

### Abstract

Individuals living with HIV may have a heightened sensitivity to behaviors of others that may signal bias or discrimination. Identifying and avoiding these behaviors may be especially important for healthcare personnel, who regularly interact with HIV-positive clientele. This interview study examines the perceptions of stigma in healthcare contexts of 50 male American military veterans living with HIV. Participants described a variety of stigmatizing behaviors performed by healthcare personnel, ranging from ambiguous nonverbal cues to blatant discrimination. These findings extend previous research by (a) focusing on healthcare personnel's actual behaviors rather than their attitudes and beliefs about HIV-positive patients, (b) including patients' perceptions of both clinical and non-clinical healthcare personnel, and (c) identifying potentially stigmatizing behaviors that are unique to healthcare contexts. These findings provide healthcare personnel with a tangible list of behaviors that should either be avoided or further explained to HIV-positive patients, as they may be interpreted as stigmatizing.

### Male Patient Perceptions of HIV Stigma in Healthcare Contexts

Recent estimates indicate that well over a million people are currently living with HIV in the United States (Glynn & Rhodes, 2005). Although the introduction of antiretroviral treatments has dramatically increased the life span of those infected by the virus (Pearlin, Aneshensel, & LeBlanc, 1997; Wood et al., 2003), progress in addressing the widespread social stigma surrounding HIV has lagged behind these biomedical advances (Botnick, 2000). A host of studies indicate that, despite public health efforts to educate the general public about HIV, misconceptions of how the virus is transmitted and disparaging attitudes towards those infected with the virus are still prevalent (Herek & Capitanio, 1999; Herek, Capitanio, & Widaman, 2002). Subsequently, people living with HIV often face ridicule, ostracism, and persecution in many forms, ranging from caustic social interactions to draconian legislative efforts designed to strip people living with HIV of their civil rights (Bennett, 1990; Gostin, 1990; Herek & Capitanio, 1993, 1994, 1997; Herek & Glunt, 1988; Price & Hsu, 1992). In its extreme form, hostile expressions of HIV stigma have even driven people from their homes and led to acts of physical violence against them (Gielen, O'Campo, Faden, & Eke, 1997; Gostin, 1990; Hunter & Rubenstein, 1992; Zierler et al., 2000).

The effects of HIV stigma on those living with the disease are significant and include diminished mental and physical health outcomes, such as elevated stress, depression, immune suppression, and suicide (Craft & Serovich, 2005; D'Augelli, 1989; Derlega, Lovejoy, & Winstead, 1998; Goldin, 1994; Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; Liebschutz, Geier, Horton, Chuang, & Samet, 2005; Marzuk et al., 1988). In addition, concern over being stigmatized can lead people to conceal their HIV status from sexual and/or drug-using partners (Chesney & Smith, 1999; Ford, Wirawan, Sumantera, Sawitri, & Stahre, 2004; Gaudio, 2005; Gielen et al., 1997). To avoid discovery and potential stigmatization, people have even been found to forego their HIV medications in the presence of others and, thus, increase their risks of both viral resistance and

clinical failure (Golin, Isasi, Bontempi, & Eng, 2002; Rintamaki, Hogan, & Weaver, 2005; Rintamaki, Wolf, Davis, Skripkauskas, & Bennett, 2006). Given its formidable range of social, psychological, and physical consequences, it is of no surprise that stigma has been labeled as the most significant social and psychological challenge of the HIV experience (Chung & Magraw, 1992; Crandall & Coleman, 1992; Moneyham et al., 1996).

One of the most troubling aspects of HIV stigma involves its prevalence and expression among healthcare personnel, who include all clinical and non-clinical workers in healthcare settings. Healthcare personnel have been instrumental in managing the HIV epidemic in the United States and abroad, serving as care providers and public educators; however, healthcare personnel are not immune to HIV stigma and some have reported disparaging attitudes towards people living with the disease (McCann, 1997, 1999; Norton, Schwartzbaum, & Wheat, 1990). Such attitudes have been documented among a variety of healthcare personnel, including practicing physicians, medical students, nurses, and psychologists (Breault & Polifroni, 1992; Dworkin, Albrecht, & Cooksey, 1991; Knox, Dow, & Cotton, 1989). Although such negative attitudes are shown to diminish as healthcare personnel gain experience working with HIV-positive patients, they may still persist even among those who have worked with such clientele for many years (Ficarrotto, Grade, & Zegans, 1991; Orlander, Samet, Kazis, Freedberg, & Libman, 1994). What's more, such attitudes have been linked to reluctance in healthcare personnel to interact with those living with the disease, in some cases leading to their refusal to provide care for HIV-positive patients (Crawford, Humfleet, Ribordy, Ho, & Vickers, 1991; Kass, Faden, Fox, & Dudley, 1992; Levin, Krantz, Driscoll, & Fleischman, 1995; Quam, 1990).

HIV stigma does not always manifest in such blatant incidents of discrimination; in fact, more subtle communicative cues may alert a person living with HIV to the presence of stigmatizing attitudes. Whether they are conscious of it or not, people frequently express their biased attitudes

during social interaction, often through nonverbal gestures (Eagly & Chaiken, 1993). In the context of HIV, relatively little research has examined expressions of stigma at such micro-social levels; however, that which does exist suggests that people living with HIV are attuned to subtle behaviors (Chapman, 2002). Perhaps because of their experiences with bias and discrimination, or simply because of their mindfulness that others may devalue them, people who belong to stigmatized groups are shown to develop a heightened sensitivity to communication cues that may indicate the presence of prejudice or discrimination (Frable, Blackstone, & Scherbaum, 1990). Some research has revealed such sensitivity among people living with HIV and shown that it may be especially heightened in interactions with the healthcare personnel on whom HIV-positive clientele must rely (Chapman, 2002). What's more, when encountering subtle or ambiguous verbal or nonverbal messages, stigmatized people may be more prone to interpret such events as indicative of social stigma rather than the result of other equally plausible explanations (Crocker & Major, 1989; Crocker, Voelkl, Testa, & Major, 1991; Major & Crocker, 1993). Subsequently, patients' heightened sensitivity to stigma may lead them to interpret ambiguous communicative cues of healthcare personnel as stigmatizing, even when it is unclear that stigma is, in fact, being expressed. This suggests that even well-intentioned healthcare personnel may inadvertently communicate in ways that HIV-positive patients interpret negatively (Pleck, O'Donnell, O'Donnell, & Snarey, 1988).

Despite the obvious implications HIV stigma has for quality of care, surprisingly little research has been conducted in this area. The literature on HIV stigma reveals that only a handful of studies have examined HIV stigma in healthcare settings, with existing studies being limited in scope (e.g., focusing solely on one type of healthcare personnel, such as physicians or nurses) and emphasizing the antecedents of stigma (e.g., attitudes towards people living with HIV) rather than its behavioral manifestations (McCann, 1997, 1999; Parker & Aggleton, 2003; Surlis & Hyde, 2001). Exploration of patients' lived experiences and perceptions of HIV stigma in healthcare contexts is

the next step in this line of inquiry and is not only of great academic interest and pragmatic value, but may hold considerable legal consequence, as well. Identifying and avoiding those behaviors that are most problematic from patients' perspectives may help healthcare personnel more quickly develop open and trusting relationships with HIV-positive patients. Avoidance of such behaviors may subsequently minimize the likelihood of malpractice lawsuits, as patients who like their care providers are less likely to sue than are those who experience troubled patient-provider relationships (Levinson, Roter, Mullooly, Dull, & Frankel, 1997).

Exploration of patients' experiences and perceptions of stigmatizing behaviors among healthcare personnel includes identification of the more blatant and extreme expressions of HIV stigma among healthcare personnel, which to date have not been documented beyond occasional refusals to provide care for HIV-positive clientele. So, too, must it include the identification of the more subtle communicative cues to which HIV-positive patients are acutely attuned. What's more, assessment of patients' experiences encountering such behaviors must include all types of healthcare personnel, not just clinical care providers. With these objectives in mind, the present study was conducted to explore patients' perceptions of and experiences with HIV stigma in healthcare contexts.

## Methods

As part of a larger study on coping with HIV stigma, American military veterans living with HIV were interviewed regarding their experiences with stigma and discrimination when interacting with healthcare personnel. A convenience sample of 50 participants was recruited through the infectious disease units at three Veterans Administration (VA) hospitals in a large, Midwestern city in the United States. Participant recruitment entailed passive solicitation via handouts distributed on-site by infectious disease staff. Participants interested in taking part in the study contacted the primary investigator, who then scheduled them for either a focus group or one-on-one interview, depending on participants' preferences and availability. Participants received \$25 in remuneration for their involvement in either the focus group or the one-on-one interviews.

This study utilized a grounded theory approach during data collection, which involved reformulating and refining research questions as the study progressed to pursue promising lines of inquiry (Charmaz, 2002). This exploratory and hypotheses-generating process consisted of two stages. Stage one involved two semi-structured focus group interviews ( $n = 3$  and  $n = 5$ , respectively) regarding participants' experiences with stigma and discrimination by healthcare personnel; stage two involved one-on-one interviews ( $n = 42$ ) on the same topics. This two-tiered process was utilized to produce a data set that combined the synergy of focus groups with the depth of responses afforded by one-on-one interviews.

In stage one, the lead author led two focus groups through a semi-structured interview. The interview included questions regarding participants' experiences with the forms and effects of stigma and discrimination resulting from their HIV-positive status, including stigmatizing experiences with healthcare personnel. Follow-up questions were included, when appropriate, to clarify issues and validate the interviewer's interpretations of responses. These focus groups lasted 120 minutes each. Based upon the findings from these focus groups, a more refined set of questions was developed to explore the problems participants experienced with healthcare personnel. The revised interview

schedule was employed during stage two of the study, which involved the primary investigator conducting in-depth, one-on-one interviews with participants regarding their stigma experiences. These one-on-one interviews lasted between 45 and 230 minutes. Digital recordings of the focus groups and interviews were transcribed verbatim and distributed to each member of the research team for coding.

Both the focus group and one-on-one interview transcripts were analyzed using latent content and constant comparative techniques (Strauss & Corbin, 1990). The entire research team independently coded both the focus group and one-on-one interviews for focal themes and then convened to compare and compile their findings. Through consensus, the team constructed a detailed categorical system for describing the problematic communicative cues of healthcare personnel identified by HIV-positive clientele. Through this process, the research team codified an inventory of the ways in which participants experienced behaviors as stigmatizing and discriminatory when interacting with personnel in healthcare contexts.

### Results

A total of 50 participants, ranging in age from 24 to 70, with a mean age of 50 ( $SD = 8.9$ ), took part in either the focus groups or one-on-one interviews. Twenty-six (52%) participants identified as African American, 17 (34%) as Caucasian, four (8%) as Latino, one (2%) as Native American, and one (2%) as other. Thirty-four (68%) identified as heterosexual and 16 (32%) as gay or bisexual. During the time of this study, no female veterans were receiving HIV care through the VA centers at which the study was advertised; subsequently, all study participants were male. Participants possessed varying degrees of formal education, with six (12%) not having completed high school, 14 (28%) having completed high school, 20 (40%) having some college or technical/trade schooling, six (12%) having a bachelor's degree, and 4 (8%) having either master's or doctoral degrees. Participants also reported a variety of occupational employments, with 12 (24%)

fully employed, six (12%) unemployed, 26 (52%) on disability, five (10%) retired, and one (2%) a full-time student. Time since diagnosis varied from one to 23 years, with a mean time of 12.8 years ( $SD = 6$  years). Participants' viral loads ranged from less than 50 virons per ml<sup>3</sup> (undetectable viral load) to 206,000, with a mean viral load of 7,710 ( $SD = 29,666$ ). CD4 counts varied from 2 to 1500, with a mean of 441 ( $SD = 329$ ). Twenty-eight (56%) of the participants had previously received an AIDS clinical diagnosis, though many had responded well to antiretroviral therapies and currently maintained CD4 counts well above 200.

Although several participants reported only positive experiences with healthcare providers, in which HIV stigma was noticeably absent, others reported encountering suspicious or explicitly stigmatizing behaviors in a variety of healthcare settings and across a broad range of healthcare personnel. Any behavior patients interpreted as conveying discomfort, ignorance, fear, contempt, or exclusion was coded as problematic and potentially stigmatizing. These behaviors, organized and presented below, involve issues of demeanor, the provision of care, or combinations thereof. During interactions in which only stigmatizing demeanor was exhibited by healthcare personnel, treatment and other services were still perceived by patients to be fully and adequately provided. In contrast, stigmatizing interactions involving the provision of care entailed denial or disruption of appropriate services for patients. In many instances, descriptions of problematic care provision also entailed stigmatizing demeanor on the part of healthcare personnel.

### *Demeanor*

Participants identified a variety of interactions in which nonverbal cues from healthcare personnel sent ambiguous or explicitly problematic signals to patients. In particular, participants reported eye contact, proxemics (distance maintained between conversational partners), and paralanguage (vocal tone and inflection) as important indicators for interpreting others' feelings towards patients with HIV. The convergence of these nonverbals communicated what participants



identified as various forms of negative affect, including irritation or anger, nervousness, or fear of HIV-positive clientele.

*Eye contact.* Participants described being mindful of the amount of eye contact during healthcare interactions. In particular, a lack of eye contact on the part of healthcare personnel was interpreted as possible discomfort with or dislike of HIV-positive patients. One participant, Evan, describes such behavior during an encounter with a neurologist, who, he explained, "...never looked me in the eye. I still don't know what his face looks like, which is not a crime, [but it] sends unfriendly signals. Or at least, cold signals." Although participants could not quantify how much eye contact was appropriate and sufficient to alleviate their perceptions of stigma, those who described such events felt confident the eye contact given by the healthcare personnel in question fell far below conventional expectations.

*Paralanguage.* Participants also described a heightened sensitivity to the vocal tones with which healthcare personnel spoke to patients. Clipped, flat, or brusque tones, in particular, were identified as indicating potential unease, dislike, or disdain of the HIV-positive patient. For instance, Kobe described how the tone of voice with which a nurse delivered his AIDS diagnosis left him feeling alienated and dismissed. He explained

She made me feel low. It was just so callous and cold the way she said it. I think my viral load or CD4, one of 'em went below 200 and she said, "You have AIDS." And I said, "What?" The way she said, "Whenever you go below 200 you got AIDS." It was just the coldness in it-- there wasn't no feeling. It's almost like a stone-faced warden or something. No concern, you know? I was like, "Wow." I felt awful.

*Proxemics.* Similarly, participants also described using the distance personnel placed between themselves and clients, or proxemics, as an indicator of providers' comfort with HIV clientele. Standing or positioning one's self close to the patient, such as within arm's reach, was

considered a reassuring sign that the provider was unafraid of a person with HIV. Conversely, participants interpreted standing further away while interacting with a patient as an indication of fear or dislike on the part of the healthcare personnel. Participants reported encounters in which healthcare personnel maximized the space between themselves and their patients by doing such things as addressing them from across a room rather than approaching their bedsides. Gabriel described one such encounter, in which, “the doctor was young, foreign. Maybe he was a med student. He went to the other side of the other patient’s bed and talked loudly to me about having AIDS.” Similar encounters involved care providers conversing with patients from hallways rather than coming into close proximity, such as an experience described by Max, in which, “[the doctor] wouldn’t even come into the room.”

*Irritation/Anger.* Participants also identified specific affective states among healthcare personnel that HIV-positive patients may be prone to attribute to HIV stigma. For instance, when healthcare personnel expressed anger or irritation around HIV positive patients, participants described wondering if those negative emotions were due to the healthcare personnel having to deal directly (and unwillingly) with HIV-positive clientele. For instance, Tyler described having dealt with clerical staff who spoke to him in ways that he described as “standoffish.” He further explained, “you get that feeling, that standoffish feeling, from the support services-- from the clerks,” which he attributed to his HIV-positive status. These problematic demeanors sometimes involved healthcare personnel expressing more than mere irritation, including what patients interpreted as full-fledged anger. Jacob’s experience with an ambulance driver provides one such example, in which he attributed the driver’s negative emotions to her having to work with an HIV-positive patient:

One time, my brother was washing dishes in the house. He had this big ceramic bowl, and he dropped it. It bounced back and cut his wrists in a perfect football shape-- took the skin right off. He couldn’t have done a better job if he had a scalpel. He was

bleeding profusely. He called 911 and the ambulance came, but he forgot to tell them right away that he had HIV. When he remembered to tell them, this ambulance driver was so pissed! It just blew me away. She took her gloves off, which were extremely bloody, and just threw them out onto the street. Left them there. And she wasn't exactly nice to him after that.

*Nervousness/Fear.* Anger was not the only affective response participants attributed to HIV stigma, as participants saw such things as awkward glances, fidgeting, and agitated speech on the part of healthcare personnel as signs of nervousness around patients with HIV. Nervousness, though possibly attributable to a variety of factors, was credited to unreasonable fear of contagion when working with HIV-positive patients. For instance, Jerome described sensing a “nervous vibe” when seeking care from a dentist. He explained

The vibe that I got from him, the energy that I got from him, or at least, the demeanor that I got from him, was that he really didn't want to work on me or he wasn't comfortable working on me. And that was real disconcerting because I thought, “Where am I going to go to be able to get this done?”

*Panic.* Participants described inferring ignorance on the part of healthcare personnel when such events occurred. In particular, patients suspected that irrational fear of contagion and/or incomplete understanding of HIV's transmission routes were to blame for such behaviors. Sometimes this translated into care providers panicking when faced with the task of working with an HIV-positive patient. For instance, Roosevelt recounted an appointment with his dentist, who was informed of his patient's HIV status, but whose assistant was not. The assistant's reaction upon learning this information left a lasting impression with Roosevelt, who explained

As I'm sitting there and we're talking, and [the assistant] comes running over. I could tell it was a big emergency. He says, “Wait a minute!” and grabs the manila folder.

Because he's writing it so large, I can tell what he's writing across the front of this manila folder on the side that I can't see, and he's writing the word "AIDS!"

*Demeanor shifts.* Such nonverbal and affective cues were particularly salient to patients when they were preceded by warmer, friendlier interactions. Participants explained that such noticeable shifts in demeanor often occurred after the patients' HIV status was revealed. Ahmad described one such example of inconsistent nonverbal behavior, stating, "I went to this office and the lady asked what my disability was. When I told her, it seemed like her whole attitude changed." Carlos explained his perception of being judged during such encounters and his resulting frustration, stating:

It usually starts out with the front desk and the support staff, who are not educated. I mean, they should not care what I have, whether it's cancer, AIDS, or whatever. They should just be concerned that I get the best care I possibly can, you know? They have no right to make a judgment on me!

In several accounts of shifts in healthcare personnel's demeanor when dealing with HIV-positive patients, particularly when the shift involved anger, the patients failed at the onset of the encounter to inform the provider of their HIV status; however, patients during these encounters were often experiencing some form of duress, such as having been injured or suffering from another acute illness. Under these circumstances, Xavier explained how disclosing one's HIV status may not be on the patient's mind:

When you're in pain, that's not the first thing you're thinking about! That's not the first thing. When they picked me up, I was in pain and that was not the first thing I thought to tell them. It came to me a little bit later in the ambulance. But when you're in intense pain, HIV is not the first thing to come out of your mouth. They tell you it should be, but I was too focused on telling them where it hurt.

*Excessive precautions.* Perhaps due to these experiences of fearfulness among healthcare personnel, some participants described a heightened awareness of the safety precautions clinicians used when working with HIV-positive patients. In particular, they described being critical of what appeared to be excessive precautions or use of protective gear. For instance, Carlos described his trepidation over the protective gear his surgeons wore when they came to talk with him well in advance of his actual surgery. He recalled wondering the following questions:

Are the doctors dressed the way they're dressed because they're afraid they're going to get infected? They looked like they were ready for war. I mean, they had shields on-- it was like looking at Roman gladiators! They were completely hermetically sealed.

Jerome further explained the confusion HIV-positive patients feel when faced with such elaborate safety measures, by asking aloud, "Is this typical? Do they do this for everyone?" Unsure as to what constitutes standard procedure and what constitutes paranoid over-precaution, in the absence of explanation from care providers the patients were inclined to infer the latter.

*Differential precautions.* Another perceived problem regarding the use of protective gear involved clinicians using one set of precautions when working with some patients, then switching to other sets when working with HIV-positive patients. Although participants who witnessed such events applauded appropriate safety measures, they also felt the application of universal precautions when working with all types of patients would avoid the conspicuous altering of procedures that provokes suspicion and resentment from HIV-positive patients. Isaiah recounted one such situation when having his labs drawn by a phlebotomist:

Even today, there was a girl down there who took my blood. There was a guy in there before me whose blood she took—she didn't put on gloves. I never would have thought about that before, except I had somebody else there who had AIDS, who was

saying, “Oh that’s discrimination, because then they should do it [use consistent precautions] with everybody.”

*Labeling.* Another set of problematic encounters some participants linked to fear and ignorance involved how healthcare personnel labeled HIV-positive patients. Although disconcerting to patients, some labeling experiences described by participants may have been part of a standard procedure. Terrell described one such situation:

I was in the emergency room and they were taking some blood and I said, “You know, you need to put some gloves on, ‘cause I’m HIV positive.” The thing was, after that I was admitted to a room and I had signs on my door. ‘Biological fluid,’ ah, ‘caution,’ you know? It was terrible. It made me feel really dirty.

Other labeling events appeared more derogatory and designed to belittle HIV-positive patients. Some accounts given by participants involved healthcare personnel insisting on labeling patients according to a particular high-risk behavior group, such as injection drug users or men who have sex with men, even when the patient was adamant that he didn’t belong to one. Malik described dealing with one such nurse practitioner, stating:

She came in and she’s like, “Well, how’d you get it?” I said, “I don’t know.” She asked me about being in the risk categories, and I said, “Well, I wasn’t.” And then she said, “No, you’re just in denial. You had to have been. You don’t ‘just get it.’” I’m like, “Well, I…” I didn’t know. I was just thinking, going by those categories, I didn’t fit in any of them. It’s like, “no, I’m not in any of them.” And she’s like, “Well, yes you are.” And I’m like, “No, I’m not.” And it became real big confrontation.

*Scaring patients.* Another set of stigma-related behaviors patients attributed to ignorance or, potentially, cruelty on the part of healthcare personnel involved scaring patients with issues of

mortality. Participants reported a variety of encounters with assorted clinicians in which patients were told their lives were over or that they were lost causes because they were HIV-positive. Noah, for example, recounted how one physician responded in such a way immediately after his diagnosis. He stated, “I was like, ‘okay, what’s the next step?’ And the immunologist just went, ‘you’re gonna die.’” DeShawn described a similar encounter with a physician who sought him out one evening in his hospital room to seemingly taunt him with his diagnosis. He explained

This little, goofy, bearded guy, says, “You know you gonna die.” And he was a doctor. He said, “Do you know what kinda AIDS you got?” I said, “Yeah. I got the AIDS that you can’t cure.” He said, “Well, you know, you don’t got long to live.”

*Mocking patients.* In addition to healthcare personnel scaring patients, participants also described being the targets of outright contempt and ridicule by a variety of healthcare personnel. Participants described these various forms of mockery and contempt as explicit expressions of HIV-stigma, which were performed by a host of healthcare personnel ranging from desk receptionists to attending physicians. Evan provided one such example, in which he explained

I had a negative thing from a dentist. He was gonna pull a tooth and he gave this sort of smug, superiority thing about “I’ve got HIV.” A smirk was part of it. He said, “So, how did you catch it?” Now for a lot of people, that’s gay sex. That shouldn’t be any of his business. The smirk told me as much as his question. Now I can’t be sure-- I think I got it from an unclean hypodermic needle, but it’s none of his business.

*Blaming patients.* Coupled with these contemptuous episodes, participants described a host of encounters in which healthcare personnel openly blamed patients for their HIV infection. Participants described feeling shamed during these episodes, even if they had contracted HIV simply while “living their lives.” Cedric described one such encounter with a phlebotomist as follows:

I had one blood draw-- she had a hard time drawing my blood. She got really angry and aggravated about it. She kept poking me and I told her it hurt, "it's hurting," you know? And she said, "If you hadn't of done this to yourself, we wouldn't have to be going through this!"

In summary, participants reported being sensitive to healthcare personnel's demeanor, which patients used to determine other's comfort and attitude towards HIV-positive patients. Nonverbal cues such as proxemics, vocal tones, and eye contact, in particular, were used to infer irritation, anger, nervousness, or discomfort among healthcare personnel when working with HIV-positive clientele. Participants were especially mindful of shifts in healthcare personnel's attitudes after one's HIV-status was revealed. Similarly, labeling patients and inconsistent or excessive use of safety precautions when working with HIV-positive clientele were each interpreted as indicative of HIV stigma. Although participants reported feeling resentful and unsatisfied after such encounters with healthcare personnel, they noted that such behaviors did not necessarily impede the delivery of sufficient and effective healthcare. In other words, they often felt their healthcare was not compromised, despite the misgivings and stigmatizing demeanors of healthcare personnel during these interactions. Unfortunately, stigmatizing behaviors exhibited by healthcare personnel did not always have such benign results, as demonstrated in the following section.

#### *Care Provision*

Although fearful and/or demeaning behaviors from healthcare personnel made for unpleasant and upsetting interactions for clients, participants also described encountering a variety of stigmatizing behaviors that far exceeded funny looks or verbal ridicule and included actions that impaired or even prevented patients' utilization of healthcare. These encounters ranged from healthcare personnel ignoring patients or denying services, up to and including the physical abuse of HIV-positive patients. Unlike facets of demeanor, which participants admitted were sometimes



ambiguous and potentially attributable to issues other than HIV stigma, events in which healthcare provision was impaired left little doubt in the minds of those affected that such experiences were rooted in bias and discrimination.

*Ignoring patients.* One behavior patients felt was clearly due to HIV stigma and impaired their healthcare involved healthcare personnel ignoring HIV patients, even when patients were in great need. Participants ascribed contempt or fear on the part of healthcare personnel during such events, which left patients not only in distress, but also angry and resentful of the care they received. Gabriel described one such encounter, in which a physician refused to respond to him, even when being directly addressed:

I was here for a week and there was a doctor who was attending. He came in my room-- he didn't say a word to me. When I caught his attention, it was as if I hadn't said anything! Yeah, I felt that was derogatory about my [HIV] status. I recall that because it actually prompted me to make a formal complaint. I went to the patient advocate and explained what had happened because he was the doctor, he was outside my door, I needed something-- I was trying to call his attention and he didn't respond!

*Sub-standard care.* Patients also recounted instances in which they received other forms of sub-standard care, ranging from healthcare personnel spending inadequate time on a patient's needs to leaving patients in pain. Jack, who reported a number of such events when seeking dental care, described a facility where he had consistently been provided inadequate care, despite the fact that he was paying full price for such services. He explained

I tell [the hygienist] I'm having problems with one tooth causing pain. The hygienist says, "ok" and two months later when I come back in I said, "you know, the pain-- it's still there and, if anything, a little worse." She calls the dentist in and the dentist

says, “Well, you’re so hard to anesthetize that we don’t, we can’t do a thorough cleaning on you. And,” he says, “in *your condition...*” You know? And I just want to turn and slug him! I’m paying you your regular prices every three months to make sure I don’t get cavities and you’re telling me you aren’t going to anesthetize me because I’m too hard and it really doesn’t matter because of *my condition?*”

Not only did Jack experience these events, he saw others deal with similar treatment. As a result, he had come to view HIV stigma and poor quality of care as essentially indistinguishable. He explained

It’s gotten to the point that the last time I was at the clinic, which I was in this week, they had a patient they wanted to pull a tooth for and couldn’t get the tooth all the way out. Instead of immediately calling Big University Hospital and getting him in, they told the patient to go home and to come back at 9:00am [the next day] as an emergency patient when the clinic opened. So there is a patient with a tooth half-pulled, in pain, and this is an HIV clinic treating an HIV-patient. So is there still a stigma? I consider that a stigma. I try to differentiate stigma and the quality of the medical care that is being given to [us], but I can’t differentiate the two anymore. They are so thoroughly entwined that everyone I know kind of expects that, as an HIV person, we’re going to get lower quality healthcare in all areas, but in dental it’s extreme.

*Denied care.* At times, participants reported being denied even substandard care because of their HIV-positive status. For instance, some reported encounters in which healthcare personnel, apparently uncomfortable with HIV-positive clientele, attempted to redirect such patients to alternative sites of care rather than provide any services themselves. For instance, Ahmad explained that after learning he had come in search of HIV services, the care provider with whom he was speaking tried to send him away to clinics in other parts of the city. In particular, he explained,

“What she did was start telling me, steering me toward other places to go and ask for the same help that they give, you know?”

Some provision of care or redirection to other helpful services is, at least, better than being fully rejected outright and denied services altogether. For some participants, such as Jack, this occurred due to the inability to find providers willing to take on HIV-positive clients. He explained, “There were years when even my private doctor didn’t know of a doctor in the entire city that would treat an [individual with] HIV.” Similar accounts were provided by participants, who described both clinical and non-clinical healthcare personnel refusing to provide services to patients living with HIV. In clinical contexts, for instance, Eric mused, “I’ve had a couple of incidents where a nurse or a phlebotomist didn’t want to draw blood because it was clear to her that she was drawing for a CD-4 count.” Similarly, he explained

One time I went to a county hospital to have a tooth pulled. I guess the dentist was a student or an intern or whatever. He refused to do it once he realized I was HIV-positive. They had to send for another doctor.

Clinicians, however, were not the only healthcare personnel described as refusing to provide services to HIV-positive clientele. Such behaviors also were exhibited by a variety of non-clinicians, including receptionists, administrative staff, and custodial staff. Evan described one such case, explaining:

I was an inpatient at Big University Hospital and I don’t know what they put on the door of the room, but a woman who would normally come in and mop up and sweep, wouldn’t. It was really wild, with her shrieking, “I ain’t goin’ in there!”

*Abusive treatment.* Perhaps the most blatant and potentially dangerous experiences with stigma reported by participants involved some form of abuse at the hands of healthcare personnel. Certain abusive events involved malignment, in which healthcare personnel strategically defamed

HIV-positive patients to other healthcare personnel, potentially ensuring these patients received less favorable treatment from these other staff members. One such instance was described by David, who explained:

I was treated like garbage. I don't know the lady's name, I could only go and look for her and see her and say, "that's her," but I couldn't say her name because I was so drugged out. She treated me like crap. She called the police on me and said I was abusive. I couldn't even move, but she said I was abusive. And she called the floor that I was gonna be admitted to and said that I was abusive, that they'd better watch themselves because I'm being abusive and she doesn't want to get next to me and get scratched, because she may get "the same thing." She didn't think I was listening and she didn't think I understood what she what she meant by that, but I did.

Finally, patients reported acts of physical abuse perpetrated against them by various healthcare personnel, attributing each of these events to their HIV status. This included patients being pummeled or put into situations in which they were likely to be hurt. David, who had endured maltreatment by a nurse in a previous encounter, also described being physically mistreated by paramedics. He explained:

Being rushed to the hospital a few times I've dealt with paramedics. I'm epileptic; I have seizures. When the paramedics do pick me up, they manhandle me. In other words, they treat me bad... Once they ask whoever's called the ambulance that knows my history, who tells'em I'm HIV-positive, they start thrashing me around. The only part they're careful of is putting in a line in my vein because they don't want to get sick. I mean, the paramedics are cruel and I prefer not to be handled by them at all. Just let me die. If I'm gonna die, let me die, but don't, don't call the ambulance. That's how bad they are.

In summary, participants described a number of stigmatizing experiences at the hands of healthcare personnel that compromised the quality and effectiveness of the healthcare patients received. This included ignoring patient needs, providing insufficient and sub-standard healthcare to HIV-positive patients, denying and refusing to provide healthcare services to these patients, and abusing HIV-positive patients, which ranged from malignment to physical abuse. Participants explained that stigmatizing events that impaired the provision of healthcare could also entail problematic demeanor, such as mocking, being angry at having to work with HIV-positive patients, and the like.

### Discussion

In this study participants reported being mindful of healthcare personnel's behaviors and sensitive to any communicative cue that may indicate bias or stigma towards HIV-positive patients. Participants reported encountering what they perceived to be expressions of HIV stigma in a variety of healthcare environments and performed by a broad range of healthcare personnel. Such encounters took place in ambulances, doctor's offices, dental care facilities, in-patient hospital rooms, and the common areas of hospitals, such as hallways and reception desks. Communicative cues identified as stigmatizing by participants included such things as awkward or nervous nonverbal behaviors, excessive safety precautions, avoidance, refusal to provide care, as well as the expression of anger towards and even abuse of HIV-positive patients. These findings extend previous research on HIV stigma in healthcare settings by (a) focusing on healthcare personnel's actual behaviors rather than their attitudes and beliefs about HIV-positive patients, (b) including patients' perceptions of both clinical and non-clinical healthcare personnel, and (c) identifying potentially stigmatizing behaviors that are unique to healthcare contexts.

These results complement and expand upon earlier findings that reveal some healthcare personnel are reluctant to interact with HIV-positive patients (Chapman, 2002; McCann, 1999). This

aversion to interacting with individuals who have HIV is especially troubling in light of evidence that being touched and being checked upon signals high quality of care to patients (Cederfjall & Wredling, 1999; Kermode, 1995). In fact, egalitarian treatment of patients, regardless of HIV status, has been linked to patients' perceptions of higher quality of care (Surlis & Hyde, 2001). Because individuals with HIV wish to be touched, cared for, and treated like any other patients, healthcare personnel's apprehensiveness could affect patients' confidence in and evaluations of a care provider's competence or the quality of care being provided.

In addition to fearful and aversive behaviors, participants also described feeling disdain, contempt, and even anger directed towards them from various healthcare personnel. Sensing dislike from care providers has special significance for patients' perceptions of the quality of care they receive, as well as their likeliness to trust or return to their care providers (Fiscella et al., 2004; Rowland, Coe, Burchard, & Pricolo, 2005; Topacoglu et al., 2004). However, patients reported experiencing far more than covert affect, including events in which healthcare personnel openly mocked or blamed them for their HIV status, unfairly labeled them or maligned them to other healthcare personnel, and even physically abused HIV-positive patients. Although violence directed towards people living with HIV has been reported in earlier HIV research, it has been discussed almost exclusively in the context of romantic relationships (Craft & Serovich, 2005; Liebschutz et al., 2005). What's more, these findings reveal a frightening dilemma, in which seeking healthcare may, in some cases, actually place HIV-positive patients' health and safety at risk.

Although such things as nervous nonverbal cues or even physical violence towards people living with HIV may also occur in other social contexts, these behaviors have special significance coming from those upon whom one must depend for healthcare. What's more, some of these behaviors are unique to healthcare contexts, such as care providers using differential or excessive protective gear when working with HIV-positive clientele. Regardless, it may be tempting to dismiss

such things as problems of the past, claiming that advances in education on HIV have eradicated these problems; however, it is noteworthy that participants described such events occurring within weeks or even days of their interviews, making these findings both timely and relevant.

Clinicians, such as physicians and nurses, should now understand the true risks involved in working with HIV-positive patients and not succumb to irrational fears of contagion; however, participants recounted problematic events occurring with both sets of clinicians within the year preceding the interviews. Although other care providers, such as laboratory technicians, emergency medical technicians, and dentists may not have received sufficient training and education regarding HIV earlier in the epidemic, this should no longer be the case. Yet, participants reported recent problems with these care providers, as well.

Although stigmatizing behaviors among clinical healthcare personnel are surprising, perhaps it should not be that participants reported encountering such behaviors among non-clinical personnel, such as custodians and administrative staff. These individuals receive little (if any) training on the biomedical aspects of HIV and may be prone to relying on knowledge they have acquired about the disease during their daily lives. Given the rampant misinformation and stereotyping of HIV still prevalent in the lay population (e.g., Herek et al., 2002), encounters with non-clinical personnel reluctant to interact with or even clean the rooms of HIV patients may be a more common problem than currently is realized.

These findings suggest that additional outreach and continuing education is required among healthcare providers and other personnel not only regarding HIV, but also regarding the impact of their behaviors on patients. Those behaviors identified in this study as problematic from patients' perspectives should be avoided or, when a necessary component of care, further explained by healthcare personnel, as they may be interpreted as discriminatory or stigmatizing by patients with HIV. This is especially important given that HIV-positive patients may sometimes identify innocent

or unintentional actions as stigmatizing (Chapman, 2002; Frable et al., 1990). Being mindful of these issues may foster the image that healthcare personnel are knowledgeable about the disease and want to provide patients with the best care possible. Failing to do so may not only impair provider-patient relations, but conceivably could lead patients to avoid healthcare in the future. What's more, failure to avoid these behaviors may increase the likelihood of legal action taken against care providers and the facilities in which they are employed, given the correlation between lawsuits and patients who are dissatisfied with or take offense to their care providers (Levinson et al., 1997).

This study raises important questions about both the perception and prevalence of stigmatizing behaviors in healthcare contexts in general, but also in certain contexts, in particular. For instance, HIV stigma in the practice of dentistry has received little attention in the research literature but was the source of considerable frustration and anxiety for a variety of participants in this study. Understanding of this problem can be enhanced by research that explores dentists' perceptions of HIV, its etiology, and transmission. Also, additional research must focus on these problems among other healthcare personnel that have, to date, received little to no attention in the HIV stigma literature. Such research could also couple attitudes or behavioral intentions of healthcare personnel with their actual performance, rather than concentrating solely on the antecedents to stigmatizing behaviors or the behaviors, themselves. Such research may even explore distinctions between provider perceptions of encounters and the perceptions of their patients, in order to identify discrepancies in what providers and patients consider appropriate or stigmatizing.

Although identification of problematic communicative cues is an important step in disarming the heightened sensitivity and anxiety patients may have about being stigmatized, knowing what behaviors send positive, reassuring signals to HIV-positive patients is of equal significance. Identification and performance of these more positive behaviors has the potential to further enhance care providers' work and inspire patients' confidence in the care they receive. Therefore, future



research should explore forms of proactive behaviors healthcare personnel can employ to generate this amity.

This study also raises questions regarding the role of stigma in the healthcare provision of other illnesses. All illness is stigmatized, though the reasons for and degree of stigmatization differ depending upon illness context (Parsons, 1951; Vash, 1981). As such, research efforts should focus on better identifying the forms and functions of stigmatizing behaviors among healthcare personnel attending to people living with other highly stigmatized illnesses.

Finally, it is worth noting how the methods used in this study are excellent for identifying the forms and functions of stigma experienced by HIV-positive patients in healthcare settings, but are unable to explain the frequency of these experiences or the magnitude of their effects on patient outcomes, such as healthcare satisfaction and likelihood of future healthcare utilization. Subsequent research is therefore needed to further explore the prevalence and effects of these events. In addition, this study was based on interviews with a sample of only 50 participants, all of whom were male and currently seeking treatment through Veteran's Administration hospitals. This serves as the foundation for similar work that explores and contrasts differences between male and female experiences with HIV stigma in healthcare contexts, as men may be subjected to some forms of stigma that differ from those experienced by women living with HIV.

### Conclusion

Participants described a variety of behaviors performed by healthcare personnel that they perceived to be indicative of HIV stigma, ranging from ambiguous nonverbal cues, such as minimal eye contact, to blatant discrimination, such as physical abuse of HIV-positive patients. These findings offer healthcare personnel a tangible list of behaviors that should be either avoided or further explained to HIV-positive patients, as they may be interpreted as stigmatizing. Also, this study reveals that patients are sensitive to such behaviors being performed by a variety of healthcare

personnel, indicating the need for all such personnel to be mindful of their actions with these patients. Further research is needed to identify the prevalence of such behaviors and their effects on HIV-positive patients.

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