

Good afternoon Chairman Nelson, Senator Collins and members of the Senate Special Committee on Aging. Let me begin by saying that I am honored to have been invited to testify before the Committee about this incredibly important issue.

Introduction:

My name is Kenney Miller, and I am the Executive Director of the Down East AIDS Network (DEAN), a small, community-based HIV Services Organization providing services throughout the rural Downeast District of Maine. I also serve as Vice-President to Maine's statutorily mandated HIV Advisory Committee, advising the Governor's cabinet, the Legislature and public and private organizations around issues related to HIV.

The state of Maine is often regarded as one of the grayest states in the nation, with 17.5% of the population aged 65 and up (35). With only 1,654 people living in Maine diagnosed with HIV as of December 2012, Maine is considered a 'low incidence' area (14). Reflecting the aged nature of Maine's population, roughly 50% of persons living with HIV in the state are age 50 or older (14).

At 43.1 persons per square mile, half that of the U.S. as a whole (35), Maine can most definitively be regarded as a rural state. While data concerning population density might seem somewhat out of place in a hearing regarding the changing face of HIV, it is important to note that while 'low incidence,' both people living with HIV and the providers that serve them face a complex set of challenges related to the rural nature of the state. While much has been said and written about HIV and aging, and HIV and rurality, there has been little exploration of intersection of these issues: HIV and aging in a rural context.

A brief biomedical overview:

The world of HIV services is entering previously unexplored territory. With the astounding success of increasingly effective treatment regimens and extensive HIV screening efforts, people are living considerably longer with HIV. Two things are clear. Long-term health outcomes and the extension of life hinge on early diagnosis and entry into care (26) and strict adherence to a carefully planned treatment regimen following diagnosis (15).

On average, in the U.S., life expectancy from diagnosis for people living with HIV increased by 12 years from 1996 to 2005, rising from 10.5 to 22.5 years (16). This dramatic increase in life expectancy is a significant victory in the fight against HIV. A victory against a wasting disease that traumatized an entire generation of gay and bisexual men, people who used injection drugs, and others who watched their friends and loved ones pass away in droves. But such success also represents new ground for people living with HIV and those who serve them, raising a host of new questions about HIV and the aging body.

Biomedical studies concerning HIV and aging are currently trending, the subject of voluminous papers, articles and conferences, all trying to grasp this new reality. From these studies a theme emerges: people living with HIV age at an accelerated rate, well beyond their chronological age, leading to a host of comorbidities that have significant bearing on quality of life.

According to Guaraldi, Orlando, Zona, et al., age-related, noninfectious comorbidities are more common in people living with HIV than the general population. So much so that, with regards to the expression of multiple pathologies, people living with HIV were comparable with persons ten years older (14). This is echoed by Onen and Overton, who argue that premature frailty, dysregulation resulting in an increased susceptibility to environmental stressors, is a manifestation of HIV-related accelerated aging (27). Such rapid aging is thought to be at least in

part the result of persistent inflammation and the gradual deterioration of the immune system (6, 7). Immunosuppression, common both with age and among people living with HIV is associated with both HIV and non-HIV related morbidity and mortality, with the lack of a strong immune system leading to the emergence of diseases normally suppressed (38).

It is clear that comorbidities common among the elderly are manifesting at an earlier age among people living with HIV. There are fewer people with no age-related diseases and more people with multiple comorbidities and earlier onset of comorbidities (32). Researchers have noted increases in illnesses including incidence of cancers (20, 11), liver disease (20, 28), cardiovascular disease (31, 15, 38, 27), reduced bone mass density (20) and renal disease (38, 27) and others.

HIV and Aging – Treatment Adherence:

Beyond the prevalence of comorbidities, the aging process comes with its own set of independent challenges. These are enhanced by an HIV diagnosis, they begin earlier. But they are also of special concern for people living with HIV.

Much like the disease conditions discussed above, people living with HIV demonstrate earlier and with more severe neurocognitive decline including the emergence of cognitive disorders such as dementia (3, 38, 2). This has real consequences for adherence to a treatment regimen, one of the most important factors to maintaining health among people living with HIV. While in general, persons aged 50 and up demonstrate better adherence, those with neurocognitive impairments were found to be at increased risk for suboptimal adherence (19, 12). Poor

adherence opens such individuals up to further immunological and neurocognitive dysfunction, compounding the issue even more (12, 3).

Neurocognitive dysfunction coupled with increased incidence of frailty, reduced bone mass density, cardiovascular disease and other ailments amounts to an early overall functional decline, as is often observed among the elderly years later. Essentially, pain, confusion and low energy make it more difficult to carry out the business of daily living. This means people aging with HIV may experience added difficulty getting to Doctor's appointments, taking their medication, maintaining their hygiene and other functions that are critical to maintaining their health, controlling the virus and preventing infection.

Both functional decline and neurocognitive decline are often cited as influential in higher rates of depression and suicidality among people aging with HIV (13, 37). Such depression is enhanced by the dual isolation experienced by the elderly and infirm and persons living with the stigma of an HIV diagnosis (10, 37). In-depth interviews conducted by C. A. Emlet among people living with HIV aged 50 and up found that 68% of participants had experienced by ageism and HIV stigma. Themes that emerged through the course of Emlet's interviews ranged from rejection, to stereotyping, to fear of contagion to internalized ageism (8). This supports findings that a growing group of aging adults is isolated from informal support networks due to the dual stigma of HIV and ageism (34). Where the quality of social relationships and established social support networks are held to be of great importance to the mental health and outlook of people aging with HIV, this trend may amplify rates of depression and suicidality (4, 24, 17, 36). Depression, meanwhile, has a well-known negative impact on Antiretroviral adherence (40, 36).

Many of DEAN's clients have isolated themselves over the years. Jack Driscoll grew up and spent most of his life in rural Maine. He suffered under the stigma of a conservative rural community, first as a gay man and later due to his HIV status. In spite of this, Jack had been one of the most vocal advocates around HIV issues since he was first diagnosed in the early years of the epidemic. Bombarded with stigma, however, over time Jack withdrew into himself, removing himself from public life. Even the gay community, with which he had felt kinship with at one point, pushed him away. At 55 his self-enforced isolation amplified his issues with alcohol, compounding his social anxiety and depression and keeping him largely homebound. His generally negative outlook on life has alienated his friends, resulting in a relatively weak support system that may be to little in later life.

To summarize, people living and aging with HIV are more susceptible to neurocognitive dysfunction, functional decline and depression. These in turn challenge treatment adherence, one of the most significant predictors of long term health for people living with HIV.

HIV in the Rural U.S. – Treatment Adherence:

Missing from the dialogue concerning HIV and aging thus far, is a consideration of geographic variation in health outcomes, adherence and those intervening variables that affect both of these.

HIV aside, rural patients generally experience barriers to accessing care. These are exacerbated by health complications and stigma for people living with disabilities such as HIV. Local health care systems in nonmetropolitan areas are frequently inadequate in addressing the complex needs of these HIV/AIDS populations, lacking the specialist and primary care physicians trained to work with such disabilities (22). Health care providers in rural settings have broadly been found

to lack the experience, knowledge and understanding needed to adequately work with people living with HIV. In some studies, providers were less likely to have HIV-positive patients and thus less likely to be experienced in the care and treatment of HIV (5). This affected patients' perceptions of their providers' capacity to help them manage their HIV (23).

Beyond sheer knowledge of HIV and HIV treatment and care, many studies indicate that increased levels of provider stigma and discrimination in rural areas constitutes a barrier to receiving needed care (30). Such provider stigma is held to have a negative relationship with receipt of care (21). This is further complicated by concerns over confidentiality, especially given the size of towns in rural areas and the likelihood of encountering people you know (30, 23).

Adam Lawrence was about 55 years old, a somewhat short, slender man from Downeast, Maine. He had contracted the virus through the use of injection drugs some years earlier. Throughout Adam's time with DEAN he was moderately psychologically disturbed, possibly the result of neurocognitive dysfunction. This made him jumpy, prone to outbursts and near conspiratorial imaginings. Over the course of a year Adam cycled through several doctors as he sought care for an open sore that refused to heal. He would enter care and be ejected just as quickly, labeled as a difficult patient due to his outbursts and the narrative that he'd developed around his wound. While overt provider stigma never rose to the fore, it is difficult to imagine that his HIV status and history with drug use did not impact their judgment of him as a patient.

Beyond the adequacy of rural health care providers, geographic distance and transportation are significant barriers for many people living with HIV/AIDS in rural areas (30, 18). This is only

fueled by concerns over the adequacy and confidentiality of local health care providers. Many people living with HIV are forced to travel long distances, and into urban areas, to receive quality care or to see the appropriate specialist (23). The inconvenience incurred by way of longer travel times leads many to put off seeing their doctor (33).

Such barriers to care pose significant risks to adherence and resultant health outcomes. Knowledge and adequacy of a patient's HIV health provider in particular is linked to the likelihood that they are on Antiretroviral Therapy (5).

It bears mention that rural settings may be home to more pronounced levels of stigma and discrimination when compared to urban settings. In a study conducted by Heckman, Somlai, Peters et al. rural persons living with HIV assigned significantly higher problem severity ratings to community residents stigma towards people living with HIV than their metropolitan counterparts (18). This is no surprise, given the closed nature of many rural communities. To this day HIV remains intrinsically linked to gay and bisexual males, people who use injection drugs and other frequently disenfranchised populations that are not always well received by rural communities. That HIV stigma should be felt with special sharpness in rural areas begs the question as to whether depression and isolation resulting from stigma, are felt more sharply in these areas as well, posing significant adherence risks.

Hayden Mitchellson is one of the most ebullient men you'll ever meet. In his late forties, Haden was born and raised in rural Maine. A gay man, Hayden suffered both family and community rejection. Fleeing his home town Hayden built a new space for himself in one of Maine's vibrant tourist communities. Very outgoing, very vocal about HIV issues, Hayden is none-the-less very protective of his status, disclosing it to few for fear of

alienation – isolation of a different sort. Burdened by his past, by his secrets, Hayden sank into depression and self-medicated with alcohol. He bounced from job to job, and eventually wound up on the streets, floating from couch to hotel to park bench. Without stable housing, without transportation, Hayden was unable to seek medical care for his HIV, resulting in prolonged periods between Doctors' visits to check his viral load and CD4 counts and discuss treatment adherence.

The intersection of HIV, Aging and Rurality:

While much has been written and said about HIV and aging, and HIV in rural contexts, there appears to be a dearth of literature concerning the intersection of these two variables as they relate to HIV care. One could reasonably hypothesize that the challenges posed by aging and living in a rural area may amplify one another, much as multiple minority statuses tend to increase risk for negative health outcomes. As such, an aging person living with HIV in a rural environment faces significantly greater barriers to care, stigma, and isolation than an HIV positive person that was either younger and/or lived in an urban setting.

Receipt of care would be negatively affected by both functional and neurocognitive decline, the adequacy of local providers, provider stigma and geographic distance from quality care. HIV stigma, potentially amplified within a closed rural community, would be exacerbated by the individual's experience of ageism. And functional and neurocognitive decline would articulate with the experience of stigma and geographic distance to enhance isolation. Stigma and isolation would in turn lead to greater levels of depression. All of the above combines to threaten the patient's adherence to their HIV treatment regimen and consequently their health.

Conclusion:

The discussion of the relationship between HIV and Aging has emerged at a critical time. As a large cohort of people living with HIV approaches old age it is important that service providers consider how they will accommodate their aging clients. Equally important is a full consideration of the complexities of geography and other variables that may affect adherence and health outcomes. In short, while many rural areas may technically be classified as ‘low-incidence,’ they face special challenges that require special attention. By necessity rural programs have had to adapt and innovate in order to provide high quality HIV services at a time when funding is largely dictated by disease prevalence.

This innovative spirit will serve rural agencies well as they prepare for this brave new world. It bears mentioning, however, that these prevalence based funding formulas do not account for the unique needs and complex problems of people aging with HIV in rural areas and the providers who serve them. Adequate resources are necessary in order to ensure that this particularly vulnerable population is not left to weather the tides of time in isolation, surrounded by stigma and discrimination. Rather they should be supported and empowered, given the tools and resources in the short run that will enable them to live long, full, healthy lives.

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