would be complete without some theoretical understanding of stigma and stigma management.

Goffman's work, *Stigma*, has become the standard reference for recognizing that those with disabilities or chronic disorders and illnesses often engage in managing information and the stereotypical myths and misconceptions that others have of them (1963). Stigma refers to an enduring condition, attribute or trait that the larger society has deemed negatively valued, one "that is deeply discrediting" to an individual (Goffman 1963). As such, the bearer of the negatively valued trait, condition, or attribute is the recipient of shame, prejudice, condemnation and perhaps fear (Goffman 1963, Herek 1999; Herek 2004; Liu, Li, Ma, & Yin 2002). More recent research has distinguished between "enacted" or "felt" stigma (Herek, need date here). Enacted stigma refers to actual discrimination experienced, whereas felt stigma refers to "an internalized sense of shame and blame" and "a frequently disruptive and sometimes disabling fear of being discriminated against" (Scrambler & Paoli 2008, pg. 1850).

The epidemic of HIV/AIDS has been accompanied by the epidemic of stigmatization against people living with HIV/AIDS (PLWHA) (Hong et al, 2008). HIV/AIDS is partially stigmatized because it is an incurable and progressive condition. Moreover, it is believed that affected people are responsible for their infection due to their risky activities (Versa-Diaz & Marian-Rodriguez, 2007). HIV related stigma can be defined as prejudice or discrediting directed toward those perceived to have HIV/AIDS, as well as individuals, groups and communities with which they are associated (Hong et al, 2008). HIV/AIDS stigma is closely associated with a large number of negative consequences including, being labeled and

stereotyped, experiencing separation from others, a loss of social status and being the recipient of discrimination and prejudice (Galvan et al, 2008). In addition, PLWHA are often assumed to be homosexual, a characteristic that carries a “sexual stigma.” According to Herek (2004), a contemporary response in most countries to homosexuality is by default one of “disapproval, disgust, or discriminatory behavior” (pg. 15). Thus, PLWHA are, by association, further devalued and responded to as if they are also homosexual, even when they are not, since that is often the underlying assumption.

Goffman (1963) contends that people must seek to manage “spoiled aspects” of their social and personal identities in a variety of contexts. In other words, one must manage discreditable identities. One way of doing so is through what Goffman termed “impression management” (1959). Stigma management translates into information management as a means of coping with a deviant identity. Individuals strategically regulate information about themselves thus allowing them to construct and protect their identities which in turn influences how they are perceived and treated in social situations (Goffman 1959, 1967; Kroeger 2003; Learly 1995; Schlenkerr 2003).

Labeling theorists also developed theoretical understandings to matters of health and illness and deviant identities. Similar to Goffman’s “stigma,” what is stigmatized or labeled as deviant varies over time and is culturally specific, rather than something intrinsic to the individual. Labeling theory’s focus is on the results of societal interaction between the alleged deviant and those who seek to define and sanction such an individual (Lemert 1951). There seems to be a transference from something one has done to the defining of someone as a deviant human being (Tannenbaum 1938). The theory suggests that the reaction of others actually solidifies the person’s self-image as a deviant. In other words, the person labeled as deviant

assumes the identity as his/her own. The individual's deviant identity, a PLWHA in this case, becomes a master status, overriding all other statuses. The individual will first be recognized as a PLWHA before being identified by any other of occupied status. Once this occurs, the theory suggests that the labeled individual will engage in further deviance to live up to the deviant identity (Becker 1963). In other words, there are unintended consequences of being labeled as having a deviant identity, an identity negatively stigmatized in society.

Symbolic interactionism also provides a theoretical understanding for those who are HIV positive attempting to manage their stigmatized identity. According to Blumer (1969) every individual brings a multitude of meanings to each social encounter. These meanings have been derived from their multitude of interactions in society. Individuals make sense of each new situation by attending to cues in the present situation. This process is referred to as defining the situation. One's "definition of the situation" (W. I. Thomas) is critical to disclosure decisions. Assessments of social interactional cues and social contexts play a role in how individuals manage their discreditable traits. Defining the situation may be complex for those who are HIV positive. It is well established that those who are HIV positive have interacted with those who hold negative, prejudicial attitudes and beliefs as a result of their illness. However, prejudicial attitudes and beliefs may not always be initially evident. According to Goffman (1959), there is much that is concealed in interaction. He says that we cannot know the real or true attitudes and beliefs of others, and so must ascertain them indirectly. Assessments of one's situational and relational factors should theoretically play a role in the process of managing the potentially damaging information regarding one's HIV status. Selective disclosure, as well as concealment, are important informational strategies employed to manage a stigmatized trait or characteristic.

## **Methodology**

Purposeful focus group interviews were conducted of males and females who have recently been diagnosed HIV positive ( as well as males and females who have been diagnosed HIV positive for over one year. We will also conduct some one-on-one interviews for those who do not wish to participate in a focus group. However, the majority of the participants will participate in a focus group interview. Focus groups are interviews with small groups, typically with fewer than 10 people, with most recommending no more than 7 per focus group (Berg 2007). We will conduct 9 focus groups (7 per focus group) and an estimated 7 individual interviews. This will result in responses from seventy individuals. Focus groups and interviews will be semi-structured and will be recorded. The focus groups and interviews will last approximately 2 hours. Participants will be voluntarily recruited, provided with informed consent forms, and will be given \$25 after participation is complete. We will guarantee respondents complete confidentiality. We will not ask for names and we will keep all information shared in the focus group or individual interviews confidential. In addition, after transcription is complete, the tapes will be erased.

We will utilize current, established relationships with potential gatekeepers to access the targeted population. Beverly Stiles has been involved with providers, groups, and individuals with access to the targeted population in Tarrant County and Wichita Falls for approximately???? (not sure about time period, but it's been over 5 years). These relationships will provide rich and expansive points of access. Furthermore, the agencies that helped with last

year's grant will do so again. These agencies include AIDS Outreach Center, Samaritan House, Tarrant County Health Department, AIDS Interfaith Network, MHMR of Tarrant County, Catholic Charities, Positive Voices Coalition, and Wichita Falls Health Department. These Service Providers will be mailed a letter describing the study and asking for their assistance in recruiting participants. We will never initiate contact with participants at these agencies because we will not know the names of those individuals who are HIV positive being served through the agencies. Therefore, agencies will set up focus groups for us. The Service Providers in the region are aware of the project and are willing to organize focus groups for us. However, it is expected that some individuals may contact us via word of mouth (via snowball sampling) for individual interviews.

### Sample

Selected descriptive characteristics of the study participants are presented in Table 1.

[Table 1 about here]

The participants in this study consisted of 17 women, 26 men, and 1 transgender (male to female). The sample consisted of twenty-six African Americans, fifteen Whites, and three Hispanics. The age range of participants was 21 to 71 years with a mean age of 43.6 years. A large percentage (52%) of the respondents had been diagnosed HIV positive for over 10 years. There were eight respondents who had been newly diagnosed (diagnosed less than a year).

### Analysis

We utilized a grounded theory methodology to assess the HIV/AIDS telling strategies and experiences of research participants. Grounded theory is a descriptive qualitative

methodology (Glaser 1976; Glaser & Strauss 1967) that focuses on the meanings of social phenomena based on the perspective of symbolic interactionist theory (Blumer 1969). Symbolic interactionism proposes that people construct meanings of phenomena based on their interpretations of interactions they have with others. Grounded theorists base their research on the assumption that individuals and groups experience shared social circumstances, and that meanings are generated from those shared circumstances. It is the role of the grounded theorist to explore and attempt to see the world from the perspective of one's respondents, to articulate their meanings, thus making sense of their social experience. When possible the grounded theorist develops a theoretical understanding of the processes involved in those experiences. This is accomplished through use of the constant comparative method in which differences and similarities among the data are observed and a theoretical scheme is developed (Glaser and Strauss 1967).

The scientific rigor of grounded theory research is assessed through the application of procedures for establishing the credibility (trustworthiness), transferability (external validity), dependability (reliability), and confirmability (objectivity) of the study findings (Guba and Lincoln 1994). Therefore, consistent with methodological and epistemological assumptions of symbolic interactionism and grounded theory, study samples are purposive, and they are chosen to reflect the fullness of experience from the perspective of the individual. Hence, this study's findings are offered as an in-depth, rich description of disclosure experiences of those who are infected with HIV/AIDS so that different insights and theoretical ideas can be generated.

Credibility will be established by having the results carefully reviewed and approved by several informants. Moreover, prolonged time in the field enhances credibility. Beverly Stiles has worked in the field for approximately 7 years thus far. In addition, talking to those in the

field about stigma issues enhances credibility (Guba & Lincoln 1994). This rich, in-depth articulation of experiences will provide the data base, enabling the reader to make transferability of findings possible. Transferability refers to whether findings are applicable to different groups or situations (Glaser 1976). Dependability refers to the reliability and consistency of the findings (Guba & Lincoln 1994). We will conduct focus groups and individual interviews with approximately seventy participants to enhance the dependability of findings. The lead researcher now has a confirmed, accepted, and trusted presence in the North Central Texas HIV Planning Council network.

### **TYPES OF DISCLOSURE**

Those diagnosed longer often talked about how coming to terms with and disclosing one's status was a "process." These comments were often used to console those who were more recently diagnosed who talked about the shame and guilt experienced as well as the considerable effort and energy expended to maintain or conceal their secret for fear that others would find out.

This "process" spoken about is learned in social interaction. The newly or more recently diagnosed base their understanding of what it means to have HIV on old myths and misconceptions that they had previously learned in a culture that stigmatizes HIV and those who contract it. As Blumer (1969) would say, every individual brings a multitude of meanings to each social encounter. These meanings have been derived from their multitude of interactions in society. Individuals make sense of each new situation by attending to cues in the present situation. That is, they "define the situation." One's "definition of the situation" plays a critical role not only in disclosure decisions, but also in how individuals manage their stigmatized traits.

However, prejudicial attitudes and beliefs may not always be initially evident. According

to Goffman (1959), there is much that is concealed in interaction. He says that we cannot know the real or true attitudes and beliefs of others, and so must ascertain them indirectly. Thus it is of no surprise that many individuals engage in activities or tactics to discern the safety of disclosure. These tactics involve maneuvers to help define the situation. For example, one respondent says that while playing a board game, she just throws HIV out as a topic of conversation to get the reaction of family and friends. The example was “Hey, I read this article in a magazine, so-and-so’s HIV positive, what do you think about it?” She then watches and listens for their reactions. Others say that they watch for evidence that someone is trustworthy. They notice how they talk about or gossip about others. Many talk about just knowing who you can trust and who you cannot. Still others talk about using the criteria, the “need-to-know” when judging the safety of disclosure. The assumption is that if they “need to know” they are likely to be individuals close enough that they are less likely to hold prejudicial attitudes. Finally, some use another’s professional status (such as a counselor or doctor) as a cue that they can disclose their status because they understand that the professional is obligated to or understands keeping information private.

We have identified six types of disclosure for telling others of one’s HIV status.

#### Educational Disclosures:

Revelations are made to either help change the attitudes of others who either do not know much about HIV, or who held prejudicial attitudes, as well as to encourage others to protect themselves. The desire was to promote change through education and to become a model of the kind of person who can be HIV positive, to dispel misconceptions about HIV. Educational disclosures also make HIV more visible. This serves to help individuals feel that they are doing

their part in dispelling myths and prejudices about HIV. This was the most common disclosure type. This is not surprising given that the majority of our sample has been diagnosed for more than 10 years. None of those who disclose for educational purposes are newly diagnosed. The following responses exemplify those who engage in educational disclosures:

...I'm not boasting, I'm not saying I'm the poster child, but I just kind of want to let them know, this is an epidemic man, that's going out there, it's like crazy, now, it's not a little thing, it's going out there like crazy, and somebody's got to do something to share, now (male, age 48, diagnosed 8 yrs.).

...I'm at a point now where I want to educate people, because there's, especially in this community, there's still a lot of people who are so, I mean so uneducated on the subject. They're still stuck on, well, I'm not gay so I don't have to worry about it, or I'm not black, I don't have to worry about it, I'm not using drugs, I don't have to worry about it, and I bring that out when I lecture, is the stories like about that one guy who was married and whose wife was about to have a baby and he went off and cheated on her with another girl and she infected him with HIV and then he infected his wife. And that's just an example that it's astronomical, it reaches anybody of any class, race, sexual orientation, it's endless, and so I try to stress that to everybody. So I want to educate (male, age 33, diagnosed 3.5 yrs.).

...it ain't going to never leave me. And this is why I confided in her, because I wanted to scare her into protecting herself (female, age 65, diagnosed 11 yrs.)

... one time I was in a group, and there was a conversation between us about HIV and they said some really ignorant things. They weren't being responsible with their comments, and I did disclose and made clear, or tried to enlighten about the situation (male, age 56, diagnosed 21 yrs.).

...I had a little sit-down, the whole father-son talk about sex and everything else, and I disclosed to him that I'm HIV positive and he actually got teary-eyed. I told him, I said, because I'm going to tell you, we talked about protected sex, because I don't believe in talking to kids about abstinence because that's just not reality, so I told him about protection, and always, always, always, and I told him let me tell you why, and I said because I personally myself have HIB, I'm HIV positive (male, age 47, diagnosed 15 yrs.).

#### Need-to-Know Disclosures:

A need-to-know disclosure results from a sense of honesty, felt responsibility to tell another. Often those who engage in this type of disclosure feel they cannot get close or be in a

relationship unless they tell the other person who they feel “needs to know.” In addition, sometimes it isn’t that the other person “needs to know” but rather the HIV positive individual has a need for another to know.

No, I didn’t even think about it, I thought, well, they’re going to ask why I haven’t got a check, why I’m not going to get one that time, because we were all living in the same boardinghouse-like situation, it was an apartment, but more like a boardinghouse, because everyone the first floor shared a restroom, and everyone on the second floor, and we all kind of shared a lot of things, partying, getting pot or whatever, enjoying stuff, so I felt like it was my duty to at least say, well, I’m not getting a check....Why not? (male, age 49, diagnosed 20 yrs.).

I know that some people wear their status on their cuff. And I can appreciate that. But if I’m going to get with someone and I know there’s nothing high-risk going on, I am not going to disclose my status. Why should I put that out there when I’m not doing anything to put them at risk? (male, age 56, diagnosed 21 yrs.).

The first one that I notified, I guess, was my partner, he was at the doctor’s office me when I got my diagnosis. And my partner is negative to this day, and the only other one that I’ve ever told on a need to know basis, my two sisters and their families know, but there was transactions that had to be made, and I notified them by certified mail (male, age 71, diagnosed 4 yrs.).

#### Cathartic Disclosures:

Cathartic disclosures are in some ways similar to those who fall into the “need-to-know” category. However, those in this category disclose as a way of soliciting support and sharing one’s emotional burden. These disclosures did not always lead respondents to feel better about themselves. Some disclosures actually had the opposite outcome. Often one tells a carefully selected friend or family member. It is quite common to tell a sibling over a parent. The following conversation exemplifies this aspect of Cathartic disclosures:

Respondent:...”just the thing about having to let her know, had to let somebody know, and my family.

Moderator: Why did you choose your sister?

Respondent: Because she's my oldest sister, and she's very strong Christian lady, and I had, like I say, I had also backslid there, and so I told her, I went out there and acted the fool, and this is what I sewed.

Moderator: Was she the most supportive person you could tell?

Respondent: She was, and I had told her, but of course I tried to tell her, whatever you do, don't tell Mom (male, age 48, diagnosed 8 yrs.).

...I told one of the clients that I have, because he's in a nursing home, and I just broke the news down to him that I am sick, too, I'm HIV positive, and I hope that made a change in his life. I went to a meet him and I had a talk with him, and like I said, I hope I made a change in his life. Life must go on (male, age 35, diagnosed 15 yrs.).

#### Preventive Disclosures:

Preventive telling is disclosing before another finds out on their own, telling an employer or landlord, for example. The following is a quote from a respondent who felt that he had to disclose to his landlady to prevent any trouble with her in the future:

...a landlady of mine intercepted my letter, and she opened it, course we were neighbors, right, course I'm an addict too, a drug addict, so she said, I don't care how sick you get, because when I seen them letters certified urgent, urgent, I already knew deep down I had a gut feeling what the reports were (male, age 48, diagnosed 8 yrs.).

#### Rehearsed Disclosures:

Respondent: I have rehearsed it a ton of times in my head with my son.

M: Your son that you talked to about sexuality?

Respondent: No, that one I didn't, either, I knew, I thought about what would be the best way to tell him is I'll give him the father-son talk. My youngest son, yes, I have, and it's come out, the result has gone several ways, it's gone from the worst of the worst, to the best.

The following comment is from someone who works with HIV positive clients:

I don't always rehearse it, just sometimes, because I get nervous, because I don't know this person. The person that I know they background and I know them, then I'm not going to rehearse. I'm very nervous when I don't know them, I actually called someone the other day that I didn't know and they happened to be on my client list and I had to talk to her at first, and of course I asked her a case manager a little bit about her and she told me course that the girl had an attitude so of course I'm looking for an attitude, and I'm like how she going to react and I'm another person calling her and she don't know about me and I'm fixing to have to tell her that I'm HIV positive too, and so I got really nervous and it actually turned out to be a good conversation afterwards and I even told her that I was real nervous about calling you because you was real particular, she was real particular about her name, how you say her name, and just people calling her all the time, and so (female, age 29, diagnosed 7 yrs.).

### Spontaneous Disclosures:

The following is a quote from a respondent who just blurted out his positive status spontaneously, without much thought or planning:

“That same day we were all in my apartment in Ft. Worth, a high-rise down there, looking out the windows, and I just turned around and we had a large group of friends there that day, and I just turned around and just told everybody. I was very open about it (male, age 49, diagnosed 20 yrs.).

### CONCEALMENT VERSUS DISCLOSURE

Kelly and McKillop (1996) suggest that before revealing a secret one should consider the consequences. They suggest that people should probably not reveal personal secrets if they lack a nonjudgmental and trustworthy person with whom to confide. Others suggest that concealment might be warranted if one has good reasons for it (Imber-Black 1998). The feeling here is that there is an unknown risk involved in revealing in that one may not be sure how the receiver of that information is going to react. Thus, the reasons given for concealing secrets may be numerous according to Vangelisti (1994). First, individuals may perceive what would happen if a secret was revealed and they believe the reaction or evaluation would be disapproval. Second,

some conceal secrets as a form of defense. That is, they often worry that the recipient would violate their trust. Third, some individuals worry that they will not be able to discuss the secret in a satisfactory manner. Fourth, some may simply feel that the secret is not relevant to others (Vangelisti 1994). The bottom line is that “people refrain from disclosing sensitive information because of the need for protection” (Afifi, Olson, & Armstrong 2005, p. 565) as well as to protect others (Afifi & Guerrero 1998; Kroeger 2003) .

The concealment surrounding one’s HIV status is a result of the stigma attached to this disease. Stigma management translates into secrecy or information management as a means of coping with an illness that is highly stigmatized, a discreditable trait. Deliberate concealment of a portion of one’s identity entails the withholding or concealment of information that could be damaging to oneself if others discovered what they work hard to keep private. These individuals are aware of the potential for stigmatization to affect their lives. Thus, they carefully control what they tell others about their health and perhaps current or prior lifestyle. However to tell or not to tell is not a simple decision. The control of this information is shaped by a variety of factors.

#### FACTORS AFFECTING DISCLOSURE VS. SECRECY

The reasons for revealing one’s HIV status are largely determined on a situational basis. We have identified four factors that affect the nature of the disclosure of one’s HIV status. Factors affecting the nature of one’s disclosure include such factors as the length of diagnosis, relational factors, situational factors, and the degree of acceptance of one’s own HIV status.

##### Length of Diagnosis

The longer one has been diagnosed the more open one is about being HIV positive and

therefore the more people who know about one's status. It appears that the newly diagnosed in our sample feel more heavily the burden of stigma and labeling. Because of this, the newly diagnosed are more likely to have told very few individuals about their HIV status, other than those individuals who they came into contact with in group meetings, or our focus group, who were also HIV positive. Those diagnosed longer were more likely to engage in "educational disclosures." Sometimes stigmatized groups can manage stigma by highlighting their "spoiled identity, while at other times attempting to minimize them. The educational disclosure is a means of highlighting one's spoiled identity, engaged in more often by those diagnosed longer.

#### Relational Factors

Individuals in relationships tended to tell their partners first. In two cases they told no one other than each other, as both were positive. These tend to be "need-to-know" disclosures. If not in a relationship, individuals tended to choose to disclose to a close relative such as a chosen sibling or a parent. These are individuals who they often perceive as trustworthy, or the individual tends to have a need for the sibling, parent, or close friend to know so as to share the burden and to obtain comfort and support. Therefore, one might say that an assessment of the likelihood of acceptance vs. rejection is a determining factor in disclosure. The assessment is that someone who one is close to on an emotional level is more likely to accept one's condition without condemnation. However, this was not always the outcome.

#### Situational factors

There are those who did not have much choice in disclosing their HIV status as some individuals happened to have a relative present at the time of diagnosis. Another situational factor that affects disclosure is a serious illness or the possibility of illness. Several individuals

told someone they were close to such as a relative or friend because they feared dying without anyone knowing why or how they died. Several feared becoming ill at some point and thought it best if others knew beforehand so as to know what to expect.

#### Acceptance of one's own HIV status

Acceptance of one's own HIV status plays a role in one's decision to disclose or to conceal. Many individuals talked about how initially they denied their diagnosis, preferring instead to pretend that it was not true. Others said they ignored the letters that arrived from the health department. Acceptance only came once one became too ill to deny. While fear played a role in the lack of acceptance, so did guilt and shame. Once again, it was those more recently diagnosed who talked extensively about the shame and guilt they felt about being HIV positive.

### STIGMA MANAGEMENT

According to Blaine (2000), one strategy of stigma management includes strategies for "improving psychological outcomes" (pg. 136). The strategies for improving psychological outcomes are "cognitive in nature and involve thinking about one's stigma and the experiences associated with it in ways that are beneficial to self-esteem and well-being" (pg. 142). There are two main strategies used for improving how individuals who are HIV positive feel about themselves.

First, sometimes stigmatized groups manage their stigma by highlighting or embracing their "spoiled identity." The educational disclosure is a means of highlighting or embracing one's spoiled identity. The educational disclosure was engaged in more often by those diagnosed longer. Second, those diagnosed longer have developed a support system by associating with others who are HIV positive, for example, serving in a mentoring capacity to

others who are HIV positive.

According to Blaine (2000), the second strategy of stigma management includes strategies for “improving interpersonal outcomes” (pg. 136). Many of those who are HIV positive choose to manage their public persona to appear like everyone else. Goffman referred to this as “passing” (1963). According to Blaine (2000) passing is a means of improving one’s interpersonal outcomes. First, many simply do not disclose their status. This works for those who have no outward signs of illness so that no one suspects. Second, many individuals talk about hiding their medications by removing them from their medicine cabinets in case anyone should see them, accidentally or otherwise, and ask why they’re taking medication, or perhaps might recognize it as HIV medication. Third, individuals, unfortunately, will simply not take their medication at times so as to not be suspected of having HIV. Some will also miss doctor appointments so that their employer will not suspect anything is wrong by taking time off from work. Others will make certain they do not leave any HIV literature around their residence. Each of these strategies is used to make them more acceptable to others or to improve their interpersonal outcomes by decreasing the costs of the stigma. In other words, while sometimes individuals embrace their “spoiled identity,” at other times they attempt to minimize it.

### CHOOSING TO DISCLOSE

Those diagnosed longer have come to terms with their HIV status. As previously mentioned, many of them view coming to terms with their HIV status as a process that occurs over time. Stigma results from cultural evaluations or labeling of PLWHA as stigmatized and perhaps deviant. In a culture that stigmatizes those who are HIV positive, from the moment others know of one’s HIV positive status, the individual’s HIV identity becomes a master status,

overriding all other statuses. The individual will first be recognized as a PLWHA before being identified by any other occupied status. This process of labeling is at work from the beginning, but over time one's own self-image is dealt with perhaps more successfully through engaging in some stigma management strategies that lessens the harshness of the deviant or stigmatized label or identity. Interaction with others who are HIV positive is a mechanism for helping the newly diagnosed to cope with their own fears, so that they can take care of themselves as well as reach out to family and friends who may then provide a more supportive environment.

We know that positive social interaction is important, especially with those who share one's experiences. It is through interaction with others that we learn about ourselves, that we are able to define or redefine our situation. In other words, those newly diagnosed can benefit from interactions with others who are HIV positive. Through this interaction, they can learn some healthy techniques for managing the social stigma of HIV. These relationships have been promoted through funding for mentoring programs and social gatherings. The problem in the United State is that funding for such programs is decreasing. This will increasingly have ramifications for those newly diagnosed. Without the learning of positive information and management strategies, we can expect that unhealthy strategies will be adopted, meaning that many will simply hide their HIV status through such strategies as nonadherence to medical regimens (not taking medications, seeing their doctor, or getting blood work completed).

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Table 1: Selected Descriptive Characteristics of Study Participants (n = 44).

<b>Variables</b>		
Gender	%	Number
Male	59	26
Female	39	17
Transgender	2	1
Race		
White	34	15
African American	59	26
Hispanic	7	3
Length of Diagnosis		
Less than 1 year	18	8
1 year – 3 years	7	3
More than 3 years but less than 6	11	5
More than 6 years but less than 10	11	5
More than 10 years	52	23