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Experience of Older Gay and Bisexual Men Living with HIV/AIDS

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Although HIV/AIDS definitely impacts gay and bisexual men of all ages, the impact on people in their later years has not been actively investigated. This exploratory study obtained detailed narratives from 14 adults between the ages of 51-72, all of whom were infected with HIV. Ten of the participants were potentially infected through male to male sexual contact. The subjects reported living with HIV for substantial periods with an average of 13 years of life since diagnosis, estimating a duration of HIV seropositivity from 1-20 years. Most had significant health problems, which may be related to aging, in addition to a number of HIV-related symptoms. They expressed community identification as people living with HIV; some were highly identified as gay men, while other were closeted or in denial regarding their same-sex activity. Half felt to some extent bisexual, and described relationships with wives or other women. Although many participants maintained active social lives, others expressed feelings of loneliness and isolation. This group was minimally active sexually and several of the participants expressed reservations about safer sex, especially condom usage. A strong theme was the sense of having lived a full life, which may help the individual cope with his diagnosis. The findings suggest the need to examine the diversity among older gay and bisexual men living with HIV, how these experiences vary by race and ethnicity, and identification of issues related to prevention and services.

KEY WORDS: AIDS; HIV; gay men; aging; older adults; sexuality; identity.

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INTRODUCTION

Men who have sex with men represent the majority of the ten percent of AIDS cases over age fifty. Older men who acknowledge same-sex attraction were socialized during periods where survival may have depended upon their ability to hide their sexual orientation and social networks. HIV has often posed the dilemma of unexpected visibility for individuals, for their friends and loved ones, and for the community in general. Whereas younger men who are intimate with other men may now be learning about HIV and risk reduction as they come out into a fairly developed service and social network, older men have not been targets of HIV education and services. Given the history of carefully hiding their gay lives, they are particularly at risk and likely to be confronted with role and identify conflicts if they discover their HIV status.

Among older gay men, who were further along in adult identity at the outbreak of HIV, perceptions about themselves and their relationship to HIV may be very different. These concerns are likely to be more prevalent in the future. Particularly as new treatments develop, including the use of combination therapies and protease inhibitors, people with HIV who were infected in earlier years may live longer, including into the later years. Although developments point to the need for research about older people affected by HIV, the impact of HIV on older gay men has received very limited attention among social sciences or the medical community.

Epidemiological data collected by the Centers for Disease Control and Prevention have consistently reported that substantial numbers of elders are being infected. Current data shows that on average nationally ten percent of AIDS cases are in individuals over age 50,[2] and that, in communities with larger populations of older adults this number is as high as 15 percent. By the next decade ten percent of persons with AIDS may be in their sixties or older (McCormick & Wood, 1992).

[2]The age of 50 has generally been used to designate older individuals with HIV. While it does not necessarily connote the elderly, it is relevant to older HIV affected adults for a number of reasons. As noted by the respondents in this study, within the gay male HIV population, people over the age of 50 are viewed as older men. Epidemiologically it has been difficult to track the older population of HIV positive individuals very precisely due to the surveillance and reporting patterns. CDC data were not initially separated into age subgroups above age 50, so all people with AIDS over age 50 were grouped together (Stall, Catania, & Pollack, 1989) and reporting has been inconsistent in the past five years. Finally, persons over age 50 are sometimes clustered with elders in terms of service eligibility, for instance through membership in such organizations as the American Association of Retired Persons and for some Older Americans Act programs. The National Association on HIV Over Fifty has defined their target as over age 50.

The number of elders who are living with HIV is difficult to ascertain. Almost all information about HIV and elders has been based on data about AIDS cases, which suggest advanced infection. In 1989, Stall et al. estimated that there were 125,000 persons with HIV over age 50. If we apply a five percent estimate of AIDS cases over age 60 to the Centers for Disease Control (CDC) estimate of 1-1.25 million persons living with HIV in this country, it is possible that as many as 60,000 people over age 60 are now HIV positive. These numbers were expected to double by the end of the century, suggesting a likely quarter million HIV-infected persons over age 50 and possibly 100,000 to 120,000 or so over age 60. The current number represents about 1.5 people for every thousand in the U.S. over age 60 (based on 42,000,000 persons over age 60, Statistical Abstract of the U.S., 1992).

While the percentages of AIDS cases in persons over age 50 are increasing in other categories, gay men continue to comprise the majority. Table I illustrates the CDC numbers of cases by risk behavior category and how these have changed since data was first available in 1982. The percentage of gay and bisexual men over fifty stating gay or bisexual contact or both gay and bisexual contact and injection drug exposure is 55 percent. A significant number of the 12 percent who report no identified risk behavior may also be men who have had sex with men, indicating that perhaps as many as two-thirds of the cases in men over age 50 are men who have had sex with other men, whether they identify as "gay." In larger U.S. cities, the percentage of older people with HIV who are gay men is percentagewise less as more injection drug users are reported, however numbers of older people infected continue to grow (Anderson, 1996). In fact, gay men in general, and certainly with regard to those over age 50, are a disproportionately affected population.

Risk Identification and Prevention

Elders have less HIV-related information than other at risk populations and are almost universally omitted from prevention programs (Linsk, 1994). The lack of prevention programs directed to older individuals, and in particular to older men having sex with men, clearly can be described as ageism. At best, the illustrations and messages on prevention materials tend to be age neutral; images typically involve physically attractive younger persons.

This dearth of HIV prevention programs raises questions about whether older men who have sex with men have obtained HIV information and incorporated the information into their sexual behavior. Older men

Table I. Transmission Sources In Persons Over Age 50

Transmission Sources	1982	1988	1992	1995
Gay/Bisexual	90%	66%	62%	52%
IV Drug Users	0%	8%	11%	16%
Gay/Bi/IDU	7%	1%	2%	3%
Hemophiliac	3%	5%	1%	1%
Heterosexual	0%	5%	6%	11%
Transfusion	0%	17%	8%	7%
Other/Undetermined	0%	0%	8%	12%

Sources: Centers for Disease Control and Prevention (1993, 1996) Stall, Catania & Pollack (1989).

may have limited information about actual risk, a situation that is compounded by "closet culture" assumptions, in which men intentionally hide their sexual orientation, and which in fact promotes denial of sexual behavior. This denial may be so pervasive as to affect the individual's belief system, yielding a sense that "I am not at risk" because I am careful, engage in only certain sex practices, or because I am old.

Contrary to their assumptions, they may in actuality be at more risk because of their age or the combination of denial and extreme caution. Risk may be intensified by an already compromised immune system through other health problems. Assumptions that they are safe because they are monogamous, "nearly monogamous," that they know their partners, or that they do not engage in receptive anal sex may create false securities. A small body of research sheds some light on HIV risk among older men who have sex with other men.

Slusher, Halman, Eshleman and Ostrow (1994) compared sexual behaviors among 432 self-identified homosexual males in Chicago ranging in age from 25-77 years. Comparison of men older and younger than age 60 showed similar frequency of sexual contacts. While the younger men were at somewhat greater risk, the older men's HIV risk was substantial. Forty-four percent of the older men reported multiple partners, while forty-five percent did so in the age 30-39 age group. Younger men, however, appeared to participate in a wider spectrum of sexual activities including receptive anal intercourse. However, fewer of the older men were in a primary relationship with another man. These authors conclude that older gay men are often at risk for sexually transmitted diseases, that prevention education needs to be directed toward them, and that "public policy that targets young people for AIDS education at the expense of educating older gay men may be flawed" (Slusher et al., p. 4).

Stall and Catania (1994) examined results of the National AIDS Behavioral Surveys (NABS) conducted in 1990-1991, focusing on risk of HIV infection among the U.S. population aged 50 and over. Two samples were analyzed: 1) 2,673 respondents, which included 1,114 age 50 or older and 2) a "high risk cities sample" of 11,429 respondents, over which 2,074 were age 50 and older. This latter sample included 31 self-identified as "gay" or "bisexual" men. Over a third (13) of the thirty-one gay or bisexual men reported having at least one risk behavior for HIV infection, and the highest reported risks were multiple sex partners (7 of the respondents) or having a primary partner at risk (3 of the respondents). The larger NABS sample indicates that, among adults overall with at least one HIV-related risk behavior, over 90 percent had not had an HIV antibody test and over 90 percent reported they never use condoms (83 percent of those in the high risk city samples with at least one risk behavior never used condoms). However, of the small sub-sample of older gay men who were at risk (n=12), only one never used condoms during sexual activity, while six reported always using condoms, and seven had been tested for HIV antibodies. At least in this small sample of older gay and bisexual men, it seems that by the early 1990s, some older gay and bisexual men had begun to practice HIV prevention.

Kooperman (1994) found that two-thirds of 191 gay and bisexual men over age 50 in the U.S., Canada, and Australia were very concerned about the HIV epidemic, but many were not able to apply their concerns to themselves. Two-thirds reported a great deal of concern about the AIDS epidemic, 62 percent reported they currently or have previously known people with AIDS, and 19 percent reported knowing between eleven and twenty people with AIDS. Of the 139 cases who reported sexual behavior to orgasm within the 30 days prior to the survey, 121 (almost 90 percent) reported they did not use condoms. While one-third of these felt sex (presumably anal sex) is less enjoyable with condoms, the most frequently reported reason (59 percent) was that they felt that "my partner and I are not at risk." Of the 138 respondents who had been tested for HIV, 132 reported testing negative and the remaining six did not report their HIV antibody status. These findings suggest that although there may be considerable concern and knowledge about HIV among older gay men, prevention behavior is infrequent, often attributable to the belief that they are not at risk.

Older gay men appear to have more difficulty negotiating the change to safer sex practices. During their adolescence and early and middle adulthood, this generation of men had little to fear from unprotected sex other than hepatitis and relatively easily treatable sexually transmitted disease. Many are finding it difficult to incorporate safer sex practices into their sexual repertoire. Although older gay men may be quite knowledgeable about HIV transmission, many express the sentiments of a 67 year old client

who said, "Our people don't use condoms." Furthermore, some older gay men who have lived alone all their lives or who may have suffered the loss of a lifetime partner may increasingly rely on hustlers for sexual companionship, a high risk situation due to the anonymity of the encounter and likelihood of not using precautions (Anderson, 1996).

Applying effective prevention behaviors may be undermined by hesitance to acknowledge risk behaviors. Older men who have sex with men may be more closeted or less likely to disclose sexual behavior than younger gay men. In fact, they may not identify as gay or bisexual; they may consider their sexual contact (even if frequent) as anomalous or irrelevant to their public sense of self. Therefore, unique prevention messages may be needed to attract and persuade older gay and bisexual men.

Psychosocial Issues in Living with HIV

HIV-positive gay men in later life may experience multiple role identities, which may either be supportive or create conflict. These individuals may confront triple co-existing stigmas of ageism, homophobia, and AIDS-phobia in their social encounters, as well as internalizing these stigmas. Given the possible role losses due to older age and HIV-related disability and discrimination, these individuals may be at risk of isolation, depression, and lack of support.

Very few studies have been conducted that provide any information about the HIV-related social and emotional concerns of older gay men. The extant literature is largely composed of very general descriptions of gay and bisexual men and HIV, and a few case studies or clinical reports (People with AIDS Coalition of New York, 1996; Hickey, 1996), with the exception of two recent contributions (Anderson, 1996; Lavick, 1994). Anderson, who began a number of programs for older gay men at the New York-based Senior Action in a Gay Environment (SAGE), notes three major psychological issues that affect gay men related to HIV: denial, guilt/resignation, and isolation. He describes an early, shut-down denial response seen in many older gay men, characterized by the following sentiment: "I don't have AIDS, I'm only HIV-positive, and who knows what that means" (Anderson, 1996, p. 72). Guilt and resignation may add to the effects of denial. For instance, many men may attribute their illness to effects of their freely chosen sexual behavior and thus feel they deserve HIV.

> These men, for whom there were so few opportunities to establish long-term relationships, have so fully internalized society's negative assessments of their sexual behavior that they find it difficult to believe that HIV is just a virus. For many of them, it is almost a message from God about a life ill spent (Anderson, 1996, p. 73).

Finally, Anderson describes extreme isolation and unwillingness to explore new relationships or friendships, particularly for HIV-positive men who have lost a partner. Anderson suggests that decreased sexual interest or impotence in older gay men with HIV is related to "a sense of contamination" that makes them feel unattractive and afraid of infecting others (irrespective of awareness of safer sex guidelines) and decreased libido, possibly attributable to medications taken due to problems of HIV or aging (e.g. medications to treat hypertension, diabetes, cancer).

Lavick (1994) identified a number of psychosocial issues identified in her analysis of a series of support groups for older gay men with AIDS. Common themes included the sense of loss of loved ones who have died of AIDS and other causes, concerns that as older adults they are not as deserving of services as younger people who have longer to live, concerns about disclosure of their HIV status and gay lives to their children, and general concerns about sexuality and intimacy.

THE HIV FIFTY PLUS STUDY

Given the lack of systematic studies and narrative data concerning the experiences of people over age fifty, I conducted a set of qualitative interviews with a small convenience sample of persons over age 50. The study sought to obtain information about the characteristics of the sample, their experience with HIV, their coping methods, perceptions of aging, and use of services. The study is exploratory and describes the population interviewed using qualitative methods to obtain and analyze the rich narratives provided by this small sample of respondents.

Description of the Sample

The overall sample includes 14 participants: 13 men and 1 woman. Participants were initially referred by health and service providers who were interested in the relationship between AIDS and aging. Most of the subjects were recruited through personal contacts of the researcher and the referral sources; some of the contacts were able to suggest other potential referral providers. A subgroup of the sample were in Chester, Pennsylvania where public health nurse case managers identified a substantial group of older people living with HIV, especially from senior housing projects. Another subgroup of older gay men with HIV were referred from a support group frequented by older people with AIDS/HIV that met at a Chicago consumer HIV organization. Other respondents were from Boston, San Francisco, New York City, and Austin, Texas.

About half concluded that their infection risk behavior is sexual contact between men, two believed their transmission was heterosexual, and a third associated their exposure to blood transfusions. The analysis below includes ten men who stated or suggested they were gay or bisexual, or suggested they may have been infected by sex with another man (in one case, the case manager suggested the possible gay or bisexual status).

Information about the men in this subsample is arrayed in Table II. Most lived in urban or suburban environments and reported widely varied socioeconomic statuses. They ranged in age from 51-72 and described diverse living situations. Half lived alone. Two described living with a female partner (in one case a wife and son; a long-term female partner without marriage in the other). One individual lived with a paid caregiver. Another lived with a family of choice consisting of himself and two "lesbian roommates." None of these men were living openly with a male lover. One African American man resided in a home he owned with a "cousin," who was thought to be his lover by his case manager, but who was not identified as his lover by the interviewer.

Most of the men had significant health problems, which may be related to aging, in addition to a number of HIV-related symptoms. These included diabetes, hypertension, weakness and recurrent fatigue, and clinically significant arthritis. Two reported clinical depression that had required treatment over many years. One reported a history of alcoholism treatment, and that he had taken intravenous drugs several times; he denied substance addictions.

With regard to HIV-related symptoms, many had opportunistic infections including tuberculosis, Kaposi's sarcoma, and Pneumocystic carinii pneumonia (PCP). Other reported symptoms included: neuropathy, weight loss, and skin and hair changes. Five took prophylactic drugs for PCP and two of these were taking aerosolized pentamidine. Six had taken antiviral drugs, two currently. Two reported antibiotics, and two reported antifungal drugs.

The participants estimated a range of duration of HIV seropositivity from 18 months to more than 20 years (traced to an event such as a transfusion or a time period they remembered risky sex). Their ages at HIV diagnosis fell into four clusters: early forties, around age fifty, around age sixty, and one was diagnosed at age 69. The subjects reported living with HIV for substantial periods, with an average of 13 years of life since diagnosis. Most were tested because of symptoms, either their own or a partner's. Three of these men identified as HIV asymptomatic, but not progressed to AIDS. Those with AIDS diagnoses reported they had AIDS an average of six years, with the maximum estimate of nineteen years.

Table 2. Descriptive Information

Name	Age	Race	Age at Diagnosis	Estimate Years of HIV	Risk Behaviors	AIDS Related Infections	Other Medical Problems
Art*	67	African Amer.	59	>8	Needlestick? M/M sex?	Possible PCP	Emphysema, COPD, Hypertension
Bill	62	White	52	12	M/M sex	None	Weakness, fatigue, arthritis, diarrhea
Bob	63	White	60	Unknown	Dental work or M/M sex	Thrush	Dental problems, some weakness, skin problems
Charles	72	White	69	12-15	M/M sex	None	Hypertension, Depression
Douglas	51	White	42	13-18	Possible needle exposure, M/M sex or transfusion	Neuropathy, weight loss, skin/hair changes	Arthritis
Grannie	68	White	50	21	Transfusion	PCP, KS, CMV, Wasting	Diabetes, Heart Disease, Deaf, Visual Problems
Mair	60	White	54	15	M/M sex	None	Arthritis
Patrick	58	White	48	15	M/M sex	TB, Weight loss, KS, zoster	Blind
Roger*	56	White	44	12	M/M sex	KS	Depression
Tom*	51	White	41	17	Transfusion	Thrush	Skin Cancer

*Name Changed due to request for confidentiality.

Abbreviations: M/M sex = Male to Male Sex. PCP = Pneumocystic carinii pneumonia; KS = Kaposi's sarcoma; CMV = cytomegalo virus.

Interview Methods

Written consent was obtained from all participants, who also were given the option of keeping their identity confidential or permission for the researcher to disclose information about them in publications or presentations.[3] The interviews were conducted in a very informal conversational manner. Participants were encouraged to tell their story, focusing on what they think is most important in their experience. Most of the interviewees were very responsive to the approach, although at times they asked for specific questions to answer. An interview guide ensured that basic topics were consistently covered. The outline of the guide appears in Figure 1.

Data Analysis

All interviews were audio-tape recorded and transcribed verbatim by the interviewer.[4] Two of the interviews and tapes were reviewed by a research assistant to assure accuracy of transcription. Data analysis occurred as follows. All interviews were coded using open coding methodology (Strauss & Corbin, 1990), which derives codes directly from the meanings expressed in the interviews. After five interviews, these codes were isolated from the text and aggregated, then sorted alphabetically into a "code-book" to be used for reference in future coding. Each coded interview was also sorted alphabetically for ease of access by topic. These codes were then clustered into themes of interest. The interviews were also examined individually for additional content that was related to the themes. The interview fragments are seen as records of individual experience, which may be informative about classes of experience in general. This emic approach is seen primarily as a method of organizing the opinions and experiences of the small sample of individuals interviewed. The findings are suggestive of questions for further research and analysis.

[3]Consent procedures were approved by the Institutional Review Board at the University of Illinois at Chicago.

[4]All interviewees provided signed informed consent for participation and indicated whether they wished to have their real names used or to be disguised when the study was described. Five of the overall fourteen subjects asked for anonymity. Those who did not request anonymity were somewhat strident in wanting their stories told, therefore in these cases the real names are used in the text.

1. Who are HIV + 50 + people?
   a. What are their background history, community and family ties?
   b. What is the history of HIV onset, illness and care needs?

2. How do HIV + 50 + people deal with their HIV?
   a. Why were they tested?
   b. Who knows about their diagnosis?
   c. What are their personal theories about their HIV illness, e.g. why have they survived? Why were they infected?
   d. What makes them function as well as they do?

3. What do they do (or not do) to deal with their illness?
   a. What "negative" coping mechanisms occur? e.g. depression, substance abuse
   b. What "positive" coping mechanisms are used? e.g. friendships and social support, spiritual connections, involvements in organizations or campaigns

4. How do HIV + 50 + people deal or perceive growing older?
   a. Do they perceive themselves as aging?
   b. How has HIV affected this? Issues that have occurred because of aging?

5. What are preferences for services?
   Do they prefer HIV specific services, elder services or generic services? Why?

Fig. 1. Interview Guide Outline

Interview Themes

Extent of Identification with the Gay Community

All participants were asked to indicate the communities with which they are identified. Seven of them felt they identified as senior citizens or older adults, although two of these were careful to indicate that they did so only partially. The strongest identification was the community of people living with HIV.

One of the individuals was extremely distant from the gay community, although he was clear that he felt most comfortable as a gay man. This man, Roger, was very remorseful about his ventures into the gay world. He described the dilemma he felt the one time he allowed himself to have a gay relationship:

> Well, when I was going with that guy up to Wisconsin, we got really thick. And he presented to me that it's either me or your family! I didn't even hesitate. I told him, I said I can't throw away twenty some years of marriage, for these gay flings or whatever they are.

Roger was very fearful about gay relationships, particularly vis-à-vis his wife and son:

> I am so paranoid of dealing with anybody now. And after I see that my wife has stuck by me and everything. I wouldn't hurt her anymore. And I'm too afraid to do anything like that anymore.

Consequently he was extremely marginalized from the gay community. Ironically AIDS once again brought him into contact with the gay community when he attended a local HIV support group.

For most, other gay men clearly served as their primary reference group, and their HIV status was clearly entangled with their sense of being gay men. Some had recently acquired a more strident gay identification than earlier in their lives. They suggested that they were now at an age where they felt that they were much less vulnerable to social judgments or homophobia. Bill described this very simply: "My feeling is, at my age — what can anybody do?" Similarly, Charles stated:

> I've gotten to an age, where I said no one can hurt me. Yet I don't give a damn who knows I'm gay. And preferably most of the people who like me, I want them if they are heterosexuals to know I'm gay. Because if they know me then I can say, well you know me and you like me. I am just one of millions of people in this world who are gay. And we're all the same people . . . . I'm not trying to hurt them. I just want them to live happily and me to live happily. And hopefully we can all help one another.

Marital/Bisexual Issues

Five of the men felt to some extent bisexual, and described meaningful extended relationships with both male and female lovers. One was extremely closeted and guilt ridden about his sexuality, having lived in a heterosexual marriage for over 30 years. Another, also married, did not express guilt about his gay life, per se, but was very upset about having brought HIV "into the family." In this case, the wife had become infected and died from AIDS-related complications, although the husband stated he had never practiced unsafe sex outside the marriage, and that the source of transmission had been a blood transfusion. The presence and experiences of several men who had sex with both sexes suggests that these individuals may have unique concerns and issues.

Both Patrick and Douglas had vacillated between men and women partners during much of their adult lives. As Patrick put it,

> Getting into the gay mode just won't do, but getting into the straight mode is definitely not it . . . . But you know it's not so much the gender of a person I am associated with as the relationship between us and the quality of the relationship. I look for that.

Several of the participants talked about how difficult it was to be gay earlier in their lives. This was particularly true of the married respondents. For example, Tom stated, "So I often tell people, they'll say, 'How come you got married?' I say, 'Back in the sixties, it wasn't cool to be gay! Today it's cool to be gay.' And there's a big difference!" He felt that his being married limited his sexual behavior when he was in his "gay world":

> Being a gay male, that is married in the heterosexual world, I was very attuned that I couldn't bring anything home. I couldn't bring boyfriends home and I couldn't bring diseases home. So I never engaged in any way that I could contract the disease. I couldn't get syphilis, I couldn't get gonorrhea, I couldn't get AIDS. I actually wasn't a very exciting person to the gay people. But I had to watch what I was doing.

Social Support and Friends

The social contacts of participants appear to parallel those of older gay men in general. They described a variety of social activities. It appears that some used conventional gay outlets. In addition to gay bars, they listed a number of sources of social contacts: breakfast clubs, art galleries, and friends who have a car to go for a ride. Many of these friends were also HIV positive. Some were eager to assure me they did not participate in stereotypical gay male activities such as the bar scene. Charles put it succinctly: "What have I got to go to a bar for? And spend money, which I haven't got anyway? Those people are not interested in me! And I'm not interested in them."

Several described a double stigma, in which the existing gay social outlets marginalized them both because they were older and because they were HIV infected. For example, Bob talked about how being over 60 made a major difference in his social life.

> I found out they had doings at the Berlin cafe on Thursdays. I went there and none of them came to talk to me. I recognized a lot of them but they didn't come to talk. The bartender was the friendliest one there. So I realized this isn't what I'm looking for.

Bob went on to describe how he found more satisfactory social connections within the HIV service community:

> Well lo and behold one guy comes in and says, "Why don't you come to the Daytimers [support group]? There are a lot of older guys there." And I said, "That's what I'm looking for."

Many found friendships or acquaintances in service-related endeavors. Examples of outlets where they could count on meeting other gay older men included a gay-run thrift shop that raised money for gay health causes, a food pantry, and an organization for men over age 30.

Although many participants maintained active social lives, others expressed feelings of loneliness and isolation. For instance, Bill described the isolation of gay and lesbian older couples. His lover had died of HIV five years before.

> You know the difference when you're young, all the gay young people say, "I don't know anybody whose been in a long relationship." And naturally not. When you're married and you get older you're not running to the bars, you're not running to the baths, you're not running around, except with a small clique of couples. . . . But we don't, we're not aware of [long-term couples] in our community because they're no longer a full part of our community. They're a separate community that doesn't go to the bars, doesn't run to the dances. They're not that involved. They're more homebodies. Like as we get older!

Several of the men had lost intimate partners, due to HIV or other causes. For example, Bill's long-term lover died in Florida and the lover's family then rejected him. Roger talked about a lover who died several years ago of HIV-related causes. Patrick and Tom described three male lovers each. It appears that these men had extended male relationships earlier, but in this point of their lives their intimate contacts were more limited.

Sexuality

The participants appear to have had somewhat limited intimate sex lives, at least with other men (see Table III). Douglas, who considered himself as bisexual, described his female lover and their apparent ongoing sexual relationship. However, Patrick was disappointed in his effort to form an ongoing relationship with a woman:

> I had an affair with a woman about three years ago, who couldn't deal with my having AIDS, just couldn't handle it. . . . She just couldn't deal with all the excitement. She couldn't deal with me. She couldn't deal with New York. She couldn't deal with AIDS. So that was the end of that!

Most described a small number of intimate sexual contacts. Charles described a very close friend. "We do a lot of fantasizing together. And he has lost two lovers with AIDS." He later chuckled as he told me "I'm not [sexually active] now; I have a VCR."

Table III illustrates the men's current statements about their sexual lives. Several were currently celibate. For the most part this was due to circumstances or decision, rather than related to health limitations. Grannie told me he chose to be celibate to avoid infecting others. Two of the men expressed the desire for a loving, intimate relationship and that perhaps sexual contact would follow. Clearly, some of the men have occasional sexual contact when they are able to meet a partner that will accept them.

Table III. Sexual Patterns Since Infection Disclosure

	None/celibate	Limited	Monogamous relationship	Comments
Art				Claims not be to very sexual since wife died a number of years ago. Casemanager questions relationship with room-mate "cousin."
Bill	×			Would like intimate relationship. None since lover died.
Bob	×			Celibate. Does not want sex outside of meaningful relationship.
Charles		×		Had only 1-2 encounters. Uncomfortable with condoms.
Douglas			×	Partner is seronegative.
Grannie	×			Choice to be celibate to avoid infecting others.
Mair		×		Occasional contacts.
Patrick		×		Had one ongoing relationship.
Roger	×			Feels wrong to be promiscuous. No sexual contacts.
Tom				Unknown. Appears looking forward to a more active gay life.

Consistent with previous research (Kooperman, 1994; Slusher et al., 1994) several of the participants expressed reservations about safer sex, especially condom usage. It seems that they had not adjusted their view of gay life to include the use of condoms. Some stated they did not need condoms because they restrict their sexual contacts to oral sex, which apparently they felt was safe. Charles expressed this sarcastically:

> And I say whatever happened to good old fashioned cocksucking? And 99 out of a hundred times it isn't that that's going to give you the virus. And all you hear is condom, condom, condom . . . . It's condom this, and condom that, and condom, condom, condom! I always laugh — I always try to get a little humor into it.

Some participants made comments about their previous sexual activities. Most agreed with Mair that they did not regret any of their activities. Mair reflected both about what he had done and suggested that he would take more precautions today:

> I don't see HIV as a plague or anything. And it does annoy me when some of my straight friends say, "Aren't you sorry you carried on ten years ago?" And I say, "No I'm not sorry I carried on ten years ago. Why should I be sorry?" If I were a youngster today I think I would practice safer sex. Because I think I'd be smart enough. And if we knew enough in the late '70s what we know now, I would have practiced safer sex then. But I'm not sorry. I'm not sorry for my life at all.

Overall it appears that HIV has had a significant impact on the sexual lives of these men. In many cases they have few opportunities for sexual expression, and some were fearful to have sex due to concerns they would infect others. In general, few were active enough sexually to determine whether they used safer sex techniques; at least two were reluctant to do so. They were well informed about safer sex, but due to age, illness, or caution had much more limited sexual lives than they desired.

Attitudes About HIV

The participants expressed a number of ideas regarding their HIV status. Several, even those who have had repeated opportunistic infections, reported surprisingly positive current feelings about health. For example, when I asked how he was feeling, Patrick stated:

> Physically? Do you know something? I don't think of how I feel. So I must feel good. If you are like me, I am so busy with my activities . . . . I am so captivated by the excitement and the creativity and the enterprise that many days I don't *feel* or realize that I have AIDS.

Charles was also eager to convince me of his independence and the fullness of his life:

> I've lived a full life. And I intend to go on living for a while. I can still wash a floor. I can still keep my house clean. I've been offered help through DORS [home services] through the social worker, and through Howard Brown [AIDS Service Organization], to clean my apartment or to shop for me. If I can do it myself, I'm going to do it. I'm independent, so far, thank God. And first place I never take anything unless I need it.

Tom expressed a robust philosophy, denying worry about his health because he cannot control it:

> I'm a firm believer that you worry about things that you have direct control over. And what you can't control you've got to give that up and get on to other things. And in that case I had no control over it . . . . I figured under these circumstances I would direct my energies somewhere else and get used to it.

Even though several reported positive attitudes about their health, they acknowledged that their HIV status was fairly compelling to them. Several talked about HIV as a constant preoccupation. For example, when I asked Charles if his HIV diagnosis had any impact upon him, he said:

> Sure it has. It's something you think of every day . . . . You wake up every morning and you know that you are HIV! I don't sit here and brood about it. I have my bad days. I have my days when I'm depressed . . .

Similarly, some of the men expressed the uncertainty about living with HIV, which leads them constantly to prepare for the worst. Patrick described this:

> You have to look at these people as living with their head on the block — with the guillotine over their heads! For five years. Well that makes you a different kind of person. It's like being on death row. And yet you make a life. At least I am, based on that reality.

As noted above, a strong theme was the sense of having lived a full life, which may help the individual cope with his diagnosis. As Mair related, "I've had a very active life. I've done everything that I ever wanted to do, essentially." And later he told me, "I am convinced that I will not live the rest of my life without some quality."

Some felt their HIV status made them unique, and part of a growing minority of older adults with HIV. Patrick told me, "It's going to get bigger; it's going to be a bigger problem because people are living longer with AIDS." Several indicated that HIV could be an asset or positive element in their lives. Douglas reflected:

> I do think about it and I think about it from the standpoint, I think I am probably more alert intellectually and in much better physical shape at my age as a result of being positive, than what I would be had I not acquired the virus and not felt the need to make changes in my emotional and physical health with the intenseness that I have done.

Bill described how he had a garden that he neglected after the death of his lover. His cousin kept after him to tend his garden. He comes to the realization that

> . . . probably it's a maturing with HIV, in that I'm going to go plant flowers, because even if I'm not here next year, at least someone will get to see it. And fortunately I can say now I've been seeing flowers and enjoying it and sharing it with people for several years. So it's something that I think younger people have to realize, that you just don't stop because you're HIV positive. There is a life to live, and to do as much as you can afford to do for yourself.

Disclosure Concerns

Some of the men have great difficulty sharing their HIV status with their families. This may be the case even though most had much earlier disclosed their sexual orientation to family members. For example, Charles described his life as an "open book" and that he had nothing to hide, yet he had not told his closest family member he has HIV.

> And I don't want her to know about this [AIDS diagnosis] unless its extremely necessary. . . . My sister is extremely hyper and she'd fall apart. And there's a lot of things that she doesn't understand. . . . And she's very nervous. And we do mean a lot to each other. We're very close. . . . But I don't see any reason to tell my sister now.

Most related positive experiences telling friends about their gayness and HIV status. Few reported rejection from their social support groups. I asked Tom if any of his and his wife's friends — all of whom were told that they both were HIV positive — abandoned them. His response was:

> Just one couple who we didn't care much for to begin with. So we figured that was an act of God and kindness. Otherwise everyone rallied. They were outstanding. And I would say it was about thirty people, and they still keep in touch with me.

Feelings About Aging

These men reported diverse responses about aging, ranging from celebrating their aged status to vehement denial of aging. For example, Tom was very eager to relate that many people tell him he looks younger than his 51 years. "Which I want to hear. Hey I got friends who are 35 who don't want to admit it."

More positively, Grannie was very proud of his age-related accomplishments: "It took a hell of a lot — and I know now because I'm in that category — it took a *hell* of a lot of energy and so forth to reach this age. I earned every day and every moment."

Several stated that there are advantages of being older with HIV. A major advantage was the sense of having lived a full life prior to the onset of their illness, which seemed to protect them against the extreme negative reactions and despair so often experienced by younger people confronting an HIV status. Bill stated this clearly:

> There are positive elements to it [being older with HIV]. I can look and say that at least I've had more in my life than young people. There isn't a thing that I have wanted that I haven't gotten to do . . . . With young people, I can understand their not being able to accept it already, because they haven't gotten out of life what one can. So there are great advantages of being old. But it's just that we get aggravated at the slight limitations, or major limitations, I get angry at.

Some felt that their advanced age would yield more entitlements. Douglas, who had extensively used the HIV service system, told me "the interesting thing for me, as I'm getting that much closer to being of an age as I head towards my sixties, is that I will be eligible for even more benefits available to me as an American citizen separate and apart from having HIV. The senior benefits, right."

Some were concerned that it was difficult to untangle which symptoms are age-related versus those that are HIV-related. Douglas said:

> I'm in a unique position because I've always had a really good memory and now I find that there are certain things that I am forgetting. It's frightening for me at first because my immediate reaction is, "Oh, my God, this is dementia." And then I calm myself down and say, "No this is not dementia. This is just because you've lived long enough to begin to forget things." So it's kind of interesting to realize there are certain things that are not as good as they used to be. That's interesting.

Others, however, focused on the increased difficulties of being older with HIV. Bob expressed his feelings about aging:

> You feel it. You feel the difference. I'm amazed. It seems like hitting sixty is a quantum leap. Before that I never had a problem with being mature. It's just a shock — a culture shock so to speak.

Bob also illustrated how he found it difficult to be an older HIV positive man within the gay community:

> Some of the problems that I think those of us who are older have is with the young. The gay community is too young oriented. And they look at us as if we're — as if we don't belong somehow. At least sometimes that's the feeling you get speaking to them. Going to meetings, where the young people sort of look at those of us who are older, they sometimes get annoyed — "Why are these old men here?" As if we don't have a right to be HIV positive and anything else. I guess sometimes you get that feeling with some of these guys.

Finally, many of these men found they had something useful to offer to younger people with HIV. Mair expressed similar feelings, describing how HIV had allowed him to become a role model for HIV positive younger gays:

> But it is fascinating, watching these guys come out. I've never been a role model before. And some of these young men — clearly some of the things they say to us, and some of us older people, we've become role models.

CONCLUSIONS

In terms of both research and policy, HIV-infected elders are often overlooked and neglected. This is particularly the case with respect to HIV-positive older gay and bisexual men. Given the larger number of people who are living longer with HIV, particularly with the emergence of new treatments, it is increasingly important to understand late life HIV experiences, especially of gay and bisexual men who are likely to continue to comprise the greatest numbers of HIV-positive elders.

Cohort Effects

In evaluating the experience of older gay and bisexual men with HIV, it is important to remember that they come from varied experiences and each belong to distinctive age and cultural subgroups. The current sample suggests multiple cohorts of older gay and bisexual men, ranging from those who consider themselves in later middle age, to those who are clearly self-identified as senior citizens. The following three age cohorts[5] are suggested

[5]These cohorts are related to B. Neugarten's delineation of young-old and old-old.

as distinct in terms of history and experience, and with respect to their knowledge and attitudes about HIV and their use of social contacts and supports. While chronological age is relevant to their self definition, they seem to define age more by their experience than by years. The following categories provide a framework to understand these men and may be useful for future development and study:

Aging Identified: These individuals are in their late sixties or older and generally identify as older adults. Most were already in their sixties when HIV was discovered, and their dominant adult experience is pre-AIDS. The result is that they may feel that HIV does not apply to them or their own personal experience. Some are surprised that they have become infected. Because they identify as older men, they may be willing to access services designed for older people, but at the same time they may be reluctant to do so because of their concerns about marginalization and discrimination due to being gay. Or they may feel that aging service programs are not equipped to deal with the particular concerns of people with HIV-related symptoms and problems. Previous writers (e.g. Anderson, 1996; Grossman, 1995) describe these individuals as having survived years of being closeted and invisible, so having HIV may be just one more secret to keep. While some men in this category may still be rather closeted about their sexual orientation and HIV status, in this sample the older men were among the most strident and open about their gayness and HIV. Examples are Grannie (age 68) and Charles (age 72). Both had appeared in news stories about their HIV status and related activities, and Grannie had become an HIV and AIDS activist.

Young Old men are approximately ages 55 to 70. They were in their forties to early fifties when the HIV epidemic began, and thus, when they first confronted HIV, they were in the prime of their lives. They have had to cope with a number of losses of lovers and friends to HIV, as they learned to confront their own illness and age-related physical decline. Those left behind are survivors.

An example is Mair, a 60 year-old former university professor who lives alone. Mair's non-HIV-related health problems seem limited to arthritis and depression, and he reports no HIV-related symptoms. Mair describes an extensive network of gay men whom he had planned to live with in a retirement situation. All of these men have since died, many of AIDS-related causes. He is, in fact, the only survivor, and is, therefore, without the anticipated social supports to help him in the future.

Becoming Older: The third cohort are men who are in mid- to late-middle age. Recently passing age fifty, they are aware they are becoming older. Within their HIV community, they are among the older members, and may be so identified. These men were clearly young when the HIV epidemic began, in their thirties and forties. This includes men who have "matured into" late-middle age with HIV, which may portend a large future population of older people living with HIV.

For many of these men, living with HIV may be one of the most important experiences of their adult lives. They were the targets of the earliest HIV prevention campaigns. Many of their age cohort who were HIV positive may have died. They may experience both survivor guilt for outliving friends and often their lovers, as well as a sense of shame and embarrassment that they have become infected despite what they knew about HIV.

Many, especially if they identify as gay men, are highly socialized as HIV-positive. They have already faced life change issues frequently associated with aging such as loss, medical monitoring, and service utilization including support groups and advocacy. Not surprisingly, most of these men did not identify at all as senior adults or even retirees, although most were retired from their usual occupations. When asked about service usage, some used transportation for the aged or disabled, but they identified with neither group. Instead, they told me, "I'm HIV."

For some, their long-term survival may have come as a surprise. They may have previously attempted to come to terms with their impending death, only to find themselves still very much alive. This may be an issue not only for themselves, but also for other people. For example, Patrick stated:

> It's only now, after five years, that they are aware that I am doing it. People that I used to know, acquaintances that I used to have, are totally amazed with my survival. . . . No I'm not dead; I'm not going to die. I don't want to die. What am I supposed to do? Apologize?

Bob is an example of this Becoming-Older cohort. He is a 63 year-old artist who was unable to tell me when he thought he became infected. He has had an HIV diagnosis for about one year. Because he is an older man, he had great difficulty convincing health care providers that he needed an HIV test. When he was tested and was positive, the providers told him he had lived his life, so HIV would not be much of a problem for him. He was outraged, both because he felt badly serviced and because he does not feel or identify as old. In fact, he continues to paint, and had a recent exhibition. He is quite mobile and is himself surprised that he is HIV positive. He asserts his sexual life has been so limited that he felt he was protected from HIV. His support network is now largely composed of friends from the HIV support group he attends.

Research Issues

This study is a preliminary examination of the experiences of older gay and bisexual men with HIV, and raises a number of possibilities for further investigation. As suggested in my effort to delineate three age specific types of experience, the first major research need is to examine the diversity among older gay and bisexual men living with HIV. Particularly given that new drug therapies have extended the life course of individuals with HIV, it is perhaps more important to distinguish the experiences of older gay and bisexual men, than it is to generalize.

Research is needed to examine the experience of these individuals in greater detail, and to better understand how their experiences vary by race and ethnicity. All of the respondents felt it was important to give detailed information about their personal cultural background, and to tell how this influenced their HIV experience. Research to date indicates that there are geographic differences as well, particularly with regard to how the gay community and the service communities deal with later life HIV. A future study should actively recruit older gay and bisexual men from communities of color, and attempt to delineate the influence of class, ethnicity, and race on issues of identity, self-perception, and on social service usage.

As the various findings about sexuality attest, older men are both at significant risk and avoid using prevention methods. Youth-oriented HIV-prevention methods will not reach this population. Future research should continue to explore how to address prevention needs of older men with HIV, including primary and secondary prevention to avoid further transmission of the disease.

The care and social support needs of older gay and bisexual men with HIV need to be carefully considered. Although most of the men interviewed have utilized the HIV service system, that system is seldom prepared to deal with an increasing population of older clients and patients. While many HIV-positive older gay and bisexual men appear to have good social connections, they are nevertheless also at risk for social isolation and depression. This is of particular concern for those who are part of an age cohort that has been decimated by HIV disease. These individuals need to construct new social networks at a time when social resources are scarce.

Older gay and bisexual men express varying perceptions about the experience of being older with HIV. Some view themselves as long-term survivors and seek support and association with others who have survived for extended periods of time. Others report extreme isolation and loneliness as the majority of their previous support systems have either been decimated or have become alienated from them. Some men view their HIV status and symptoms as only one part of a cluster of health related and

social issues with which they must contend. They may perceive their HIV experience as an "on-time" experience (Neugarten & Hagestad, 1976). As such this is a relative advantage as compared to younger HIV-infected people, who experience their HIV illness as a departure from the normative life course.

HIV in older gay and bisexual men constitutes an intersection of identities that are usually not considered together: HIV, male-to-male sexuality, and aging. Some individuals may be fortunate enough to find social supports that may help mentor them through this confluence of identities, or they may find supportive others from outside these communities. Some may become extremely isolated and marginalized; clearly the most isolated will be the most difficult to access for purposes of research or service delivery. To date, both the HIV and aging professional communities have largely ignored this group, even though known trends suggest that this group will increase and will eventually represent a more normative HIV experience. Further research is essential to better understand the experiences and needs of later-life gay and bisexual men with HIV disease.

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