

“You’re Awfully Old to Have *This* Disease”: Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS

Charles A. Emler, PhD, MSW¹

Purpose: Older adults living with HIV infection may be doubly stigmatized, as they are branded by both age as well as HIV status. Through semistructured interviews, this study sought to examine whether older adults with HIV/AIDS experience both ageism and HIV stigma and how those experiences manifest in their lives. **Design and Methods:** This was a qualitative study in which 25 in-depth interviews were completed with adults aged 50 years and older who were living with HIV or AIDS. Purposive sampling was used to recruit these individuals who shared their experiences. Open coding and axial coding of interview transcripts were completed on all interviews, resulting in the development of a framework of these experiences. **Results:** The majority (68%) of the respondents experienced both ageism and HIV-associated stigma. The experiences were often separate, although some interrelated stigma did occur. Nine themes emerged from the interviews, including rejection, stereotyping, fear of contagion, violations of confidentiality, and internalized ageism. All themes fell into four categories: social discrimination, institutional discrimination, anticipatory stigma, and other. **Implications:** The research identified themes that may be sources of felt as well as enacted stigma and discrimination related to both aging and HIV. This concept of double jeopardy exists in the lives of the majority of people interviewed and has relevance to the creation of appropriate intervention strategies.

Key Words: Ageism, Discrimination, HIV/AIDS, Qualitative methods, Stigma

HIV/AIDS has been traditionally seen as a disease of younger people (Riley, 1989). The advent of highly active antiretroviral therapies, however, has extended survival and allows individuals to live into “old age.” Therefore, not only will some older adults become newly infected with HIV, but the numbers of long-term survivors will continue to increase. Surveillance data from the Centers for Disease Control and Prevention (CDC) reflect these trends. The estimated number of individuals aged 50 years and older who are living with AIDS in the United States increased from 59,649 to 112,447 between 2000 and 2004 (CDC, 2005). Cities, which are considered epicenters in the epidemic, are reporting increasing numbers of older adults with HIV/AIDS. In New York City, for example, approximately 30% of the reported individuals living with HIV/AIDS are 50 years of age or older (New York City Department of Health and Mental Hygiene, 2005). Uranga (2005) reported that more than 25% of the people living with AIDS in Los Angeles County are 50 years of age or older. Sociocultural factors including age, gender, and race or ethnicity as well as individual factors such as substance use and mental health issues have been found to increase the risk of HIV infection in older adults (Neundorfer, Harris, Britton, & Lynch, 2005).

Stigma and Discrimination

Although we are in the third decade of the epidemic, people living with HIV/AIDS continue to experience stigma. In his classic work *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) defined stigma as attributes “that are deeply discrediting” (p. 3). With this definition in mind, Orel, Spence, and Steele (2005) suggest that older adults living with HIV/AIDS face two primary

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Address correspondence to Charles A. Emler, PhD, University of Washington, Tacoma, 1900 Commerce Street, Tacoma, WA 98402. E-mail: caemler@u.washington.edu

¹University of Washington, Tacoma.

sources of stigma: that related to AIDS, and that related to ageism. Furthermore, Sheets (2005) suggests that people who are old with a disability (including HIV/AIDS) are at *double jeopardy* of experiencing prejudice and discrimination. What the gerontological literature and HIV literature lack is an examination of these two stigmatizing conditions in concert. Do older adults living with HIV/AIDS experience both ageism and HIV stigma? What are the connective experiences? To date, the literature has given us only glimpses into these phenomena, primarily through anecdotal accounts and case studies. A small number of studies have explored these issues, but the issues have yet to be examined together. In my literature review I could not identify one study that examined both ageism and HIV stigma in older adults simultaneously. My purpose in this article is to provide, through a qualitative analysis of 25 semistructured interviews, an account of how HIV stigma and ageism manifest in the lives of older adults with HIV/AIDS. Before I discuss the study, however, I define these two constructs and discuss what we do know about their impact on older people.

HIV Stigma

HIV stigma has been defined as prejudice, discrediting, and discrimination directed at people perceived to have HIV or AIDS (Herek, Mitnick, & Burris, 1998). HIV stigma is a multidimensional construct and may be enacted or felt (Green & Platt, 1997). *Enacted* stigma refers to individually or collectively applied sanctions such as discrimination or prejudice, whereas *felt* stigma relates to feelings of shame or guilt and the oppressive fear of enacted stigma. Although there has been some decline in HIV-related stigma, a substantial portion of individuals in the general population still hold stigmatizing beliefs. In a study of HIV-related stigma using a nationally representative sample of U.S. households, Herek, Capitanio, and Widaman (2002) found that although overt expressions of stigma declined in the 1990s, one fifth of the people surveyed still fear individuals living with AIDS and one sixth expressed disgust or supported name reporting of individuals with HIV. One fourth of the respondents still felt uncomfortable having direct or symbolic contact with individuals living with AIDS.

Our understanding of HIV stigma in older adults is limited by the fact that stigma research has typically not included older adults (Bennett, 1990; Clark, Lindner, Armistead, & Austin, 2003; Green & Platt, 1997; Laryea & Gien, 1993; Lee et al., 2005; Surlis & Hyde, 2001). Other studies on HIV stigma have neglected age as a variable in the analysis (Crandall & Coleman, 1992; Varas-Díaz, Serrano-García, & Toro-Alfonso, 2005; Weitz, 1990). However, a small number of studies have examined various aspects

of HIV stigma in older adults. Heckman, Kochman, and Sikkema (2002) studied 83 adults over the age of 50 with HIV/AIDS, and they found stigma associated with cognitive affective symptoms of depression, similar to younger adults. Lee, Kochman, and Sikkema (2002) examined internalized stigma in 268 HIV-infected men and women, including older adults, and found no significant difference in age between those with high and low levels of internalized stigma. In a recent study of 44 older and 44 younger adults with HIV/AIDS, Emler (2006) found that 50% of older adults reported they were ashamed of their illness sometimes or often, and 39% stated they had lost friends as a result of their illness. Younger adults reported similar feelings. Although it is questionable whether older adults experience greater levels of HIV stigma than their younger counterparts, stigma continues to be a formidable psychosocial issue for older adults with HIV infection.

Ageism

Ageism has been defined as a negative attitude toward aging based on the belief that ageing “makes people unattractive, unintelligent, asexual, unemployable, and mentally incompetent” (Atchley & Barusch, 2004, p. 439). Ageism permeates our culture through media, language, and values and is composed of prejudice, beliefs, and attitudes as well as discriminatory practices (Wilkinson & Ferraro, 2002). Levy (2001) suggests that after a lifetime of exposure to ageist stereotypes, older adults direct such stereotypes inward, employing what Levy and Banaji (2002) refer to as implicit ageism, in which ageist beliefs operate “outside the purview of conscious awareness, control, and intention” (p. 52). A very small number of studies have explored ageism among older adults with HIV/AIDS.

In a qualitative study of 63 older adults living with HIV/AIDS, Siegel, Raveis, and Karus (1998) identified numerous experiences that could be considered examples of ageism. Respondents reported feeling that they received less compassion and sympathy than their younger counterparts, felt blamed and judged more harshly, and felt medical providers were more highly motivated to help restore younger adults to optimal health. In a reanalysis of those same interviews, Schrimshaw and Siegel (2003) discussed how gay men in this sample communicated the emphasis on youth and vitality in the gay community. Nichols and colleagues (2002) reported that HIV service providers in Florida identified ageism and stigma as barriers to HIV prevention and education efforts aimed at the older, African American population. Similarly, Neundorfer and colleagues (2005) noted the lack of appropriate HIV-prevention messages for older women as a factor in HIV risk. This lack of focus on older adults as being at risk for HIV suggests

ageist assumptions concerning age, behavior, and sexuality.

Sheets (2005) suggested that older adults with disabilities are “ostracized, feared, hidden and stripped of power” (p. 38). Those living with HIV/AIDS may experience an amplification of those practices. We do know that both ageism and HIV-related stigma share common characteristics and similarities in definitions. It is time to examine these stigmatizing experiences together.

Methods

All study procedures were approved by the University of Washington Institutional Review Board for this study alone. I recruited participants from the local AIDS service organization, county public health clinics, infectious disease clinics, and medical centers in an urban county in the Pacific Northwest. I used purposive sampling techniques because of the relatively small number of potential participants. I chose the age criteria of 50 years of age and older because there was historical precedent (Poindexter & Emler, 2006) resulting from the stratification of age by the CDC in the early years of the pandemic. From that historical precedent emerged the commonly used definition of *older adults* as adults who are 50 years of age and older as related to HIV/AIDS; in fact, the national organization focusing on HIV/AIDS and aging is known as the National Association on HIV Over Fifty. All potential participants who were successfully contacted agreed to participate.

Staff members from participating agencies identified potential informants and briefly described the study; those interested were linked to me, the Principal Investigator. At the initial Principal Investigator appointment, I described the study in detail, and participants signed informed consent forms. I told participants that the interview would be audiotaped with their approval. No participants refused being recorded. I conducted semistructured interviews, which lasted between 1 and 2 hours, with all participants, and I gave participants compensation in the form of a \$25 payment. I interviewed participants at the local AIDS service organization, my office, or their home. Interviews in public places were discouraged because of sensitivity and confidentiality issues, as well as the potential for disruptive background noise. I interviewed all participants between November 2003 and December 2004.

Measures and Interview

Participants provided information on sociodemographic characteristics, including age, gender, race and ethnicity, education, income, employment status, Medicaid eligibility, and HIV diagnosis (HIV vs AIDS). In addition, I asked participants to supply

a pseudonym (used throughout this document) that would be used for the remainder of the interview. This procedure ensured confidentiality while personalizing conversations and subsequent reporting of qualitative data. A semistructured interview consisted of two open-ended questions:

1. Could you tell me about a time that you felt discriminated against or mistreated because of being older or having HIV disease?
2. What do you think society should know about being older and having HIV disease?

Analytical Methods

Assistants transcribed the audiotapes of each completed interview verbatim. A research assistant and I then reviewed the written transcripts for accuracy. After we reviewed each transcript, I undertook a process of open coding. Open coding is designed to “open up the text and expose thoughts, ideas, and meanings contained therein” (Strauss & Corbin, 1998, p. 102). Lowenberg (1993) suggests that, in qualitative research, the meaning is constructed and negotiated during the interaction between researcher and informant. The researcher is therefore “a participant in creating meaning and analysis” (Lowenberg, 1997, p. 451). Although it may be ideal from some vantage points to have multiple individuals do the coding, Lowenberg posits that the meaning lies in the interaction between researcher and informant.

Initially, I open coded the data for Question 1 line by line, with the interviewee’s comments broken down into specific concepts relevant to ageism, stigma, or discrimination. This process produced a total of 107 relevant codes, which included researcher-labeled as well as in vivo codes taken directly from the language of respondents. I used the constant comparative method (Strauss & Corbin, 1998) to identify variations within those concepts and to identify broader categories of phenomena. For example, whereas I identified codes such as *other* or *ostracized*, in vivo codes such as *invisible* or *feeling radioactive* ultimately converged into broader concepts of rejection or feeling *other*. From the iterative process of constant comparison, all open codes fell into two distinct areas: (a) experiences of stigma and ageism that involved others (social) and (b) those that were predominately intrapersonal. Additional theoretical comparisons revealed that social and individual experiences of stigma were common to all respondents. Through the process of rereading all 25 transcripts and examining the codes in relation to the model, I obtained theoretical saturation (Glaser & Strauss, 1967). I used a similar process for Question 2. I used line-by-line open coding to identify consistent themes that emerged in the interviews. In this instance,

Table 1. Participant Characteristics (N = 25)

Variable	N (% or M ± SD)
Age (years)	50–72 (56.1 ± 5.75)
Gender	
Male	17 (68)
Female	8 (32)
Race or ethnicity	
White	15 (60)
African American	9 (36)
Non-White Hispanic	1 (4)
Living arrangements	
Alone	13 (56)
With family of origin	4 (16)
With partner or spouse	7 (28)
HIV exposure	
Men having sex with men	9 (36)
Heterosexual intercourse	9 (36)
Injection drug use	4 (16)
Unknown	2 (8)
Contaminated blood products	1 (4)
Education	7–17 (12.9 ± 2.6)
Diagnosis	
AIDS	19 (76)
HIV	6 (24)

Note: SD = standard deviation.

however, I identified no a priori themes; rather, I considered any potential patterns concerning the question. I then further examined those four themes that were consistently identified by the informants.

The final step in the analysis involved the use of HyperRESEARCH 2.6, a qualitative software package. Qualitative analysis software allows for the compact storage of transcription materials (Drisko, 2004), and HyperRESEARCH specifically assists with the coding of text, the retrieval of coded text, categorization, and the statistical analysis of frequency of code occurrence (Hesse-Biber & Dupuis, 2000). I entered all 25 transcripts into HyperRESEARCH after I manually completed the process of coding. The process of first examining data manually has been referred to as “preening the data” and has the benefit of obligating the researcher to “in-depth involvement with the data” (Drisko, p. 193). I then used the software as a data-management tool to determine the frequency of codes and for the retrieval of qualitative material related to specific codes.

Results

Sample Description

Table 1 provides data on the 25 participants, who ranged in age from 50 to 72 years ($M = 56.1$, $SD = 5.75$). The majority of individuals (68%) were male and 40% were people of color. All but one of the non-White participants was African American.

Participants had an average of 12.9 years of education. Six participants (24%) had no educational degree, 15 (60%) had completed high school, and 4 (16%) held a college degree or higher. The majority of the participants (72%) were retired; 56% lived alone. Twenty-eight percent lived with a partner or spouse and, of those, the length of cohabitation varied dramatically from 1 to 47 years. The vast majority of participants, 76%, had met criteria for an AIDS diagnosis (CDC, 1993); 60% had been on Medicaid in the past year. Nine participants (36%) had been exposed to HIV through men having sex with men and the same number identified heterosexual intercourse as their exposure risk. Four individuals were infected through injection drug use and one individual was exposed through contaminated blood products. Two had an unknown risk factor.

Qualitative Results

The qualitative interviews revealed that 17 individuals (68%) had combined experiences of ageism and HIV stigma. Of the 8 remaining individuals, 7 had experienced HIV-related stigma but not ageism. These individuals were in their early 50s, and they can be considered late-middle-aged adults by many standards. Jim, aged 64, was the only individual interviewed who had voiced experiences of ageism without HIV stigma. (Jim practices sexual abstinence and lives a very insular life with a very small network of friends). This double-jeopardy experience appears to cut across race, gender, and sexual orientation. Racial background did not appear to shape the experiences of ageism and HIV stigma among these individuals.

The qualitative analysis related to Question 1 is depicted in the Venn diagram shown in Figure 1. The experiences of ageism and HIV stigma, although often distinct, have some overlapping characteristics. In addition, the findings support the previous theory that stigma, regardless of discrediting condition, can come through social exchange (self–other) or be an intrapersonal (self–self) response. A description of the major themes follows.

Ageism–HIV Stigma Intersection

Although many of the discrediting experiences of these individuals were clearly related to ageism or HIV stigma, a number of experiences overlapped; this suggests an intersection of these two phenomena. As seen in the intersecting portion of the Venn diagram, these themes included rejection, stereotyping, and feeling separate or alone.

Rejection.—Rejection caused by having HIV disease was a unifying experience, found in the majority of those interviewed. The sources of rejection varied from service providers, friends, family, and church

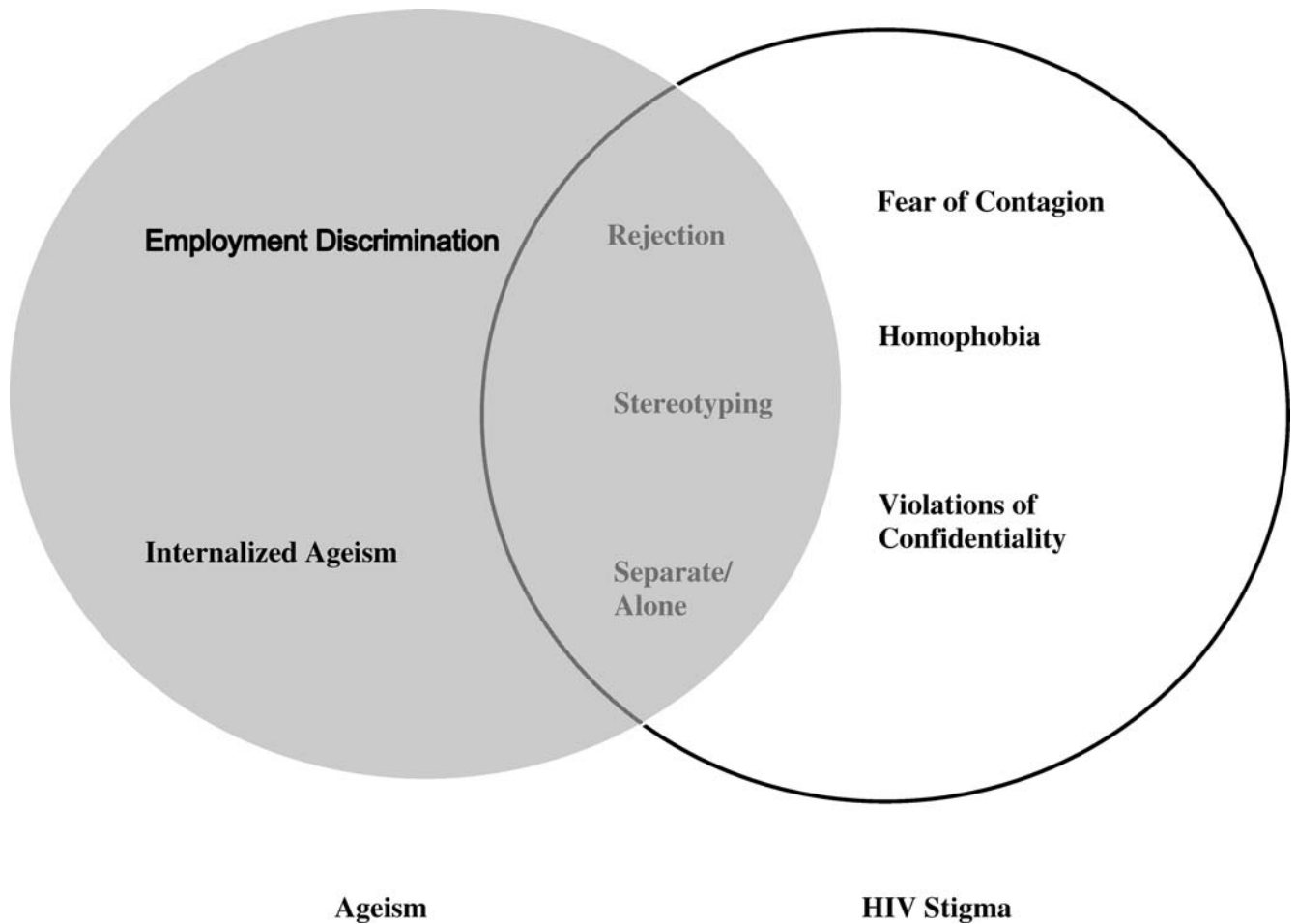


Figure 1. Venn diagram depicting separate as well as intersection elements of ageism and HIV stigma.

members to potential sexual partners. For example, Taleef talked about the rejection he felt as the only person with HIV living in a senior community.

The staff, when they found out I had HIV they really stayed away from me. They didn't pay me any attention as they did the other seniors that were there. This stuff is everlasting, you're treated differently you know. You feel like you're outcast.

Paul recounts rejection by his religious community;

It'd gotten around the church that I'm HIV positive. I find myself sitting and eating a piece of cake and drinking punch on one whole aisle of chairs by myself, no one sitting next to me, no one wanting to talk to me.

Cricket was rejected by her family. "My brothers found out and they was just like distanced from me for awhile . . . I'd say for about three years." Several respondents discussed the rejection from potential sexual partners. Steve shared, "if I meet a girl or something and I want to be close to her, then I would have to tell her. She'll usually say forget it."

Rejection by others was associated not only with

HIV status but included rejection based on age. This appeared to be a particularly common experience of older, gay men. Terry shared, "I think most of the time they [younger men] want to deal with their own people, their own age group, you know, you feel like an outcast when you're a little bit older." George spoke eloquently about feeling rejected by younger men in his community: "when you are older, you're not as attractive as when you're younger." He went on to comment "yeah, ageism, it's a far mightier sword than HIV." Numerous individuals discussed experiences of social rejection based on age, running the gamut from name-calling and victimization to lowered social expectations. Taisong recalled being called a derogatory name during an altercation in her neighborhood. "There was a fight out in the parking lot and one of the guys was saying to somebody 'that old lady is going to call the cops.'" Eric commented about society as a whole. "People expect less of you, of what you are able to do, of what your feelings are, what your capabilities are." Similarly, Bob said, "I don't think I have as much expected of me."

Stereotyping.—Another form of social discrimination was being stereotyped by others. The stereotyping involved attitudes about aging and sexuality

or assumptions about how one becomes infected with HIV. It was common for respondents to report ageist interactions with others. It is interesting to note that interviewees did not initially identify these behaviors as ageism, yet ageist stereotypes and assumptions clearly emerged in the analysis. These social interactions involved assumptions about lifestyle and were often related to sexuality. Some respondents spoke of how society expects older people to be more knowledgeable about the disease simply because they are older. Christa said, "In some cases I believe older people are held to a different standard that, well, for crying out loud, you should have know better." At the same time, multiple participants experienced society's puritanical beliefs about age and sex. Christa continued, "Doctors would not even have looked at you as being likely to have HIV even if they saw the same symptoms." Juanita simply put it, "The fact we [are] 50, we're old and somebody's grandma, it can't be you." Wayne shared, "there's a lot of people that go—'you're awfully old to have this disease.'" Several respondents spoke of societal stereotypes and assumptions based on age. Paul, whose life partner is considerably younger, spoke of instances in which younger gay men attempted to convince his partner that Paul was too old. He shared one instance in which his partner was told the following:

He's going to be old and he'll get sick and he'll be in the hospital and, you know what that will do to you. You should really be with me. I'm younger and we can have a far better time together.

Juanita shared an experience of being victimized by younger people she knew.

They think you are a stone fool. You get labeled you know, "she old and she dizzy, you can get all her money."

Some respondents talked about stereotypes and assumptions that people make when they are dealing with an HIV-positive individual. Alex, a heterosexual male, said that "a lot of women my age or around my age, I mean, their going to think that I'm gay or bi or something, you know." Mary, who was infected with HIV from injection drug use, stated that "people who are over 50 will assume that if you say you are HIV positive, that you're gay and that you got it through sexual intercourse." It is interesting to note that some respondents such as Mary and Alex feared the stigma that resulted from the assumption that they were infected with HIV through a mechanism other than the means by which they were exposed to the virus.

Separate or Alone.—A considerable number of respondents talked of internalized stigma that was ultimately labeled *separate or alone*. This label was

given to a variety of experiences that set the respondents apart from society and caused them to feel alone, isolated, or separate. The majority of respondents shared feelings that were consistent with this theme. For some it was a feeling of aloneness and isolation. Juanita said, "I don't have anybody to share with. It's lonely sometimes; it really is." Louis was graphic about being single and living alone: "To be old and live all alone in your little mobile home, I don't have a partner, you know. I could drop dead in my house and no one might know about it for 3 weeks." For others, this feeling was more about being estranged from society. Terry said, "you feel more closed [as you get older], you just don't feel like you can socialize anymore." Wayne shared that "I kind of feel I'm radioactive."

HIV Stigma

Ninety-six percent of the interviewees shared experiences that were clearly related to HIV stigma. Some experiences were primarily internal, whereas others were societal responses to the disease. Four primary themes emerged from the analysis and are subsequently discussed here.

Fear of Contagion.—A form of social discrimination that a substantial number of respondents experienced is what was ultimately labeled fear of contagion. This label was given to a specific form of social response that has at its root fear of HIV. The overarching theme was the irrational fear of contracting HIV from the participant. Steve told of his mistreatment while being in jail.

I was in jail one time and they all freaked out and put me in solitary confinement, which I didn't think was right. They didn't realize the way you contract it, I guess. They wouldn't let me have any jobs because of that. So that's pretty devastating.

Ohms shared his experience with a physician's fear after hip surgery:

In December of last year I had another total hip replacement surgery. And my doctor got stuck while performing the surgery and when I went for my follow-up treatment it was one of the first things he brought up. That was the first time I felt somebody wanted to back away from me. I felt like he doesn't want to treat me, you know, I felt that I needed to apologize for it—for *him* [emphasis added] getting stuck.

Wayne recounted a situation in which "I met one guy's parents about 6 months ago and his dad wouldn't shake my hand."

Homophobia.—The second form of stigma that was indirectly related to HIV was homophobia. Three of the interviewed individuals reported experiencing stigma related to sexual orientation. Todd accounts being ostracized by childhood friends. “We’ve not talked. But I’m thinking that the word is clearly out that I’m gay and have been forever. It’s the only reason I can think of for them not having anything to do with me.” Eric, aged 72, expressed concern about how friends might view him because of his sexual orientation: “I guess you do look for approval from some people—close friends. You don’t want [them] to think less of you because of your lifestyle.”

Violations of Confidentiality.—Approximately one fourth of the respondents discussed a grave and devastating form of stigma involving the violation of confidentiality related to their HIV status. This violation of rights sometimes took the form of gossip or was associated with insensitive institutional practices. In two instances, the perpetrators were professionals who interacted with respondents in their institutional roles. In one case, the perpetrator was a correctional officer working in public service; the second case was associated with the office of a medical clinic. Steve recounts a situation in which a correctional officer violated his confidentiality while incarcerated. “The guard asked what I was taking all those medicines for. The nurse told the guard and the guard told my sister. Then everybody found out. I would have rathered [*sic*] told them myself.” Louis talked about insensitive treatment at the office of a medical provider, suggesting the office policy supported the violation of confidentiality.

So when I got there [to the medical clinic] they hand me my chart and I’d go see the blood pressure nurse, then I’d go see the nurse that draws blood, then I’d go see the doctor. I’d walk around with this big chart with this big sticker on it—HIV Positive. Everyplace I went I was carrying this. I felt, why don’t they just tattoo my forehead.

Protective Silence.—A common mechanism for managing the fear of anticipated stigma of HIV was protective silence; this is the nondisclosure of one’s serostatus to others. More than half of the respondents utilized protective silence, or not telling others, as a method of stigma management. Mary lives with her parents (both in their 80s) but has not disclosed her diagnosis to them. She commented, “I just keep thinking I’m going to outlive them. I can’t see a good reason to tell them.” Louis shared in his interview that he has disclosed his HIV status to fewer than six people in 9 years. Eric said, “I would rather get run over by a truck than die of AIDS. That’s what I’m hoping for. I’m hoping that nobody else finds out about the AIDS.” The majority of respondents

feared the stigma they would endure if people learned of their HIV status. This involved the fear of telling their family, friends, or potential sexual partners. Taleef said, “My biggest fear of all was tellin’ my daughters about it and the most important person was my mom. I hid it from her for a long time.” Ohms feared the reaction of close friends: “I do have some friends that I’ve met and they don’t know it. I contemplated being as honest as I can with them. I’m a little afraid because I don’t know how they’re going to react to me.” Similarly, Eric worried about the impact on his and his wife’s social life if friends found out: “I think there are people—in the church group of friends—who would cut both me and my wife off.” Several people feared the reaction of potential sexual partners. Alex said, “It is a very difficult disease to have when you still want to have a partner—companion. Very difficult disease to have, not like a lot of other diseases.”

Ageism

The majority of interviewees (72%) shared experiences that were considered ageism. A number of such experiences have already been discussed under the ageism–HIV stigma intersection. There were, however, respondents who reported internal ageism as well as social discrimination based on age.

Employment Discrimination.—Although such experiences were not widespread, several respondents discussed experiences that would be considered institutional ageism. Alex stated, “Where I work, a lot of people between 50 and 55 get let go.” Interestingly, Taisong, who works for the same employer as Alex, commented about the disadvantage of age, “being older, ah, advancement at [name of company].” She also commented she was considering the purchase of real estate and was concerned about ageism among mortgage lenders. “I don’t know how they look, the lending community, as far as buying a house at an older age and if I’m going to be required to fork up more money because of my age.”

Internalized Ageism.—One of the most insidious forms of ageism is that which is internalized. Here, internalized ageism manifested as feelings, expressions, or beliefs that stereotype older people but come from within. Approximately one third of the respondents voiced some sentiment or belief that was labeled internal ageism. Three of the individuals made comments that took the form of jokes related to memory loss, such as having a “senior moment,” whereas two others commented on the stereotypical physical decline of aging. Louis commented, “at my age I’m suppose to have cholesterol and arthritis—I’m not suppose to have HIV.” In a conversation about the future, Nolan said, “I’m now to an age where anything can happen. . . . I might be walkin’

a little bit too slow crossin' the street, you know.” (Note that Nolan is in his early 50s.)

With Question 2, I sought to glean what society needs to know about living with HIV/AIDS as an older person. The question was very open ended and yielded information not only about stigma and discrimination but also about several other important points.

Comorbidity

The issue of comorbidity and difficulty managing multiple health conditions was a common topic brought out in these discussions. Prior to the interview, Pete had been diagnosed with Parkinson's disease and was attempting to cope with his new diagnosis. Eric has a history of heart disease and previously suffered a heart attack, and still others have been diagnosed with diabetes, arthritis, hearing loss, and other chronic diseases associated with aging. Referring to the seriousness of non-HIV-related illnesses, Eric said, “it could be a heart attack before anything else.” One respondent talked about the additional limitations his arthritis imposes: “I have to walk or take the bus and it cuts down on my activities a little bit.” Participants acknowledged that other chronic conditions are common and complicate daily living as well as medication regimes.

Living With AIDS

The complications of managing HIV and other chronic illnesses were balanced by an optimistic and philosophical vantage point. Several individuals voiced the same sentiment as Paul: “I'm living with AIDS. I'm living with AIDS, I'm not dying with it.” Several individuals voiced optimism about the future. Taisong shared: “Barring sudden accident, I see a lot of years ahead now.” Mary stated, “As long as I have a good, full social life and good friends, life is good.” Regardless of age, individuals were able to visualize a future in which they managed their disease processes.

Practicality

Several participants voiced a very practical view of living with HIV disease. For example, Terry talked about his reactions to the opinions of others: “They don't like it, that's their problem, not mine.” Barb discussed the practical element of being in her 50s with HIV and looking for a partner: “I live life for myself and if he walks into my life, I enjoy that; if he walks out, then I clean up my act and keep on going on.”

Late Diagnosis

Although data on this topic were not routinely gathered as part of the interview, several respondents discussed the issue of late diagnosis. This term is typically used when one's first HIV diagnosis is within 1 month of also receiving an AIDS diagnosis. Several informants discussed not knowing they were HIV positive until they had been hospitalized with an AIDS-defining illness.

Finally, Eric shared his hope that society can be accepting and compassionate toward older adults living with HIV/AIDS. When asked what people need to know, he said, “Be patient. Older people with HIV still have feelings. Accept us for what we are; we're all different. Learn to live with the differences.”

Discussion

My purpose in this study was to examine the experiences of HIV stigma and ageism through semi-structured interviews with 25 HIV-infected older adults. I also sought to determine whether these phenomena existed simultaneously, and what impact these discrediting conditions have on people's lives. This study is one of the first to my knowledge to focus specifically on both HIV stigma and ageism.

The themes that emerged from this study reinforce previous research on stigma or ageism, and they also suggest new insights and interpretations. The results provide support for the notion that older adults with HIV/AIDS are in double jeopardy in regard to stigmatizing conditions (Sheets, 2005) or that stigma can be layered (Reidpath & Chan, 2005) as a result of multiple discrediting conditions. All but one informant reported experiences of stigma related to HIV, and the majority reported ageist interactions as well. The findings are also consistent with those of Green and Platt (1997), who hypothesized stigma as being both enacted and felt. The prevalence of rejection among these older adults reinforces my earlier quantitative findings (Emlet, 2006), in which I noted that 40% of older respondents had been rejected by friends as a result of their HIV, and 50% felt others were uncomfortable being with them. The individuals in the current study experienced rejection from a variety of sources, including family, friends, clergy, and service providers. The identification of fear of contagion as a major theme reinforces the notion of fear that society continues to hold toward HIV disease and the notion that AIDS stigma continues to persist (Herek et al., 1998). Friends, family, and even health care providers felt and acted on these fears. A number of participants experienced stigma as associated with their sexual orientation. HIV-positive sexual minorities must manage disclosure of and the stigma attached to their HIV status as well as sexual orientation. The fact that nearly one fourth of those interviewed had the confidentiality of their HIV

status violated by others is disturbing. Because disclosure of HIV status opens up the potential for stigma and the shame of having HIV (Landau & York, 2004), having one's HIV status exposed without permission is unconscionable. More disturbing is the fact that, in several instances, such violations came from people in the public trust. These findings suggest that we cannot assume that confidentiality is being respected and disclosure policies adhered to. For practitioners as well as researchers, this is a call to be vigilant in maintaining the confidentiality of HIV-infected clients and to challenge unethical policies or behaviors. For consumer advocates, it is a reminder of the need for efforts to uphold clients' rights.

The experiences of ageism reinforce findings related not only to HIV but also to ageism in the gay community. Society's stereotyping of older adults as asexual and heterosexual is anything but rare (Barker, 2004), and the types of experiences these older gay men shared of being shunned by younger men is also well documented (Gorman & Nelson, 2004; Schrimshaw & Siegel, 2003). It is also important to note that some aspects of ageism, such as name-calling and institutional discrimination, were based solely on age and had little to do with HIV status or sexual orientation.

The internal response to HIV stigma and ageism by the informants provides important insights. The high proportion of interviewees that engaged in anticipatory stigma manifesting primarily as protective silence reinforces Green and Platt's (1997) position that felt stigma is in part the oppressive fear of enacted stigma. The concept of self-protection from stigma through silence is consistent with the finding of Nokes, Holzemer, and Corless (2000) and Shehan and colleagues (2005), who found older adults to be less willing to disclose their HIV status than younger adults. It is important to note that the realms of social exchange and intrapersonal response do not work in a vacuum, but rather serve to influence each other. The intrapersonal response of feared stigma and rejection may have been influenced by previous experiences of actual rejection, creating a vicious cycle that is difficult to escape. In addition, the connection between stereotypical ageist beliefs voiced by others undoubtedly assisted in the development of internalized ageism felt by a number of respondents. As Levy (2001) suggests, older adults commonly direct these stereotypes inward, creating subtle forms of ageism that must be brought to awareness if ageism is to be eradicated.

For practitioners and advocates, these findings have important implications. Through the identification of the types of stigma the person experiences, appropriate interventions can be tailored to the individual. Weiss and Ramakrishna (2006) have suggested that interventions designed to mitigate stigma must vary with the conditions being considered. For example, should one's experience of stigma be pri-

marily intrapersonal, including negative self-image and self-stigmatizing beliefs, supportive and insight-oriented approaches may be appropriate. Although they were not targeting stigma specifically, Heckman and colleagues (2006) studied the impact of group intervention with HIV-infected older adults. The researchers randomized individuals into two groups, and they noted that those receiving immediate group interventions reported fewer psychological symptoms and reduced depression symptoms from pre-intervention levels than did those who did not receive such immediate interventions. Should the primary experience of stigma be one of discrimination in housing, employment, or other similar circumstances, appropriate interventions may involve advocacy, that is, challenging the discriminatory practices of the perpetrators. Ramirez-Valles and Brown (2003) have documented that, despite the obstacle of stigma, Latino men who became involved in community-level HIV-related activities discovered a sense of empowerment, self-esteem, and reciprocity. If stigma-mitigating activities are to be successful, people living with HIV/AIDS must be viewed not only as recipients of services but as equal partners (Health Resources and Services Administration, 2004). The findings from this study suggest that individuals will often experience social and intrapersonal stigma simultaneously. Interventions addressing both ageist and HIV-stigmatizing attitudes at the level of community and social policy will become increasingly important in the coming years.

This study has several limitations that must be acknowledged. First, participants were recruited from a limited geographical area, through the use of purposive sampling techniques. Such recruitment strategies, combined with small sample size, limit the generalizability of these findings. Second, this research sought to capture the lived experience of these individuals. Therefore, their accounts were taken without question and no attempts were made to prove or disprove their encounters of stigma and discrimination. Third, the fact that all participants were compensated with \$25 could have influenced the willingness of some individuals to participate. The majority of participants, however, were eager to tell of their experiences. One woman said, "When I saw your sign outside, I thought, I was so happy to see that finally, finally somebody's addressing our needs." Because the majority of informants were between the ages of 50 and 65 years, it remains unclear if the experiences of an older sample of individuals might yield different findings.

Despite the limitations of the study design, the research has uncovered and deconstructed elements of both HIV stigma and ageism. Both sources of stigma carry the potential for considerable destructive power. It will be the responsibility of service providers, academics, researchers, and older adults themselves to work toward the elimination of societal views that perpetuate HIV stigma and ageism.

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