
Aging and HIV/AIDS: Lessons Learned...moving forward

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Introduction

It is a tremendous honor and great pleasure to have been recognized by my peers and the administration at the University of Washington, Tacoma for my research, and to be able to share some of what I've learned over the past few years with you today. Along with being an honor and pleasure, it is also a bit daunting . As evidenced by the title of this presentation, my intent is not to present to you the results of a single study, but rather to summarize what I have learned from my informants who live each day with HIV disease. I also want to suggest where the research might go from here, as the face of the epidemic seems to change with each passing day.

For the past 5 or 6 years, my research has taken a variety of shapes and approaches. It has included secondary analysis of existing data, a two-year quantitative study and finally, for the past year and a half, a mixed-methods study that includes the gathering of quantitative data along with qualitative interviews.

These project have been funded by a variety of public and private sources including:

- The University of Washington, Tacoma Founder's Endowment
- The John A. Hartford Foundation and The Gerontological Society of America
- The National Institute of Mental Health grant #1 R03 MH69334-01

The research I have carried out over time is delicate and sensitive. It involves the openness and willingness of many people with HIV/AIDS to share their lives and stories. I am indebted to them beyond words. It has required the trust and cooperation of numerous agencies throughout Pierce County to open their doors to me and provide various types of support. In particular the Pierce County AIDS Foundation has my deepest gratitude.

UWT's Office of the Chancellor must be recognized for their support of bringing research more into the public eye through the establishment of the Distinguished Research Award as well as the sponsorship of today's event. I would also like to thank my colleagues in the Social Work program for supporting a rather aggressive research agenda, which as required a considerable amount of course release over several years.

Historical Context

If we are going to understand HIV/AIDS among older people we need to see it in its historical context. AIDS in an older individual was first documented as a case study in 1986 when a 57-year-old man, diagnosed with Alzheimer's Disease (AD) was found on autopsy to have progressive dementia caused by HTLV-III (the term used at that time for HIV) (Mirra, Anand, & Spira, 1986). By the end of the 1980s, various papers and one book had been published on the topic by a variety of disciplines in addition to the popular press such as AARP (Zablotsky & Kennedy, 2004). It was about this time, while establishing an AIDS case management project in northern California, that I began to recognize this phenomenon myself, as a practicing social worker, piquing an interest that has been sustained for nearly 20 years.

Since 1986, only 5 books have been published on this topic. Comparatively, a recent search of books in print on the general topic of HIV/AIDS yielded over 2600 hits.

In addition to the five books, the past 20 years have also produced 6 special issues of peer-reviewed journals devoted solely to the topic and of course many individual journal articles. While the literature on aging and HIV has grown many times over during this period, it pales compared to the vast literatures on this disease in general.

Demographics

The data from national, state as well as local sources suggests a slow but consistent "graying" of HIV in this country. Figure 1 provides national data from the CDC over a ten -year period and you can see the slow but consistent increase in age on a number of important indicators.

During this period the median age at diagnosis with AIDS has risen from 37 to 39 years. The median age of individuals with AIDS has risen 3 years while the median age at death has increased from 39 to 43 years of age.

Figure 1. Median Age at Diagnosis, at Death and for those with AIDS in the U.S.: 1994-2000

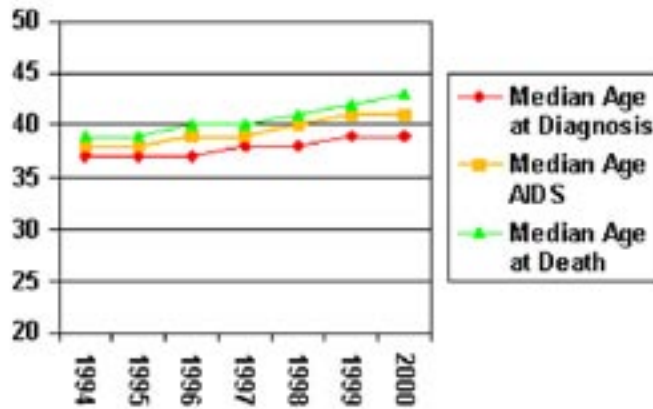
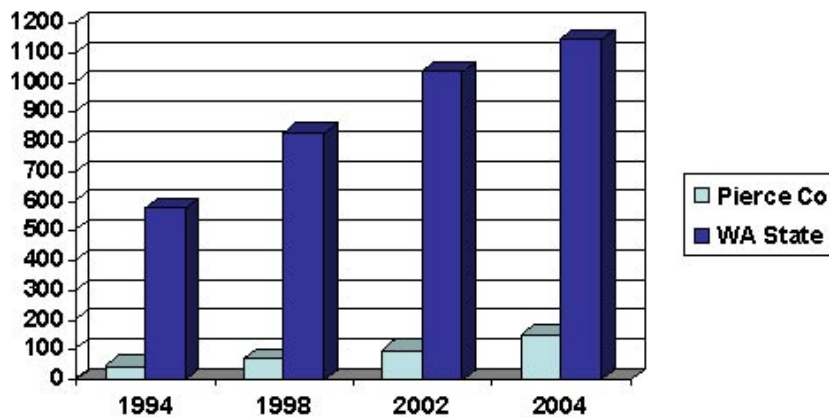


Figure 2 shows the increase in cumulative number of AIDS cases in persons age 50 and over in Washington State and Pierce County. The large discrepancy in bars would be filled by data from King county. Currently Pierce County is second in the number of AIDS cases in Washington state, accounting for approximately 10% of cases. King, Pierce and Snohomish Counties combined account for over 80% of all cases in the state.

Figure 2. Cumulative AIDS Cases in Washington State and Pierce County in those 50+, 1994-2004



The data in Figure 3 shows the percent of AIDS cases in persons 50 and over for Washington state and Pierce County for a ten-year period. Currently 11 percent of all cases of AIDS in Pierce County are in persons age 50+. Combined, these data suggest two phenomenon: One is the increase in older persons being diagnosed with HIV or AIDS as well as the increasing numbers of individuals infected at a younger age and living longer lives due to Highly Active Antiretroviral Therapy (HAART).

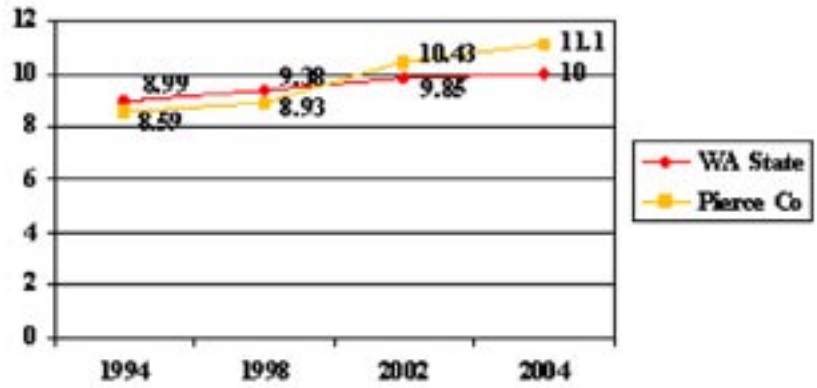


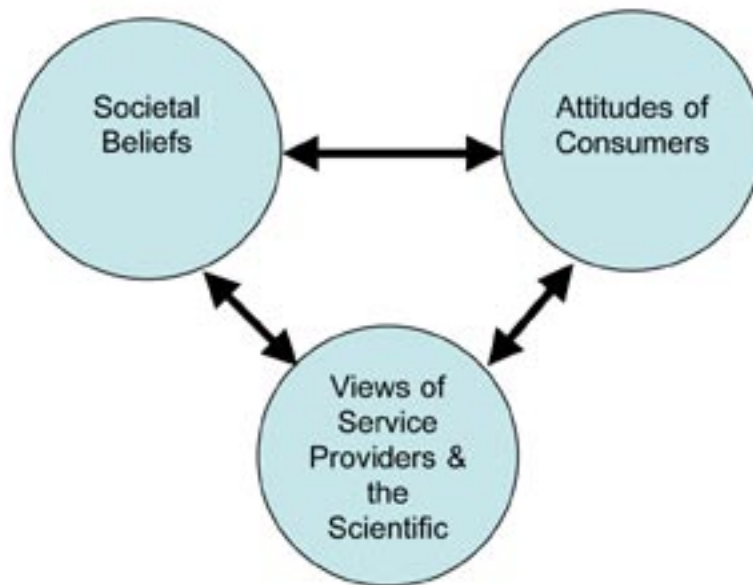
Figure 3. Percent of AIDS Cases 50+ in Washington State and Pierce Co, 1994-2004

At the time I began HIV work in the 1980s, life expectancy after AIDS diagnosis was somewhere between 6 and 24 months. To be older with AIDS at that time, one had to be diagnosed in late life. There are now two distinct populations of older adults with HIV/AIDS: those diagnosed later in life and those long-term survivors who can now grow old with this disease.

Social Response

If we are going to make progress in areas of education and prevention, one of the issues we need to confront is the attitudes and beliefs of the public, older adults as well as medical and service providers about aging and sexuality (see figure 4). The misconception and ageist attitudes infused in our society result in poor prevention efforts, unnecessary infections, delays in diagnosis, misdiagnosis and ultimately unnecessary deaths.

Figure 4. Elements Contributing to Societal Misconceptions of Aging and HIV



Despite the fact that AIDS among older persons was first acknowledged nearly 20 years ago, misconceptions continue. Older people are seen as asexual, and if by some strange chance they manage to have sex, they are obviously heterosexual and certainly monogamous. Additionally, our inability to acknowledge older persons use of illicit drugs seems systemic.

HIV however is a disease transmitted through unprotected sex and exposure to contaminated blood. Older adults, despite our strongest denial, are exposed to HIV by the same means as younger persons. These risk factors will certainly continue to increase in the coming years with the aging of the Baby Boom generation and their generational mindset related to drug use and sexuality (Nichols, 2004). The experiences of several informants from the NIMH study reinforce society's beliefs related to age and HIV.

“The fact we 50, old and somebody’s grandma...it can’t be you”

Juanita, age 51

“At my age I’m suppose to have my cholesterol and arthritis, I’m not suppose to have HIV”

Louis, age 64

“There’s a lot of people that go – ‘you’re awfully old to have this disease’”

Wayne, age 59

*“In some cases, I believe older people are held to a different standard,
that ‘well, for crying out loud, you should have known better’”*

Christa, age 64

It is perhaps not surprising that the beliefs of older consumers mirror the myths perpetuated by larger society. Many older persons see their age or sexual orientation as immunity from risk. Evidence indicates that compared to younger persons, those 50+ are less likely to use condoms or practice methods of safe sex, to be tested for HIV or to know their own serostatus. In a study in Central Florida, Nichols and colleagues (2002) found that over 60% of older respondents had minimal knowledge of behaviors that are associated with risk for HIV exposure. One informant commented to me that older adults were not educated in a time when HIV/AIDS existed, nor did they have the advantage of health education in school related to this topic.

*“People who are over 50 went through school, received health information...
at a time when HIV wasn’t on anybody’s radar screen”*

Christa, age 64

These commonly held beliefs and ageist attitudes are commonplace among our medical practitioners and service providers. Sexual histories are routinely absent in assessing older adults (Skiest & Keiser, 1997), making dangerous assumptions about sexual behavior and lack of risk. As one informant puts it: “Doctors would not even have looked at you as being likely to have HIV even if they saw the same symptoms as in a younger person”. Christa, age 64

Lessons Learned

Social Resources

As we age, our social resources may decline through loss of friends, family and other informal supports, such as work colleagues. I have attempted to examine this phenomenon through a variety of means and venues. Literature on HIV and aging suggest that older persons are at greater risk of diminished social resources compared to their younger counterparts (Crystal & Sambamoorthi, 1998).

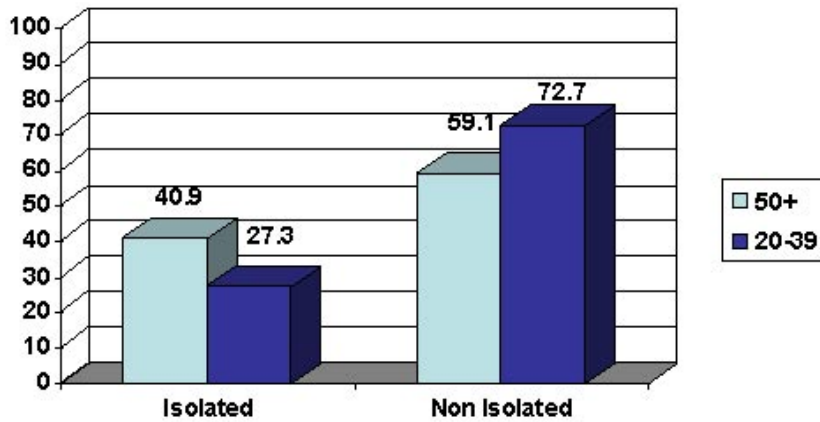
Table 1 provides data on three separate studies I have conducted suggesting that persons age 50+ have a high likelihood of living alone. In all three studies, those 50 and over with HIV/AIDS had approximately a 1 in 2 chance of living alone. Differences with the younger comparison groups showed a consistent pattern of living arrangements.

Table 1. Percentage of Subjects Living Alone by Study

	Founders N=287	Hartford N=88	NIMH N=25
Older Adults	50.0	47.7	50.0
Comparison Group of younger adults	39.0	18.2	NA
Difference	$p<.20$	$p=.003$	NA

One measure used in the Hartford study was an instrument designed to measure one's social network, know as the Lubben Social Network Scale (Lubben & Girona, 2003). The LSNS has identified a clinical cut-off indicative of social isolation, and data from this study (see Figure 5) indicates approximately 41% of those 50+ had LSNS scores low enough to be considered socially isolated. This compared to 27% of those ages 20-39.

Figure 5. Hartford Study: Percentage of Study and Comparison Group Socially Isolated



In-depth interviews with older adults provided qualitative evidence that social isolation is a potential problem for this population. As noted by several informants in the NIMH study:

“You feel more closed...I don’t know, You just don’t feel like you can socialize anymore”

Terry, age 51

“I’ve been pretty good about keeping my business to myself, because I’m afraid to make friends. I don’t have a whole lotta friends, I kinda isolate myself a lot of the time”

Nolan, age 56

“Whenever you have something that you can’t share, it’s a wall, I don’t like that”

Mary, age 55

“I think attitudes are changing, but there’s still a fear of people finding out. You don’t want people to know that you have this dreaded disease”

Eric, age 72

Stigma

An important element that affects the quality of life of all persons with HIV disease is stigma. HIV stigma is a ubiquitous phenomenon which the Joint United Nations Programme on HIV/AIDS (UNAIDS) (2002) suggests is “universal, occurring in every county and region of the world”. Despite the fact we have entered the third decade of the pandemic, HIV-stigma continues to exist and is therefore deserving of study.

The theoretical underpinning of stigma related to HIV disease has evolved over time. Beginning with Goffman’s (1963) concept of spoiled identity, stigma associated with HIV has been more recently defined as prejudice, discounting, discrediting and discrimination that are directed at people perceived to have HIV or AIDS (Herek, 1999; Herek et al, 1998). UNAIDS sees a progressive process of devaluation of humanity, beginning with stigma, ultimately leading to the violation of human rights. Stigma is not a single construct, but rather a multidimensional phenomenon with multiple components and characteristics. Green and Platt (1997) suggested that stigma may be felt, a personal and internal reaction, or enacted, suggesting societal behaviors that are the source of stigma.

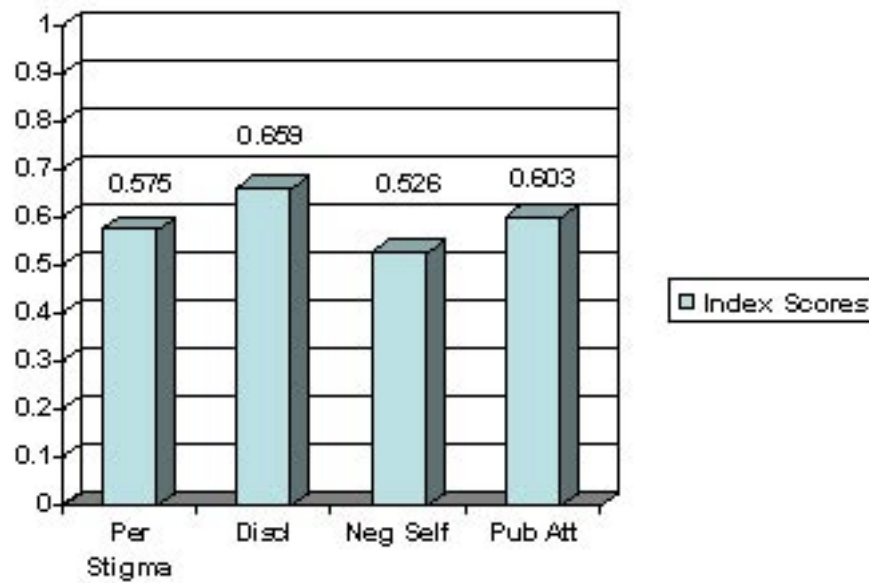
While I have examined this phenomenon in two different studies, I would like to focus for a few moments on the data collected through the NIMH study.

Acknowledging its multifaceted nature, this study used an objective, quantitative measure along with semi-structured qualitative interview to attempt to learn more about how older adults see and experience stigma. The stigma measure used was a 40- item instrument developed out of the University of Illinois, Chicago School of nursing (Berger, Ferrans & Lashley, 1997) which included 4 subscales with good internal consistency. Qualitative data was gathered from all informants through semi-structured interviews. In addition, all respondents completed the CES-D, a 20-item scale for assessing depression (Radloff, 1977). Each of the subscales measures various aspects of stigma.

- ✦ Personalized stigma is associated with factors such as feelings of isolation, rejection, and experiences of negative relations with others due to HIV.
- ✦ Disclosure subscale focuses on feeling of telling others and their real or anticipated reaction. This also includes fear of forced disclosure by other people without one’s permission.
- ✦ Negative self image includes feelings of guilt, shame, self deprecation.
- ✦ Public attitudes includes items associated with the attitudes of others, discrimination, social discomfort, etc.

Because each of the subscales in the stigma instrument contain different numbers of items, index scores were calculated that compensate for these differences. With index scores, we can compare scores across subscales and determine if any one facet of stigma seems more pronounced than others for these individuals. While index scores are fairly similar, Figure 6 shows disclosure and public attitudes seem more pronounced.

Figure 6. Index Scores for Stigma Subscales



The next series of seven slides compare subscale scores across variables and to illustrate the personal experiences of individuals related to these phenomenon as captured by in-depth interviews. Figure 7 shows a comparison of subscale scores by gender. While differences were not significant, you see a consistent pattern of men indicating higher levels of stigma across all scales than their female counterparts.

Figure 7. Stigma Subscale Scores by Gender

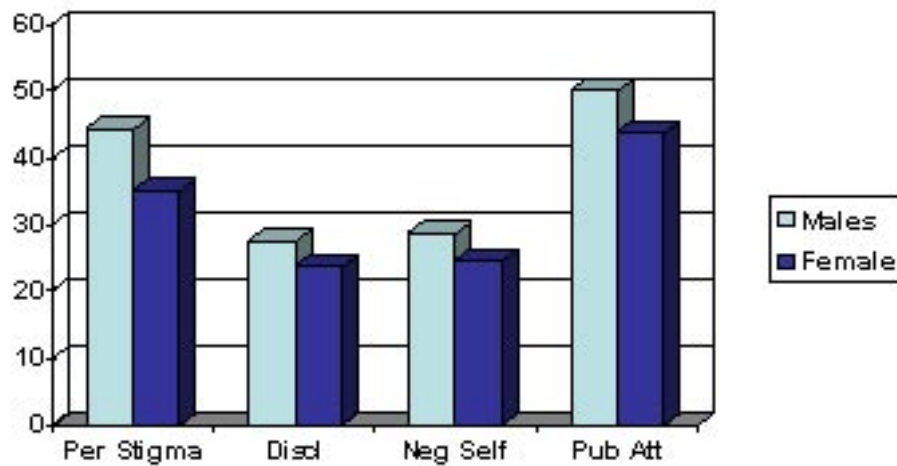


Figure 8 illustrates a comparison of scores by race. You will note the differences in all subscale scores are statistically significant with African American informants experiencing greater stigma than the white respondents. These findings are particularly important considering recent data concerning the continued disproportionality of HIV in communities of color.

Figure 8. Stigma Subscale Scores by Race/Ethnicity

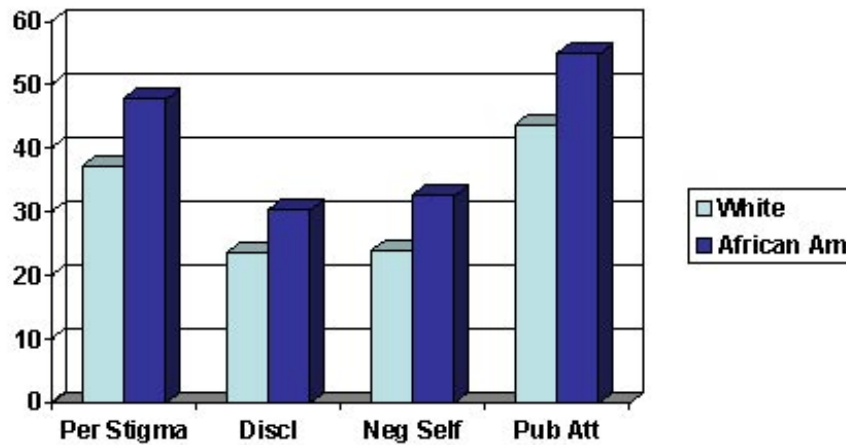
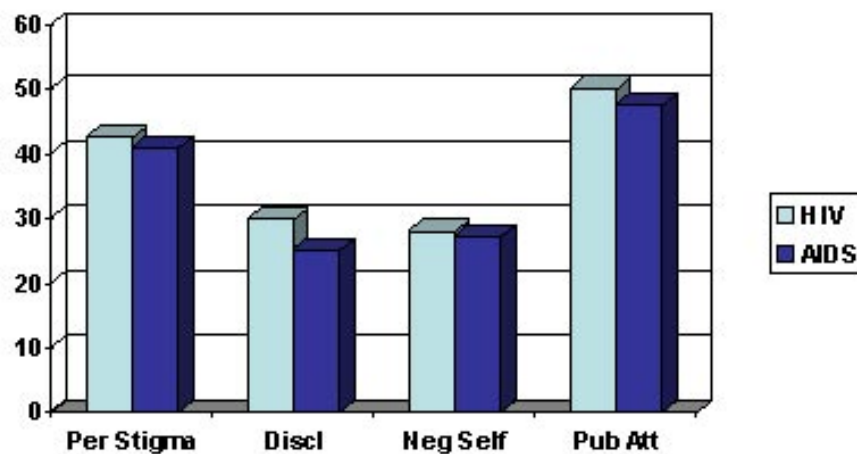


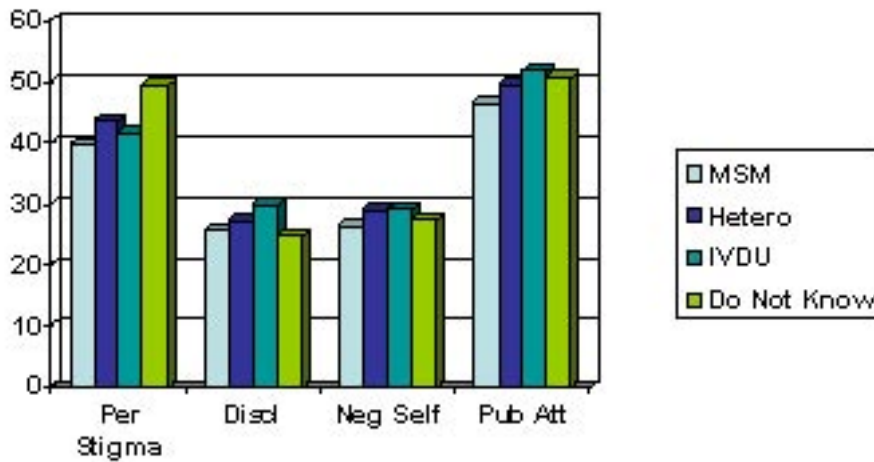
Figure 9 suggests HIV status has little effect on stigma with those having HIV versus AIDS indicating slightly higher indicators of stigma across the four scales.

Figure 9. Stigma Subscale Scores by HIV Status



No significant differences were seen when comparing scores by exposure risk. You will note in Figure 10 that in all cases, those exposed through men having sex with men has small but consistently lower scores on all scales. One thought is that a history of marginalization and stigmatization has created a sense of endurance and coping perhaps not know by other risk groups.

Figure 10. Stigma Subscale Scores by HIV Exposure



The following quotes are intended to provide you with some glimpse into the experiences of some informants as they relate to these various elements of stigma. Information on disclosure is omitted as will be discussed later.

Personalized Stigma

“You don’t want people to know you have this dreaded disease...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”

Eric, age 72

“I feel I’m radioactive”

Wayne, age 59

Negative Self Image

“I wouldn’t get into a relationship with anybody you know, I wouldn’t think anybody would want me for one thing. I don’t have anything good to offer this person cause I’m just, I’m, I’m like run down baggage”

Juanita, age 51

“I met one guy’s parents about 6 months ago — his father wouldn’t shake my hand even”

Pete, age 51

Public Attitudes

“The discrimination is a problem for us. A lot of times if you tell somebody, you know, they’ll back off and they’ll judge you”

Terry, age 51

“Some of the people we associate with socially, ah it could be ‘okay, you got yourself into this, so you deserve what you got”

Eric, age 72

Literature has shown a relationship between HIV stigma and psychological distress in younger populations. Table 2 shows bivariate correlations between stigma scores and subscores and the CES-D, an instrument established by the National Institute of Mental Health to indicate possible depressive symptoms. In all instance except for disclosure, stigma was significantly correlated with depression.

Table 2. Zero Order Correlations Between HIV Stigma and Depression

	(1)	(2)	(3)	(4)	(5)	(6)
CES-D (1)	1.00					
Total Stigma (2)	.627**	1.00				
Public Attitudes (3)	.573**	.981**	1.00			
Negative Self Image (4)	.709**	.940**	.905**	1.00		
Disclosure (5)	.343	.888**	.840**	.737**	1.00	
Personalized Stigma (6)	.668**	.954**	.952**	.919**	.761**	1.00

**p<.01

Stigma and Social Support

Table 3 circles back to the issue of social support. These data from the Hartford study indicate the primary importance of social networks as they relate to stigma. While scores from the LSNS were not significantly associated with stigma, two important elements did emerge – having a confidant (having someone you feel at ease with that you can talk about private matters) and receiving help (having someone you feel close to, such that you could call on them for help).

The possibility that social support may mitigate some effects of stigma deserves further attention.

Table 3. Zero Order Correlations Between HIV Stigma and Social Support

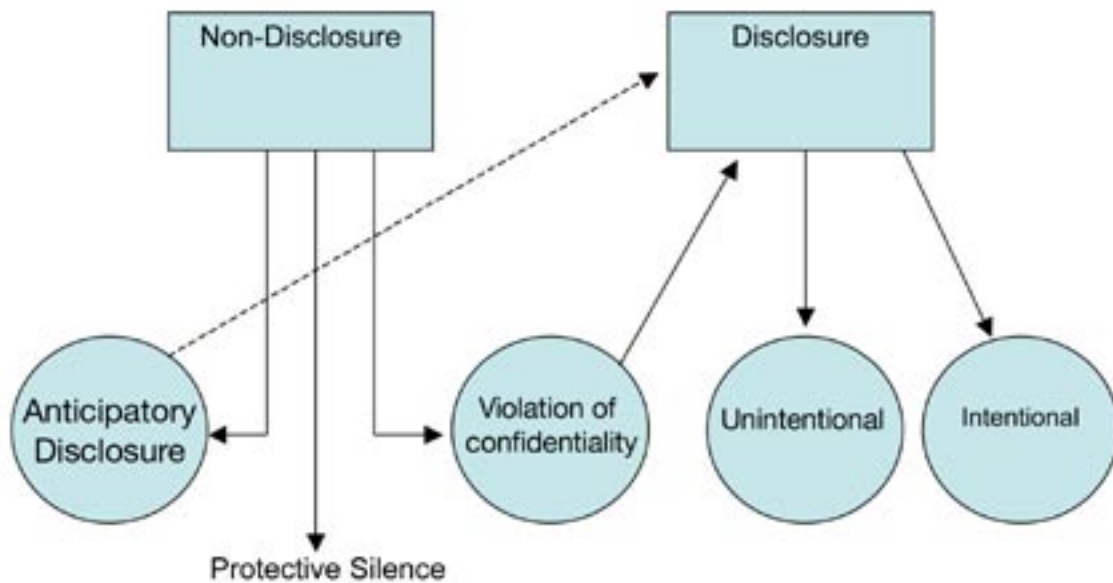
	(1)	(2)	(3)	(4)
Stigma (1)	1.00			
Confidant (2)	-.309**	1.00		
Receives Help (3)	-.286**	.704	1.00	
Total Social Support (4)	-.182	.735	.742	1.00

$p < .01$ **

Disclosure

One particularly wonderful aspect of qualitative research is the ability to unearth important aspects of a topic which were unidentified at the onset. What has emerged from the qualitative data obtained in the NIMH study is the complex process of disclosure. More than simply telling someone about your serostatus, this phenomenon is emerging as a potential primary element of study. The model shown in Figure 11 helps communicate the complexity of the disclosure process. I have come to realize through my informants that disclosure of one's serostatus takes on many forms and routes. Disclosure can be intentional, unintentional or forced. By choosing not to disclose, many individuals live lives of what I am calling protective silence in order to keep their status secret. This protective silence has its own complications. Those individuals who are anticipating how to disclose their status are preparing for that process and this state of mind carries its own anxieties.

Figure 11. Conceptual Model of the Disclosure Process



What I have termed anticipatory disclosure is the time in which an individual is determining if and who to tell about their status. This may include very specific individuals such as with Taleef and Ohms, or be associated with a more general concern as Nolan discusses.

Anticipatory Disclosure

“My biggest fear of all was telling my daughters bout it and the most important person was my Mom”

Taleef, age 50

“I do have some friends that I’ve met and they don’t know yet. 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”

Ohms, age 56

“You meet somebody and you’re afraid, afraid to like somebody because if you like somebody, you know, you have to tell ‘em and then you’re afraid of what their reaction will be”

Nolan, age 56

Protective Silence

A number of informants discussed the silence they endure in order to keep their HIV status unknown to others. This point is the process can create social isolation and alienation from others.

“When I was first diagnosed I never said anything to anybody except one person, I think it was maybe six months to a year after I was told”

Taisong, 57

“I’ve never told anybody in AA that I’m HIV positive, and it bothers me. I feel if I were to mention at my AA group that I have that disease, some people would just back off, so I haven’t told anybody there.”

Louis, age 64

Forced Disclosure

Disclosure can come not from choice or even accidentally but from blatant violations of rights.

“I wasn’t going to tell them [family] right off, like I said, I went to jail. 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”

Steve, Age 51

Unintentional Disclosure

Some individuals shared experiences such as Louis where the potential for unintended disclosure existed by an insensitive provider. Others shared stories of unintended disclosure through such things as visitors seeing medicine bottles or lesions (KS) noted by others.

“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”

Louis, age 64

Intentional Disclosure

Others are very open about their status and seems to have little concern about societal reaction as was the case for Wayne and Pete. Note how Wayne goes beyond intentional disclosure by purposively sharing his status and story with students and a means of education and prevention.

[Speaks to college classes] *“I tell them my story, how I became involved with AIDS and HIV. Then I talk about prevention and how dangerous it [HIV] is, what it does to a person”*

Wayne, age 59

Well, most of the people I’ve talked to and I know who are over 50 they’re more open about it [disclosure] an it’s as if, you don’t like me, get the hell out of my life”

Pete, age 51

Resilience and Generativity

Despite the complex physical and social issues faced by many of these individuals, there are consistent themes of survival, resilience and even generativity, a concern for others. Pete and Ellie portray a spirit of survivorship, Pete communicating a profound sense of resilience while Ellie compares herself to Mt. Rainier as a survivor.

“The younger ones can’t change as fast, I mean if my roommate was to throw me out tomorrow, fine. I’ll go find someplace else to live. I’m not as scared, I’ve started over before and I’ll do it again if I have to”

Pete, age 51

“It’s [age] majestic. Half a century. Right there with Mt. Rainier, two biggies”

Ellie, age 59

Beyond resilience, generativity—a term coined by Eric Ericson—suggests a concern and mentoring responsibility toward others (Hooyman and Kiyak, 2005). Several of these older informants discussed a deep need to see beyond their own situation and to reach out to other, younger, individuals.

“We can give them [younger people] advice. We’ve been through what they’re going through now”

Terry, age 51

“I just think that people who are living with HIV over 50, ah, have a huge responsibility to be educators. My position has always been that I’m more concerned for the next generation than I am for myself”

Christa, age 64

Moving Forward

One advantage to involvement in a relatively new field of exploration is that we are never without an opportunity to move our research forward. Some ideas for the coming years:

1. Because a larger, more representative sample is desirable, I am working with colleagues on the Seattle campus on a proposal for a five-year study that would examine the issues of older adults with HIV and their caregivers. This study would hope to recruit participants from Pierce, King and Snohomish Counties.
2. Virtually no work has been done to create and test an intervention study aimed lowering stigma in older persons. Something to look to.
3. One area I did not discuss today was that of service delivery. While the population we have examined can receive services through what is called the aging network a national system of services and providers, little is know about the knowledge of those providers related to HIV disease. A colleague at UNC and I are examining the possibility of conducting a national survey of AAA's to determine what these 680+ agencies know about or are doing for the HIV infected elders in their area.

Conclusion

I want to leave you with a quote from a 72 y/o man who had recently been diagnosed with AIDS. He reminds us to look beyond myths, prejudices and stereotypes and asks us to embrace our own diversity.

“Older people and older people with HIV still have feelings. Many of us are still capable of doing some things. Be patient with us. Accept us for what we are, we’re all different, learn to live with the differences”

Eric, 72

Thank you for your attention today and I hope you have found some of this what I have shared with you interesting, perhaps even useful.

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