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RESEARCHER ILLUMINATES LIVES OF THOSE AGING WITH HIV/AIDS

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“My biggest fear of all was telling my daughters about it and the most important person was my Mom.”
—Taleef, age 50

“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

The history of AIDS in older individuals was first documented in a 1986 case study involving a 57-year-old man who was diagnosed with Alzheimer’s disease but was found on autopsy to have progressive dementia caused by HTLV-III, the term used at that time for HIV. By the end of the 1980s, various papers and one book had been published on the subject of HIV/AIDS among adults ages 50-plus, along with some articles in the popular press. About this time, while establishing an AIDS case management project in Northern California, I began to recognize the phenomenon of older people infected with the HIV virus. As a practicing social worker, I found my interest piqued—an interest that has been sustained for two decades.

From 1986 to 2005, only five books were published on HIV/AIDS and aging, along with six special issues of peer-reviewed journals and numerous individual journal articles. For the past several years, my own research has taken a variety of shapes and approaches, including secondary analysis of existing data, a two-year quantitative study and, more recently, a mixed-methods study that included not only gathering quantitative data but also doing qualitative interviews. Much of this research has been delicate and sensitive because it required the openness and willingness of many people with HIV/AIDS to share details of their lives and personal stories. I am indebted to these individuals beyond words. This work has also required the trust and cooperation of numerous agencies, especially the Pierce County AIDS Foundation, which serves the Pierce County, Wash., area.

EDUCATION AND PREVENTION

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

Older adults, despite our culture’s strongest denial, are exposed to HIV by the same means as younger people: unprotected sex and drug use. These risk factors will certainly continue to increase in the coming years with the aging of the boomer generation. The experiences of several participants from

one of my studies, funded by the National Institute of Mental Health (NIMH), confirmed that society's beliefs regarding age and HIV need to be updated. One 64-year-old informant, Christa, observed, "In some cases, I believe older people are held to a different standard, that 'Well, for crying out loud, you should have known better.'"

In addition, many older people see their age or sexual orientation as conferring immunity from risk. Evidence indicates that compared with younger people, those ages 50-plus are less likely to use condoms or practice methods of safe sex, to be tested for HIV or to know their own HIV status. In a study in Central Florida, Janice E. Nichols and colleagues reported in *Aging With HIV: Psychological, Social and Health Issues* (San Diego: Academic Press, 2002) that more than 60% of older respondents had minimal knowledge of behaviors associated with risk for HIV exposure. In my research, one informant commented that older adults were neither educated at the time when HIV/AIDS came to the fore, nor had the advantage of school health education related to this topic.

These erroneous beliefs and ageist attitudes are also commonplace among medical practitioners and service providers. Sexual histories are routinely absent in health assessments of older adults, indicating a pattern of dangerous assumptions about sexual behavior and lack of risk. As informant Christa put 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."

LESSONS LEARNED

As people age, their social resources may decline through loss of friends, family and other informal supports, such as work colleagues. Literature on HIV and aging has suggested that elders are at greater risk of diminished social resources than their younger counterparts. Data from three studies I conducted suggest that those 50 or older with HIV/AIDS have approximately a 50% chance of living alone.

An important element that affects the quality of life of all individuals with HIV is stigma, which the Joint United Nations Programme on HIV/AIDS suggested in a 2002 report is "universal, occurring in every country and region of the world."

I have examined this phenomenon in two different studies. In particular, for the NIMH study, I used an objective, quantitative measure along with semistructured qualitative interviews to attempt to learn more about how older adults perceive and experience stigma. To measure stigma, I used a 40-item instrument developed at the University of Illinois at Chicago School of Nursing that included four subscales with good internal consistency. In addition, all informants provided qualitative data through semistructured interviews and completed the 20-item Center for Epidemiological Studies Depression Scale.

Among the findings were that men indicated a modest but consistently higher level of stigma across all scales than their female counterparts, and that African American informants experienced greater stigma than white respondents. The latter finding is particularly important considering recent data showing that HIV is disproportionately high in communities of color.

The effect of social stigma against people with HIV can be devastating. As Wayne, age 59, stated, "I feel I'm radioactive." And Terry, age 51, commented, "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."

The second of these studies, funded by the John A. Hartford Foundation, revealed two important elements that involve stigma and social support: having a confidant—someone with whom a person feels enough at ease to talk about private matters—and receiving help from someone who is close enough to call on for assistance. The possibility that social support may mitigate some effects of stigma deserves further attention.

DISCLOSURE

One particularly wonderful aspect of qualitative research is the ability to unearth important aspects of a topic that were unidentified at the onset. What has emerged from the qualitative data obtained in the NIMH study is the complexity of the disclosure process. More than simply telling someone about one's HIV status, this phenomenon is emerging as a potential primary element of research.

I have come to realize through my informants that disclosure of one's HIV status 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 call protective silence in order to keep their status secret, but this silence has its own complications.

What I term anticipatory disclosure is the time in which individuals are determining whether and whom to tell about their status. One study participant, Nolan, age 56, revealed, "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."

A number of informants discussed the silence they endure in order to keep their HIV status unknown to others, a process that can create social isolation and alienation. Sometimes disclosure can result not from choice or even accident but from blatant violations of rights. One respondent, Steve, age 51, had been arrested, and a guard in the jail asked about his medications. "The nurse told the guard and the guard told my sister . . . then everybody found out. I would have rathered [sic] told them myself," he said.

Some informants shared stories of unintended disclosure through such things as visitors seeing medicine bottles or lesions from Karposi's sarcoma, an AIDS-defining condition. Still others had been very open about their status and seemed to have little concern about societal reaction, as was the case for Wayne, who shared his story with students as a means of educating them about HIV. Regarding his speaking to college classes, Wayne said, "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."

Despite the complex physical and social issues many of these individuals have faced, their stories hold consistent themes of survival, resilience and even generativity, a term coined by psychologist Erik Erikson to describe the concern and mentoring responsibility that older people often feel toward others. Several older informants discussed a deep need to see beyond their own situation and reach out to younger individuals. For example, Christa commented, "I just think that people who are living with HIV over 50 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."

One advantage to involvement in a relatively new field of exploration is the continuing opportunity to move research forward. For example, I've been working with colleagues to develop a five-year study that would examine the issues of older adults with HIV and their caregivers in Seattle-Tacoma and adjacent areas. Other researchers might create and test an intervention study aimed at lowering stigma in older individuals, an area in which virtually no work has been done. Another promising topic for study is service delivery: Little is known about the HIV-related expertise of providers in the national network of agencies serving elders.

I want to leave you with a quote from Eric, age 72, who reminded us to look beyond myths, prejudices and stereotypes and asked us to embrace 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." ♦

Charles A. Emlert is the editor of HIV/AIDS and Older Adults: Challenges for Individuals, Families and Communities (New York City: Springer, 2004). This article is based on his 2005 Distinguished Research Lecture at the University of Washington, Tacoma, where he is an associate professor of social work. The lecture is posted online at www.tacoma.washington.edu/library/resources/dr.htm.