

Red Ribbon Silver Threads Healthy Aging in the Era of HIV/AIDS

Forum Proceedings



The AIDS Institute
New York State Department of Health
September 2010

Table of Contents

	<u>Page</u>
I. Introduction.....	3
II. Summary of Forum Recommendations.....	4
III. Plenary Sessions.....	9
A Public Health Blueprint for Healthy Aging.....	9
- Dr. Linda Fried	
HIV Clinical Issues in Older Adults and Research from the Front Lines.....	10
- Dr. Amy Justice	
- Dr. Stephen Karpiak	
- Dr. Judith Aberg	
Data Overview and Current Planning and Programs: Federal, State, Local.....	12
- Dr. Deborah Parham Hopson	
- Dr. Monica Sweeney	
- Dr. Alvaro Carrascal	
IV. Workshops	
1. HIV Disease and Co-morbidities in Older Adults.....	14
2. Healthy Aging with HIV: Clinical and Individual Perspectives.....	18
3. Designing a Model of HIV Care and Service for Older Adults.....	24
4. Factors that Increase or Decrease HIV Risk.....	30
5. Sexuality and Sexual Health in an Aging Population.....	34
6. Funding Programs/Paying the Bills.....	41
7. Educating the Workforce, the Community, and the Individual.....	46
V. Access to Additional Forum Materials.....	50

Red Ribbon, Silver Threads: Healthy Aging in the Era of HIV/AIDS

I. Introduction

The increasing number of older adults living with HIV and the often unrecognized threat of HIV infection in people over 50 prompted the AIDS Institute (the Institute) of the New York State Department of Health to sponsor a forum on December 7, 2009, titled “Red Ribbon, Silver Threads: Healthy Aging in the Era of HIV/AIDS.”

Substantial numbers of people aging with HIV was not an issue that clinicians and researchers expected to face even 10 years ago. However, thanks in large part to the success of HIV treatment, in 2007 more than a third of people with HIV in New York State were over 50 and nearly 75% were over 40, reported Humberto Cruz, Director of the AIDS Institute, in opening remarks at the forum.

Medications have dramatically lengthened and improved the quality of life for people with HIV, but life spans are still not normal, and people struggling with long term HIV infection face the many other chronic diseases that challenge all older adults. The possibility of new HIV infection is also a threat to sexually active but uninformed or misinformed seniors, who are often diagnosed with HIV infection late in the course of the disease. Lack of knowledge or the stigma still associated with HIV keeps many people from learning their status or seeking treatment.

The forum was intended to highlight these issues and bring experts from the fields of HIV/AIDS, chronic disease, and geriatrics together with consumers, caregivers, and community members to recommend steps to improve HIV prevention and care for older adults.

More than 170 forum participants, including clinicians, researchers, program directors, government officials, policy planners, and interested older adults were invited to the City University of New York Graduate Center to make specific program, policy, and funding recommendations to the Institute. They attended plenary sessions and workshops designed to allow in depth discussions among a cross section of people on issues related to clinical care, prevention, financing, and public and professional education and training and to help formulate an effective model of care for older adults with HIV.

This report presents the program, policy, and funding recommendations from the forum. It is provided as a resource for policy makers, funders, public and private organizations, and individuals who are interested in issues related to HIV/AIDS and aging.

II. Summary of Forum Recommendations

A particular focus of the forum, reflected in its title, was *healthy* aging; that is, the intent to extend not only the length of life, but its quality. Healthy aging for people with and without HIV infection means preventing or delaying conditions that can become chronic and disabling, thus compressing any illness or disability into a shorter period at the end of life, a goal of obvious individual and societal value. Healthy aging requires personal commitment to good health habits and, for older people with HIV, it requires that clinicians understand the ways that HIV can accelerate the process of aging and aging can change the course of HIV disease.

Recommendations to serve these objectives addressed topics in several broad categories:

Education targeted to individuals:

- healthy behavior and healthy aging
- risk of HIV infection for older adults
- importance of HIV and STI testing
- symptoms of acute HIV infection

Education and planning targeted to communities:

- implications of HIV and aging for individuals and communities
- social networks, support, and infrastructure for aging adults
- ageism and the stigma of HIV

Clinical care:

- HIV prevention, including discussion of sexual behavior and sexual health care
- routine HIV testing for all sexually active adults
- screening for and treatment of diseases of aging that may have earlier onset in people with HIV
- assessment of the total burden of HIV and co-occurring diseases and their impact on functional status
- coordination of care encompassing primary, specialty, and support services

Workforce planning and training:

- appropriate care for older adults regardless of setting or type of provider
- adequate number of providers skilled in chronic disease management, geriatrics and HIV care
- cross training, interdisciplinary collaboration, and team management

Policy and funding:

- models of care integrating the management of chronic disease, geriatrics and HIV services
- reduction of health disparities
- improved access to care for seniors
- active participation of older adults in the design and implementation of services

- provider reimbursement for assessment, counseling, and care coordination

Research:

- interaction of HIV disease and the aging process
 - HIV incidence and transmission among seniors
 - evaluation of clinical outcomes
-

The body of the report offers presentation summaries and details specific recommendations and discussion points from each workshop, which readers are urged to review. However, since many proposals overlap, the primary issues are summarized below.

Forum Recommendations:

Education Targeted to Individuals

- I. Develop and implement a multi-faceted public education campaign about sexual health and HIV prevention and treatment specifically for older adults.*

HIV prevention messages should be designed for seniors with varied backgrounds and needs. Prevention programs should use a range of strategies (including social media) and settings (traditional places seniors gather and non-traditional places they may be reached).

Education and Planning Targeted to Communities

- II. Design community education strategies to increase public understanding of healthy aging, HIV risk factors, and HIV and STI testing and treatment, and to decrease stigma surrounding both HIV and aging.*
- III. Establish a senior Consumer Advisory Board (CAB) and engage older adult peers in community education and in designing and improving services.*

Education should address the many HIV and STI risk factors for older adults, including lack of access to health care, HIV information, and testing; inadequate support services; social isolation; cultural, community, and provider assumptions that seniors are sexually inactive; and issues such as poverty, immigration status, mental health, and drug use, which can affect sexual behavior and health care outcomes.

Communities should undertake activities and infrastructure improvements to address these issues and to encourage healthy aging in a variety of ways, including utilizing the skills and experience of older adults with and without HIV and recognizing the vital roles they can play.

Clinical Care

- IV. Amend HIV Clinical Guidelines to focus recommendations specifically on assessment and treatment of aging patients, particularly co-morbidities and the impact of an individual's total disease burden, and revisit the HIV primary care medical model to highlight issues of aging.***
- V. Discuss sexual behavior and injection drug use with older adults and make HIV and STI testing a routine part of health care for sexually active people of any age.***
- VI. Devise strategies to improve communication with older adults, especially those with hearing, vision, health literacy, dementia, or other problems, in order to facilitate patient disclosure of symptoms and encourage earlier identification and treatment of HIV infection and co-morbidities.***

Physicians should be aware of the possibility of rapid aging in PLWHAs and variation in the presentation of diseases of the aging, which may require earlier treatment than current age defined protocols.

Standard care for older adults should include screening for frailty; determination of functional status; discussions about sexuality and HIV/STIs; screening for physical abuse, substance abuse, and mental health; assessment of socioeconomic issues such as isolation and poverty (that may lead to depression, poor nutrition, and other problems), and attention to generational barriers to care, polypharmacy, and health care coordination. New tools should be developed and used to assess total disease burden and impact.

Physiological diversity increases with age. Providers should understand that there is no one senior population, but rather differences in health and service needs among various older age groups and among individuals at any given age. Further, behaviors and beliefs vary with sexual orientation, marital status, socioeconomic status, and culture.

Professional Education/Workforce Planning and Training

- VII. Expand professional education and workforce training about HIV and aging at all levels to assure adequate and culturally competent HIV and chronic disease management and staffing, encourage clinicians and health care teams to discuss sexuality and provide sexual health care to older adults, and improve coordination of care.***

Education should cross-train providers, including HIV, primary care, and geriatrics MDs, Pas, NPs, and case managers, as well as specialists in mental health, substance use, and specific populations (LGBT, women, immigrants).

Agencies should support collaborations with educational institutions to address workforce development and ensure that providers are able to meet the needs of aging PLWHAs.

Policy and Funding

- VIII. Engage existing government-sponsored task forces of agency planners, providers, consumers, and workplace organizations to review emerging models of geriatric and HIV care. Approaches to outreach, training, and care coordination should also be examined to reflect new models appropriate to various aging populations.*
- IX. Encourage the development of best practices, networks, and collaborations for co-located, integrated, accessible HIV and aging services.*
- X. Review existing models of care for geriatric and chronically ill populations to determine how they may be modified and enhanced for use by aging PLWHAs. In addition, review current HIV program models, including COBRA comprehensive case management, AIDS nursing homes, and AIDS adult day care to meet the health care, social support, and other needs of the aging HIV/AIDS population.*
- XI. Develop an expanded continuum of supportive and residential care options, such as supportive housing, social day care, naturally occurring retirement communities, and assisted living for persons aging with HIV.*

Program models should incorporate prevention and treatment for co-occurring conditions, and comprehensive systems of care for PLWHAs should address multiple medical needs. Prevention programs should raise HIV and STI awareness and encourage testing among older people. Innovative strategies should be engaged to reduce the main risk factors for chronic diseases among PLWHAs (smoking, lack of physical activity, and poor diet).

Intra- and interagency collaboration among New York State agencies, including the AIDS Institute, the Department of Aging, Office of Mental Health, Office of Alcoholism and Substance Abuse Services, Office of Temporary and Disability Assistance, and other units within the Department of Health should focus upon developing effective program models for aging adults.

Care and services should be established in communities where older and retired adults are located. Home and community based care for aging in place with HIV should be provided in residential settings, such as supportive housing and assisted living programs.

Care should be further facilitated by improving supportive services for seniors, such as transportation, mental health and substance abuse treatment, and case management.

Interoperable electronic health record systems should permit patient access to personal health records and provider sharing of health information consistent with confidentiality law.

Research

XII. Encourage research on the interaction of HIV disease and the aging process. Collect and analyze data on HIV risk factors and HIV incidence and transmission among seniors. Evaluate clinical outcomes, using research findings to inform programs and services.

Multi-disciplinary collaboration, meaningful community partnerships, and continuous quality improvement of programs and planning based on research data could substantially and quickly improve understanding of HIV and aging issues and interventions for older adults.

Emerging Federal and State Law

Passage of the Federal Patient Protection and Affordable Care Act (PPACA), New York State's multiyear health care restructuring now underway, and the newly expanded HIV testing law will influence the HIV and aging recommendations outlined in this report. The AIDS Institute is currently analyzing the impact of federal health care reform on the delivery of health care and supportive services to persons with HIV. Efforts are underway to ensure HIV inclusion in new federal funding streams for prevention, wellness, health disparities, and work force investments. Federal health care reform includes opportunities for support of new models of care coordination, primary care, and community based long term care services using Medicaid, Medicare, and private insurance. The AIDS Institute will participate in health care reform implementation teams within the Department and through interagency work groups. During this multi-year transition, clear communication channels will be established among stakeholders, including government agencies, health providers, community organizations, and PLWHAs. Multiple new health insurance options will bring a renewed focus on health education, case management, and benefit coordination.

Implementation of the NY State expanded HIV testing law is a priority for the AIDS Institute. The law requires that an HIV test be offered to every individual between the ages of 13 and 64 years of age (and younger or older if there is evidence of HIV related risk activity) in most health care sites. This requirement will have a direct impact on older adults, who have historically received inadequate assessment for HIV risk factors and had limited access to testing.

Additional Forum materials: This document offers summaries of slides and oral presentations submitted by forum speakers. Text included here should not be construed as a transcript of the live presentation.

The slide presentations of plenary and workshop panel speakers, the forum agenda, a webcast of the morning plenaries, a resource list of websites and articles, the full text of some publications, and other materials and links are available online at:

<http://www.health.state.ny.us/diseases/aids/conference/index.htm>

III. Plenary Sessions

A Public Health Blueprint for Healthy Aging

Linda Fried, MD, MPH

Dean of the Mailman School of Public Health

Professor of Medicine and Epidemiology

Columbia University

Member, MacArthur Foundation Research Network on an Aging Society

Aging societies are a national and international trend. By 2030, nearly a quarter of the US population will be over 65. There will be as many seniors as children – compared to only 4% over 65 about 100 years ago. Although this will be the best educated, healthiest group of seniors in history, how healthy they remain in their last decades will be critical to families, to cities, and to society.

Generally people move through a continuum from robust health to chronic disease, then disability, frailty, and dependency to end of life. Currently, 80% of those over 65 have at least one chronic disease, and 50% have two or more. Disability generally follows rapidly after a major health incident, such as a heart attack or stroke. Frailty (weight loss, weak grip, slow movement, low physical activity, and exhaustion) often develops after the onset of disability and, in turn, increases the risk of additional health crises. Frailty predicts poor survival. The longer the time with chronic HIV infection, the greater the risk of frailty.

Healthy aging, that is, compressing morbidity by delaying the onset of increasingly disabling conditions, is an important clinical, economic, and public health goal. In developed countries, people will live a third or more of their lives after retirement. It is important to increase the proportion of people who live not just longer but more of their later years as healthy, productive, physically and socially active adults, adding “life to our years.”

A life course, multi-faceted approach to prevention of chronic disease is essential. In the last half century, improved care and all three types of prevention -- primary, secondary, and tertiary (treatment that minimizes the symptoms and consequences of disease) – have decreased deaths from heart disease and stroke, even in the oldest age groups, and have had dramatic impact on health. It is known that regular physical exercise and cognitive stimulation, together with social engagement that includes supportive social networks, structured activity, and meaningful roles all contribute to healthy aging, and other predictors have been identified. Risk factors are varied and synergistic. Prevention of dementia, for example, involves education, environment, activities, and decreasing the risk of stroke. Hearing loss also predicts dementia.

Health disparities persist. African Americans aged 49 to 65 in inner cities experience disabilities ten years earlier than suburban African Americans or whites, not because of genetic predisposition but because they have more risk factors.

Health professionals must work harder to prevent chronic disease from a very young age. We must

train a health care workforce that understands how risks and health needs change with age. Obesity and low strength, for example, result in difficulty walking later in life, which is not a disease but affects the quality of life.

Public health must end the division of issues into silos of aging, HIV, and other chronic diseases. Providers should take a multi-disciplinary approach to chronic HIV infection, design a new integrated approach to health care and public health, and re-think expectations about health at every age.

HIV Clinical Issues in Older Adults and Research from the Front Lines

Amy Justice, MD

Principal Investigator

Veterans Aging Cohort Study (VACS)

Associate Professor of Medicine

Yale University School of Medicine

While life spans for people with HIV have increased, they are still not normal. On average, those in treatment with CD4 counts over 200 will lose an estimated 14% of their remaining life expectancy, while those with CD4 counts under 100 will lose 46%. And HIV diagnoses in people over 50 are a larger share of new infections: 20% in 2005, compared to about 15% in 2001. While older patients tend to follow medication regimens better, and thus show a more robust decline in viral load, their first year increase in CD4 count is not as large as that in younger patients (although it catches up within three years).

As people age, outcomes for those with HIV are increasingly affected by non-HIV conditions as well as behavior and other factors. AIDS-defining conditions are increasingly rare and have variable impact on mortality. HIV infection increases the risk and the progression of non-AIDS conditions, which may justify earlier HIV treatment, but HIV treatment itself may cause or intensify non-AIDS conditions.

While researchers try to disentangle the normal process of aging from HIV-related issues, clinicians should focus on the total burden of disease for each individual, the degree of disability it produces, and its impact on the patient's life. They should assume that every clinical problem in people with HIV has some relation to the infection, and that every risk factor has far reaching, interdependent consequences. HIV and length of time on antiretroviral treatment, for example, are associated with low bone density. But other factors are also relevant: smoking, alcohol use, weight bearing exercise, menopause, and nutrition, especially vitamin D. The interaction of HIV, hepatitis, and substance abuse is also complex.

Thus, CD4 levels and viral load are insufficient indicators of outcome. Even looking at functional status is insufficient. New assessment tools, such as the VACS Risk Index, should be used to provide a comprehensive measure of disease burden. Providers need a new paradigm that takes many factors into account to provide estimates of treatment outcomes.

Stephen Karpiak, PhD

Associate Director for Research
AIDS Community Research Initiative of America (ACRIA)

ACRIA's study of 1,000 older adults with HIV in New York City, titled "Research on Older Adults with HIV" (ROAH), found high rates of isolation, smoking, alcohol use, and untreated depression. Depression was the leading health problem after HIV. Two thirds of participants were clinically assessed to be moderately to severely depressed, although all were in medical care, suggesting inadequate diagnosis of depression and follow-up for treatment.

About 70% of study subjects lived alone. Depression and social isolation are associated with decreased adherence to HIV medications and are correlated with concurrent medical problems, or comorbidities. Treatment of depression and promotion of social networks, an important health care resource, could have substantial impact on healthy aging.

Judith Aberg, MD

Director of Virology and of the AIDS Clinical Trials Unit
Bellevue Hospital Center
New York University School of Medicine

In clinical care, the term "payoff time" is the point at which there is a net benefit of a treatment greater than its risks. When life expectancy is short, some longer term treatments or procedures may not be indicated. This principle guides the development of standards of care and the actual practice of health care tailored to individual patients.

However, assumptions about life expectancy, course of disease, and other medical conditions may be different for people with HIV and thus affect payoff times. People with HIV have the same or increased risk for other diseases as people without HIV; 80% have at least one other chronic disease. Older age also has an impact on HIV infection and treatment. For example, the elderly suffer two to three times the rate of adverse drug reactions.

Prevention and early detection are extremely valuable. Screening for chronic diseases in people with HIV should begin earlier, perhaps at age 40, and tools should be devised that take HIV into account as a factor that increases risk for many or most conditions of aging. Even a self-administered screen, like the Geriatric Periodic Health Exam, which takes less than 30 minutes, can be a useful indication of frailty, sensory loss, depression, and other issues. A high percent of some chronic diseases, 90% of diabetes mellitus and 80% of coronary heart disease, could be prevented through nutrition, exercise, smoking cessation, and stress management. Nutrition could help prevent 20% of cancers; screening could prevent 90% of cervical cancer; and mammography about one third of breast cancers. Screening for these and other conditions, like fracture risk and vitamin D deficiency, could be very helpful for people with HIV.

Data Overview and Current Planning and Programs: Federal, State, Local

Deborah Parham Hopson, PhD, MSPH, RN

Associate Administrator
HIV/AIDS Bureau
U.S. Health Research and Services Administration

By 2015, 50% of people with HIV in the country will be over 50. Federal and state agency partners are focused on four major goals: HIV prevention and education, clinical and behavioral research, earlier diagnosis of HIV, and treatment for all who test positive. Efforts should address the needs of specific populations, especially African Americans and Hispanics, who have much higher rates of infection than whites. Best practices for people over 50 should be identified.

New and ongoing research at NIH focuses on the biology of HIV in older adults, the interaction of HIV with other diseases of aging, behavioral research, services in various regions, performance measures and statistics, and Medicaid/Medicare policies. The issue of aging with HIV will influence national AIDS strategies.

Monica Sweeney, MD, MPH

Assistant Commissioner
Bureau of HIV/AIDS Prevention and Control
New York City Department of Health and Mental Hygiene

New York City has less than 3% of the U.S. population, but 17% of AIDS deaths, with a case rate still three times the U.S. average. From 2001 to 2007, the proportion of people with HIV who are over 50 increased from 22 to 35%. Three fourths are black or Hispanic, and more than 80% of those newly diagnosed over 50 are black or Hispanic.

Although New York City is funding community programs, distributing materials and condoms, and increasing testing, the greatest impact on HIV rates will come with changes in socioeconomic factors like poverty, housing, and education that change the context for HIV risk. Other improvements would result from research and from policy and program changes, like better workforce training, new service models, and reimbursement that would allow patients to arrange appointments with several providers in one visit.

Alvaro Carrascal, MD, MPH

Director of the Division of HIV Health Care
New York State Department of Health AIDS Institute

Data comparing people with HIV/AIDS in New York State in 2002 and 2008 show a dramatic 67% increase in those aged 50-59 (from 20,473 to 34,140), and an increase of more than 140% in those over age 60 (from 5,341 to 12,881). At the end of 2008, three fourths of the people living with HIV/AIDS were over age 40 and 38% were 50 and older. New York State now has 47,000 people over age 50 with HIV/AIDS, the great majority African American and Hispanic.

They face, in addition to HIV, all of the normal problems of aging, especially diabetes, cardiovascular disease, and cancer. These and other conditions can affect people with HIV earlier in the aging process. People with HIV/AIDS also have a high incidence of risk factors for chronic conditions, such as smoking, sedentary lifestyle, poor diet, and obesity. For example, the rate of smoking in the HIV/AIDS population was found to be nearly 60% in 2005, three times higher than in the general population. However, these risks are modifiable and should, therefore, receive increased attention.

The aging of the HIV/AIDS population also has implications for costs and health care financing. In 2007, New York State Medicaid spending per recipient with HIV/AIDS was approximately \$25,000 for people under age 40, but \$40,000 for those age 40 and older. The data suggest that health care and prevention programs in NY State must better address issues of aging with HIV/AIDS.

Discussion

Although it's difficult to bring the HIV, aging, and chronic care approaches together in the setting of community based organizations, this integration could be facilitated by cross training at HIV and geriatrics centers, provider collaboration, and sharing of information.

It's also difficult to know how to change socioeconomic conditions so they will be more conducive to health. It is essential to broaden the conversation, to include not only the usual health providers and policy planners but people concerned with transportation, employment, education, and other issues. Medicine alone will not solve health problems. It is essential to prevent them. "We need a health system, not a health care system."

Geriatricians are experienced in designing coordinated care. There must be an integrated system of services for seniors, as well as help with transitions of various kinds (adjusting to loss, dysfunction and disability, moves, changes in providers). In other countries, services for older adults are coordinated and co-located.

In New York, the HIV models of care were based on the geriatric model of a continuum of services and care coordination. They were further developed in the Special Needs Plans. But HIV should not be separate from other types of care. Service planning should take a holistic view of patients.

Another difficulty will be getting providers to address the issue of sexuality in older adults. HRSA has a relationship with medical schools but does not set curricula. HIV providers generally do discuss sexual behavior, but other providers do not. Perhaps the AIDS Education and Training Centers and HIV providers everywhere could play a role in educating others about this issue. It would also be helpful to increase awareness and decrease stigma among providers concerning patients with substance use.

The current CDC age cap for routine HIV testing is 64. There should be no cap, especially now that Medicare will pay for testing.

IV. Workshops

Workshop #1 – Clinical

HIV Disease and Co-Morbidities in Older Adults

Panel Presentations (See also slide presentations.)

Moderator:

Peter A. Selwyn, MD, MPH
Professor and Chair
Department of Family and Social Medicine
Albert Einstein College of Medicine
Montefiore Medical Center

HIV, Aging, and Co-Morbidities

Sanjiv Shah, MD
North Shore University Hospital
Medical Director, HIV Services, MetroPlus Health Plan

Aging may increase the damaging effects of HIV on the immune system and HIV disease progression, decreasing time from HIV infection to AIDS diagnosis and decreasing survival time after diagnosis. Among people diagnosed with AIDS from 1996 to 2003, 75% of those aged 25-35 survived nine years, while only about 50% of those over 55 did. Although older patients initiating drug treatment have poorer CD4 recovery levels in some studies, they have better viral suppression, presumably because of better treatment adherence, and are less likely to die of HIV-related illness.

While more than a third of all people will have a chronic condition affecting normal functioning by age 65, those over 55 with HIV have four times as many chronic conditions as those with HIV under 45. In a study of 165 older people with HIV, each had an average of 2.4 chronic conditions besides HIV and used an average of 2.7 chronic non-HIV medications, but these did not have any impact on HIV treatment, viral load, or discontinuation of medications because of side effects.

Although HIV increases vulnerability to some uncommon chronic conditions, such as hyperlipidemia or hepatitis C, many conditions associated with the normal process of aging also overlap with those of HIV disease, such as cardiovascular disease, diabetes, osteoporosis, malignancies, and neurocognitive disorders. According to the D.A.D. study, higher CD4 count and lower viral load decrease death from HIV and non-HIV causes, suggesting a role for immunosuppression in deaths not typically considered HIV-related.

HIV-related dementia is at least three times more likely in people over 50 with HIV than in those from 20 to 40, and may complicate treatment adherence. However, common age-related comorbidities, such as atherosclerosis, hypertension, hyperlipidemia, and diabetes, are also linked to dementia. Mental status assessment should be part of routine care for people with HIV.

People with HIV also have higher rates of osteoporosis, vitamin D deficiency, heart attack, lipodystrophies, and a number of cancers. African Americans are at particularly increased risk for kidney failure. The impact of HIV on the risk of diabetes is unclear. The advent of co-morbidities is dependent on the interaction of factors related to HIV, the genetics and aging of the individual, and the personal and social environment (medications, nutrition, housing, etc.).

Activation of the immune system and the consequent inflammation produced by HIV infection and treatment leads to immune exhaustion, more rapid HIV disease progression, and vulnerability to other disorders, very much like the normal aging process. Monitoring of patients with HIV should include screening for the normal diseases of aging, as well as for problems associated with issues such as polypharmacy and depression. While HIV is increasingly prevalent in older adults and complicated by aging, HIV can still be successfully treated despite co-morbidities. More research on HIV in aging people, including clinical trials, should be undertaken. Providers should discuss sexuality with all older adults.

Reaching Families: An Intergenerational Approach

J. Edward Shaw

Chair, Public Policy/Advocacy Committee

NY Association on HIV Over 50, Inc.

Although in New York City and State, people over 50 constitute more than a third of those with HIV, many others are affected as caregivers, wage earners, foster parents, family, and community members. Older adults infected and affected by HIV have a wide range of needs, which should be addressed through partnerships among many types of agencies and individuals: clinical providers, government, politicians, aging services, education groups, faith-based organizations, family, and friends.

An intergenerational approach to HIV prevention and projects in a great variety of settings incorporating lessons from existing HIV programs would be most effective. These include especially transportation and co-location of services, as well as case management, peer education, and other strategies. New paradigms as well as adaptation of existing services will be required. In addition to the co-morbidities of age and faster progression of HIV disease in older adults, challenges include the denial of HIV risk among older adults and clinicians, the lack of HIV information and services designed for seniors, unwillingness to disclose HIV status, ageism, and HIV stigma.

Discussion

There is a need for better guidance regarding older patients in the HIV clinical guidelines and modification of the primary care model to better address the needs of aging patients. In addition to clinical concerns, issues include more attention to prevention and screening for co-morbidities, co-location and coordination of subspecialty care, and oversight of the clinical team.

Public and professional education and training regarding prevention and treatment services for older adults are essential.

RECOMMENDATIONS

- 1. Amend the HIV Clinical Guidelines to incorporate guidance concerning assessment of the needs of aging patients, particularly the impact of their “cumulative injury,” or total disease burden.**
 - Changes should be made in the screening protocols for older patients.
 - Treatment protocols for physicians should increase awareness of the possibility of rapid aging in PLWHAs and variation in the presentation of diseases of the aging. These factors may require earlier treatment than current age defined protocols.

- 2. Revisit the HIV primary care medical model, which may require a broader view inclusive of issues of aging.**
 - A new model of care coordination should be identified that includes issues of aging, better collaboration among sub-specialties, and a clear leader of the clinical team. However, HIV primary care is still central, and issues of aging should not overshadow the need for comprehensive HIV specific care.
 - There is a need for additional attention to prevention issues in the general aging population and additional screening for co-morbidities so that diagnoses do not occur simultaneously with or after HIV infection.
 - The AIDS Institute should expand data gathering and analysis to better understand issues that affect aging PLWHAs in comparison with non-HIV infected aging populations.
 - Additional funding through RFAs should support wellness and health promotion for aging populations, including behavioral programs, such as smoking cessation, better nutrition, and exercise.
 - Resources should also be expanded for HIV-testing in sites that serve older populations, such as cardiac care units.

- 3. Develop media campaigns and public education materials concerning HIV and aging.**
 - Prevention health messages about aging issues should be tailored for and marketed to HIV aging populations.
 - Web based programs for patient medical information should be designed. These would be secure systems maintained by patients with access granted to clinicians through patient release.

4. Maximize co-located services for sub-specialty care, and strengthen linkages with off-site sub-specialty services.

- Sub-specialist care should be located at the same site as HIV primary care, allowing for same day patient care visits.
- Enhanced support should be provided for the use of medical case managers for care coordination.
- Reimbursement structures should be re-examined to incentivize consultation.
- Existing resources should be re-examined for optimal use.

5. Expand the scope of the current Clinical Education Initiative to include medical school and residency programs.

- Education specific to HIV and aging for clinicians in practice and in medical school should be instituted.
- The Nicholas Rango Clinical Scholars Program should be expanded to include a mental health track for education of HIV mental health specialists.

Workshop #2 - Clinical

Healthy Aging with HIV: Clinical and Individual Perspectives

Panel Presentations (See also slide presentations.)

Moderator:

Jan Carl Park

Director

Health and Human Services Planning

New York City Department of Health and Mental Hygiene

Healthy Aging with HIV/AIDS

Kathleen M. Nokes, PhD, RN, FAAN

Professor, Hunter-Bellevue School of Nursing

Hunter College, City University of New York.

In the Veterans Aging Cohort Study of more than 100,000 people, two thirds of whom were HIV-positive, uninfected veterans overall had more medical conditions than non-veterans, but study participants older than 50 with HIV had more substance use, psychiatric, and medical disorders than older HIV-negative veterans. Older age, race, and cultural beliefs were correlated with symptom disclosure.

Better preparation for health care visits by both patients and providers can improve outcomes. In the chronic care model, support for patient self management and decisions, as well as design of health care information and delivery systems, can have impact. The Institute for Healthcare Improvement's Self-Monitoring Symptom Log can be very useful to improve symptom reporting and track health care goals. This tool allows patients to see how changes in diet, medications, activity, emotions, or other factors affect their symptoms, can be used to inform health care providers, and helps patients track progress on self-management goals.

The Graying of HIV in America

L. Jeannine Bookhardt-Murray, MD

Medical Director, Harlem United Community AIDS Center

Consultant to the Medical Director,

NY State Department of Health AIDS Institute

Physiological diversity increases within each age cohort as people age. The definitions of senior, elderly, and old are variable, although the term "frail elderly" includes anyone over 50 dependent on others for care.

A number of trends are converging with ominous implications:

- 120 million Americans with inadequate or no health insurance;
- increasing cost of primary, chronic, and end of life care;
- increasing bureaucratic and clinical demands on primary care providers;

- decreasing medical student interest in primary care coupled with an exodus of experienced providers from medical practice;
- a projected shortage of subspecialists like geriatricians;
- projected shortfalls in Medicare;
- decreasing support for teaching hospitals;
- inadequate physician voice in policy development;
- the imminent retirement of the “baby boom” generation;
- a much larger percent of the population in general that is or will soon be over 50. (By 2050, 21% of all Americans will be over 65, part of a global demographic shift);
- much greater cultural diversity among older adults, which may increase communication barriers. (By 2030, 72% of people over 65 in the US will be non-white.).

The process of normal aging, together with the impact of HIV on aging and of aging on HIV, presents challenges for both HIV specialists and general primary care providers. Treatment issues for older adults, detailed in a number of studies, include later HIV diagnosis, faster progression to AIDS, and possible medication adherence problems related to memory, vision, disability, or drug interactions and side effects. While older people with HIV in treatment have a five-year mortality rate of 50%, those receiving inadequate care have a 25% mortality rate within 12 months.

By 2015, 50% of PLWHAs will be over 50. However the needs of the newly diagnosed differ from those with a long term HIV diagnosis. In addition, many people over 50 do not know their HIV status and/or are at risk of infection. These demographics require a paradigm shift for clinicians. Formerly concerned with enhancing immune response and preventing opportunistic infections, HIV specialists must now become generalists focused equally on non-HIV related disorders. People with HIV have an increased risk of cardiovascular disease, metabolic disorders including diabetes, and many forms of cancer. Glaucoma, osteoporosis, influenza, TB, pneumonia, substance use, mental health, cognitive function, sexual function, nutrition, social isolation, housing, and transportation are all of concern. Screening must be comprehensive.

The Graying of the HIV Epidemic

Jan Carl Park

Director, Health and Human Services Planning Council of New York
New York City Department of Health and Mental Hygiene

In New York City in 2007, there were more than 102,000 people living with HIV, more than 38% in their 40s, nearly 26% in their 50s, and more than 9% in their 60s.

Older people are diagnosed with HIV later in the course of disease, often with a concurrent diagnosis of AIDS. Of 3,787 new diagnoses in 2007, 25.8% overall but 30.6% of those with concurrent HIV/AIDS diagnosis were in their 40s; just over 12% overall but 18% of concurrently diagnosed were in their 50s; and just over 5% overall but 8.8% of concurrently diagnosed were in their 60s. (By contrast, people in their 20s accounted for nearly 26% of all HIV diagnoses but 16.9% of concurrent diagnoses.)

More than 66,000 people over 50 with HIV received Ryan White funded services in New York City in FY 2008. The most frequently used services (in order from 65% to 31% of clients) were hepatitis C screening, transportation, home care, nutrition, treatment adherence, outpatient, care maintenance, housing, mental health, and case management. More than one third also received housing referral coordination for PLWHAs living in single room occupancy hotels; more than one quarter received supportive counseling and family stabilization; and a similar percent received services offered to prison releasees.

Discussion

Part of good communication between provider and patient is understanding the difference in perspective. Healthy may mean something very different to service providers than it does to patients. Providers offer health recommendations, but individuals also decide what is healthy for them.

Patient education should include how to provide information about symptoms to doctors and to advocate for themselves. Self monitoring tools can be very useful. Medical visits are short, and there is often a serious disconnect between patient and provider. The physician wants to focus on the number one issue; others may be addressed at the next visit or never. Part of the job is to determine what older PLWHAs can do to take responsibility for their own care and what providers can do. Only the patient knows his or her complete health status, but many people have language barriers or other issues like depression or agitation and have no advocate.

Patient health education, determining the best system for getting information, and building patient skills at symptom reporting must happen before the doctor visit, perhaps in community education programs. However, providers should also explain to patients concepts like “medical home” and why sharing of information among providers is critical.

Part of the Ryan White coordinated model of care directs funding into new RFPs to develop teams of providers, including a patient navigator and care coordinator, so that patients can speak with peers, who can even do some screening. A network of care coordinators in the community, like that for Cobra, would be useful. The medical case management program is an advocate care model, but the bureaucratic logistics are onerous. The geriatric care model features coordination of services. There is a need for more adult day care programs and community centers for older people, like LGBT centers. It would be helpful to explore the barriers to putting good ideas into practice.

The AIDS community must not be left out of the discussion about electronic medical records, medical homes, and reimbursement structures. Providers want to provide comprehensive care and still be cost effective. But they often don't know when a patient has been admitted to a hospital and don't get test results or other information, so efforts are duplicated. Patients suffer and so does the cost of health care. Hospitals should be mandated to send information to the community organizations where people get care. Consent forms must be applicable across agencies and facilities. Personal health record systems should be standardized and complete, including information on substance use, nutrition, etc., and software developed for easy use. Reimbursement should cover all tests, like vitamin D level, that are recommended for seniors.

HIV is a chronic disease. HIV providers should be current on recommendations concerning primary care, and primary care providers must know how to treat HIV. Cross training of geriatrics, HIV, family practitioners, and primary care providers, including nurse practitioners and physician assistants, is essential.

Guidelines should add a “functional status” screening and tools to address the frailty issue. Self-reports and comparisons over time would be an indicator of decline. The ideal is to be healthy until a precipitous decline prior to death.

Other provider education issues include the appropriate use of mental health and substance use services --detoxification is the most expensive treatment; regular counseling is more cost effective -- and cultural competency concerning sexual health. Standard patient forms indicate single or married status, but there is no place to indicate partner or bisexual. Providers ask about age but not about sexual practices. There is still a lot of stigma about HIV, mental illness, substance use, and sexual behavior. Depression and social isolation are significant problems for older people.

RECOMMENDATIONS

1. Develop strategies to improve patient disclosure of symptoms to primary care providers.

- Strategies for better symptom reporting should include assessment of patient literacy level, patient education concerning symptom prioritizing and self-monitoring (perhaps using the Institute for Healthcare Improvement’s self-monitoring symptom log), and education for providers concerning screening for functional status and other issues.
- Insurance and reimbursement policies should be reviewed to be sure that diagnostic tests and procedures are covered.
- Reducing excessive paperwork and bureaucratic requirements would streamline care.

2. Institute broad-based patient, provider, and community education about the needs of aging patients.

- Provider education should utilize cross training of multidisciplinary team members and involve all staff involved in patient care.
- Provider education should recognize that provider and patient perspectives differ, that providers have an important role in patient education, and that specific skills are required for care of the aging.
- The medical home model provides continuity and coordination of patient care and is useful in understanding the implications of aging.

- Ways should be devised to increase patient knowledge about aging and clinical tests and to increase patient empowerment and input into the education process.
- Community education programs should be aimed at improving awareness about and within aging populations, greater understanding of aging issues, and reducing the stigma of ageism and HIV.
- An advocacy care network would be valuable to promote and maintain better care for the aging.

3. Increase the competence of providers regarding specific aging issues in the clinical setting, including assessment of frailty, functional status, substance use, and mental health, and particularly addressing sexuality, stigma, medication management, and the critical need for care coordination.

- Standard care for older adults should include screening for frailty, determination of functional status, discussions about sexuality and HIV/STIs, screening for abuse, assessment of social and mental health issues such as isolation and poverty (that may lead to depression, poor nutrition, and other problems), and attention to generational barriers to care, polypharmacy, and health care coordination.
- Policy changes should increase substance use and mental health services for the aging, and providers should be made more aware of the resources available for referrals.
- Best practices from gerontology should be adapted for use with aging PLWHAs.
- Older adult peers should be involved in expanding education and improving services.
- Cross-training of providers, especially concerning sexuality, stigma, substance use, and mental health, should include HIV and internal medicine MDs, PAs (Physician Assistants), and NPs (Nurse Practitioners).
- A program for the aging comparable to COBRA case management may be needed to ensure care coordination and service continuity.

4. Address barriers to the sharing of patient medical information among providers and with patients without violating patient confidentiality.

- Provider organizations, e.g. CBOs and hospitals, should have access to patient health records, and patients should have access to their personal health records, including lab results and other information. Policies should conform to HIPAA and HIV confidentiality law that while permitting better coordination of patient care.

- Software should be developed and used that permits health record system interoperability.

Workshop #3 - Models of Care

Designing a Model of HIV Care and Service for Older Adults

Panel Presentations (See also slide presentations.)

Moderator:

Christopher Miller
Director of Public Affairs
New York City Department for the Aging

Health Aging in the Era of HIV/AIDS

Carmen Sanchez, MSW
Aging Services Program Specialist
U.S. Department of Health and Human Services
Administration on Aging

Although the Administration on Aging (AOA) does not have programs dedicated to HIV/AIDS, the agency administers Title III D of the Older American's Act, which supports health promotion and disease prevention information and services. Settings are senior centers, meal sites, and others particularly focused on the medically underserved.

Currently, people working in aging services view HIV as important but not a high priority. However, a number of regions have begun to implement HIV programs:

- New York City has distributed condoms to senior centers and developed the HIV Older Adult Initiative, a training program in partnership with local HIV and aging organizations.
- Puerto Rico collaborates with its local health department on activities for seniors, including talks by health educators on STDs and HIV and training of nurses and social workers as HIV pre- and post test counselors at 23 senior centers.
- In Delaware, HIV/AIDS prevention is a part of many community outreach efforts. The Delaware Division of Services for Aging and Adults with Disabilities provides professional development training on HIV/AIDS to providers of healthcare services to seniors and has collaborated with two community organizations to provide HIV counseling, testing, support, and education.
- The Florida Senior HIV Intervention Project (SHIP) provides HIV/AIDS prevention education and early intervention to people over 50, especially black and Hispanic women. Older peer educators lead education and safer sex seminars, and there is outreach to healthcare professionals and aging services workers regarding the HIV risk posed to seniors.

- In Ohio, collaboration has begun between an area agency on aging and a local board of health, and work has begun on an educational module for seniors and professionals.

The Administration on Aging will establish the nation's first resource center to assist community organizations to understand aging issues and implement programs for older lesbian, gay, bisexual, and transgender people. AOA is collaborating to streamline access to long term care for the elderly and people with physical, mental, or developmental and intellectual disabilities. AOA's Community Living Program provides grants to assist individuals who are at risk of nursing home placement but not eligible for Medicaid to continue to live in their communities. A supplemental portion of this grant is directed to eligible veterans of any age.

HIV and the Aging: Shifting our Practice to Meet the Needs

Stephanie Howze, MPA

Vice President for Healthcare

Harlem United Community AIDS Center, Inc.,

Harlem United has a multi-disciplinary one-stop-shop approach to work with older PLWAs. One-third of adults with HIV receiving primary care through the agency are over 50. They have an average of more than six chronic illnesses in addition to HIV, most with one or more of the top five conditions: alcohol, tobacco, and/or other drug use; cardiovascular disease; hepatitis C; lung disease; and neuropathy or chronic pain.

The need is for a paradigm shift from nursing home and end of life care to preventive services in outpatient settings and to medical homes that provide comprehensive healthy aging services. That requires less focus on HIV specialists and more on generalists and an approach to HIV management that emphasizes health literacy, screenings and treatment for chronic conditions, and care coordination. It means integrating behavioral health and primary care, wider use of technology, larger investments in infrastructure and health education, better specialty care, and other changes to improve health outcomes.

Harlem United has taken a number of steps to adapt to these changing needs:

- It is developing a hepatitis C clinic.
- It is increasing capacity for primary care and substance abuse treatment.
- The agency has strengthened relationships with academic institutions.
- It has created partnerships with local hospitals to fast track specialty appointments and coordinate care via electronic medical records.
- It has improved its electronic systems for data gathering and clinical care tracking.
- It is integrating Medicaid billing with electronic health records to minimize error and duplicate data entry.
- It will scan and electronically file program records.
- It will receive medical home accreditation in 2010.
- It will work toward additional satellite clinics and expanded psychological services and will continue to fully utilize AmidaCare (HIV Special Needs Plan) providers.

SPOP: A Model of Mental Health Services for Older Adults

Maryann Kenney, LCSW

Clinical Director

Service Program for Older People

SPOP is a leader in geriatric mental health and one of the few agencies in New York City dedicated exclusively to the mental health needs of older people. While mental illness is treatable, few seniors receive services, underutilizing treatment more than any other group. The cost of untreated mental illness is increasing dysfunction and possible physical disability and hospitalization. Isolation, loss, illness, poverty, and life changes contribute to mental problems, including anxiety, depression, dementia, sleep disorders, drug and alcohol abuse, and sexual dysfunction, among others. Co-existing medical, psychiatric, and cognitive problems are common. SPOP provides a wide range of programs, services, and outreach activities, including home visits.

Frail adults over 75 are the fastest growing segment of the elderly population. Traditional service models assume that older people will come to offices for care, but many are too frail or disabled to travel. Visiting seniors in the familiar environment of their homes removes treatment barriers, facilitates diagnosis, reduces cost, and allows assessment of mental health as well as social service needs within the context of the person's surroundings.

As the aging population grows and advances in neuroscience become available, new culturally diverse models, expanded workforce training, and other resources will be required.

Discussion

An integrated care model works well. Medical homes geared to older people would give access to specialty care, coordination of care, and comprehensive services with cost efficiency, much as the Designated AIDS Centers have been doing for many years. Co-location offers multiple services at one place and on one date, but reimbursement is a problem. If agencies can't be reimbursed for multiple services on the same day, they will not provide them. HIV-specific agencies will also have difficulty navigating the reimbursement systems for other types of care.

A one-stop model integrating HIV, geriatrics, and chronic care should be practical, replicable, and adaptable and should offer transportation as well as care for the home bound. But while the principles for a model of care may be clear, implementing them is difficult. People access care in various settings: urban, rural, specialty clinics, family centers, community centers, and hospitals. There is no single HIV epidemic, and people at different stages of aging have vastly different needs. Many 50 year olds do not see themselves as seniors, and many older seniors are still working while others are frail and disabled. Some, including retirees, who want flexible schedules and have good skills are a great resource to agencies, especially since many seniors would rather work with people their own age. Senior centers are even changing their names to wellness centers, since seniors are not a monolithic group.

HIV services should be integrated into geriatrics facilities, and aging services into HIV care. Coordination with national groups and among federal, state, and city agencies is essential. Partnering will be more important, and agencies must talk to each other. The different agency reporting requirements cause a lot of confusion and lost revenue. Planners will have to collaborate with workplaces and unions as well. There is a need for RFAs on collaborative models and best practices nationally.

Mental health services should be an equal partner in any model, and undocumented people should not be overlooked. The lack of affordable housing will be even more a problem than it currently is as large numbers of older people retire on fixed incomes.

Although HIV service providers have long fought for specialized funding, the trend is toward a holistic assessment of patient needs, including activities of daily living. Providers must look at the whole patient through multiple lenses, using all types of strategies rather than one model. They will not be able to identify patient problems with standard assessments.

New settings for delivering services will include assisted living and naturally occurring retirement communities. Routinizing HIV testing will help to integrated services.

RECOMMENDATIONS

- 1. Define the stages of aging, acknowledging that there is no one senior population, but rather differences in health and service needs among various older age groups (younger compared to older and the oldest seniors) and among individuals at any given age. Services and messages should be designed and care provided accordingly.**
 - Interventions should be designed for various stages of aging.
 - Individuals should be treated holistically, taking into consideration all social, medical, psychological, and other aspects of their care.
 - Since many older adults do not consider themselves senior citizens, planners should carefully consider what terminology is used and how services are provided in order to encourage access and improve education.

- 2. Convene a government-sponsored task force to focus on the integration of services to aging populations with and at risk for HIV; to explore existing models for care coordination, such as a medical home and co-located providers, as well as models for outreach and training; and to develop new models appropriate to various aging populations.**
 - The task force should include direct line providers and representatives from HIV centers of excellence and from geriatric care.

- Any new model of care should utilize lessons from established models for HIV/AIDS, chronic disease, and geriatrics. Less emphasis on HIV or aging exclusively and more on integrated care is unconventional but essential to address issues that are interdependent in older adults.
- Models must be replicable, integrated, client centered, and comprehensive, including issues such as transportation, housing, home visits, homecare services, and the impact of fixed incomes on access to services and on the feasibility of healthy aging in various settings.
- Mental health issues are barriers to care and to treatment adherence. Older adults experience multiple traumatic life events and co-existing medical, psychiatric, and cognitive conditions. Mental health services, including neuro-psychological evaluations, should be an equal partner in any service model.
- Discussion of models for care coordination, education, and training should involve agencies at the federal, state, city and local levels, including SAMSHA, HRSA, and other cross sector collaborators, such as NASUA (National Association of State Units on Aging), the federal HHS Administration on Aging, and other national associations.
- Communication and collaboration should be encouraged with employee assistance programs (EAPs), unions, and other workplace organizations, since many older adults are working well into their 70s.
- With the goal of increasing access to and scope of services for older adults, the process should examine the medical home model, which provides comprehensive primary care, and the various models for co-location of primary, specialty, and other care, including a one-stop model that fosters a multidisciplinary approach to need assessment and care.
- Existing models such as those used in the NYS Special Needs Plans (SNP) and in Community Health Centers could be adapted and expanded. Other initiatives should be examined, such as AOA's Aging and Disability Resource Centers and Community Living Program. In NYC, the HIV Older Adult Initiative is a partnership among public and government sectors to provide educational training programs on HIV and the older adult. This program should be examined. Other intervention examples include the demonstration project in Puerto Rico in which clinical staff are trained to conduct HIV testing targeting seniors and projects in Delaware, Florida (SHIP), and Ohio.
- Models should take multiple perspectives into account, e.g., those of urban and rural settings, specialty and non-specialized clinics and providers. The process should examine how individuals state they prefer to use and how they actually use services. Co-located services may not be ideal for all. Some want to go to an HIV/AIDS specific center, whereas others, particularly those in smaller communities, prefer anonymity.

- 3. Resources permitting, release an RFP targeting both HIV/AIDS and aging service providers in order to identify and/or encourage the development of best practices for co-located, integrated HIV and aging services.**
 - Partnerships should be established and nurtured among HIV/AIDS and aging service providers in order to share information and resources.
 - Funding should be combination of federal, state, and city resources. Funders should communicate with each other and coordinate efforts in order to maximize revenue and minimize contradictory reporting requirements.
- 4. Establish care and services in communities where older and retired adults are located, such as NORCS (naturally occurring retirement communities), and provide home-based care for aging in place.**
 - Collaborations with existing senior sites and programs should be established.
 - Assessments and services provided in individual homes and senior communities reduce cost and barriers to care posed by illness, frailty, and mental health problems.
 - A day program could be designed for medically and psychosocially stable older adults which would enhance socialization, provide HIV prevention and health education, improve negotiation skills, and offer exercise, care coordination/case management, and other services.
- 5. Re-examine the current reimbursement structure, which does not cover multiple services in a single day and poses a barrier to the one-stop and co-located models.**
- 6. Establish guidelines regarding the inclusion of staff who are age and culturally appropriate to deliver services and education to the HIV aging population and to provide professional training for all staff.**
 - Examples such as Florida's SHIP Program, which makes effective use of peers, should be investigated.
 - Attention should be paid to older undocumented and uninsured PLWHAs and the needs of individuals entering the country.

Workshop #4 - Prevention

Factors that Increase or Decrease HIV Risk

Panel Presentations (See also slide presentations.)

Moderator:

Doreen Bermudez

Manager, Advocacy and Training Program

Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)

Factors that Increase or Decrease HIV Risk

Doreen Bermudez

Manager, Advocacy and Training Program

Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)

Factors that increase HIV risk include undisclosed infection, ageism, isolation, sexual orientation, culture, lack of access to care, and a variety of assumptions about older adults. Consideration should be given to when, where, how, and why these factors have impact and to defining factors that decrease risk.

Programs should ask how to decrease risk as effectively, broadly, and consistently as possible, using appropriate language and sensitivity to the beliefs and experience of older people, as well as awareness of possible misinformation. Clinicians should be engaged in patient education and discuss sexuality with older patients. Planners should determine what lessons can be learned from data, current trends, and research and what staffing and resources are needed for the best programs.

Sex and Other HIV Risk Behaviors Among Adults 50+

Mark Brennen, PhD

Senior Research Scientist

AIDS Community Research Initiative of America (ACRIA)

In a 2007 study of sexuality and health among older adults in the U.S., people reporting better health were also more likely to report sexual activity, although health status did not affect the type or frequency of sexual behavior among those who were sexually active. More than 80% of men and over 60% of women aged 57-64 were sexually active, as were more than 65% of men and 40% of women aged 65 to 74. An older (1997) study noted that more than two thirds of physicians rarely or never discussed sex with patients over 50 and more than 60% never discussed HIV, although more than 40% of patients testing positive were over 50.

ACRIA's own recent study of 1,000 people in New York City, Research on Older Adults with HIV (ROAH), confirmed that HIV transmission through needle sharing and unprotected anal sex has decreased substantially, while transmission through unprotected vaginal sex has greatly increased. More than 45% of sexually active heterosexual women and gay/bisexual men and nearly 40% of sexually active heterosexual men reported unprotected sex within the previous three months. The

most commonly cited reasons were the request of a partner (32%) and drug use (27%), adding additional evidence to the documented association between drug use and unsafe sexual activity. ROAH study participants had high rates of substance use.

Despite their high risk for HIV transmission, older adults are not counseled by physicians about HIV prevention and are less likely to be tested for HIV and other STIs. There is a great need for education of both older adults and providers about HIV risk in this population and for better secondary prevention and care for older people with HIV. The CDC should recommend HIV testing of sexually active people regardless of age.

Empowering Older Heterosexual Women

Brenda Lee Curry

Co-Founder

Copasetic Women over 50, Inc.

Diagnosed with HIV in 1995 and now a PLWA, Ms. Curry joined a women's organization in 1996 and started training as an advocate but by 1999 began looking for a group that addressed the needs of heterosexual women over 50. At NYAHOF (New York Association on HIV Over Fifty, Inc) people were talking about aging. However, many women over 50 are still isolated.

She was a co-founder of Copasetic Women over 50, Inc., originally an organization of 16 women, now with have eight members, four with HIV, one married and not positive. The oldest member, aged 80, went back to school to learn computer skills and now works, since she didn't want to "sit around dwelling on HIV and her aches and pains." Another member volunteers. The organization motivates women to get out into the world, not just worry about children and grandchildren. They say, "if there is anything in your closet you are saving, wear it today." The motto is to take care of yourself and live. Members also talk about legislation and policy. All organizations should provide a place to feel safe and get information.

Discussion

There are many types of recognized and unrecognized risk. Data show there is greater risk through heterosexual sex and less through intravenous drug use (IDU), but women also become infected because of their partner's IDU. Many types of behavior contribute to risk, not just that in relationships, and people are at risk in lots of settings. A broad conversation about HIV and aging, for example, would include the use of clean needles for diabetic care and issues like depression and educational level. Older people have many morbidities, so they ignore the risk of HIV. Other diseases, like diabetes and heart disease, are more threatening.

More education about HIV and HIV services is vital. Older people should not have to go an HIV organization to learn about HIV and don't want to be seen at the HIV table at public events. HIV prevention should be standard in traditional settings like senior centers and also in non-traditional settings. People should be engaged through activities that are not specifically HIV-focused. Testing is important, but it is also important to encourage dialogue about all aspects of sexual behavior, risk,

and services.

Clinicians and young people are embarrassed to ask older people about sexual behavior or drugs. All people in an organization should be trained – providers, executive directors, case managers, researchers, the cook, the driver, everyone -- because education about HIV can happen everywhere and be facilitated by anyone. If an older person is uncomfortable with the social worker, perhaps the cleaning lady or the driver is her buddy. There should be a consciousness about HIV in the day to day operation of an organization, hospital, or research setting and language to reach everyone in a community, including transgendered people, down low men, and young people. The conversation should be constantly expanding.

Social networking and social marketing are also important and allow people to develop their own resources. Peer group members can take care of each other and help decrease the risk of transmission. There are lots of commercials for Viagra. Why not billboards about HIV and older people? They should be aware they are at risk.

Partnerships among agencies are difficult to establish but necessary. Coalitions should involve churches and other settings where older people access services and activities. Community ideas and leadership are often not recognized, and homegrown interventions that clearly work are not formally evaluated. The community should be more involved in planning and programs.

Although funding is limited to the requested deliverables, clients bring their own issues, and everything, including socioeconomic factors, work together to help prevent HIV. Planners shouldn't be categorical with messages, approach, or funding. Organizations need to have more flexible approaches and address the person in a holistic way.

RECOMMENDATIONS

1. Develop an array of HIV education strategies for older adults.

- HIV prevention messages should be designed for seniors with a great variety of backgrounds and needs. HIV risk factors for older adults include not only lack of access to health care and information, but also cultural, community, and provider assumptions that seniors are sexually inactive. There are inadequate social networks and support for seniors. Issues such as poverty, immigration status, mental health, and drug use also affect sexual behavior.
- HIV education should utilize social marketing and other non-traditional tools.
- HIV prevention, testing, and treatment information should be available in all settings where seniors gather and should be integrated with other health information. Educators must recognize that not all seniors are willing to go to an organization identified with HIV services or will respond to messages focused exclusively or primarily on HIV.

- Education should recognize that the primary mode of HIV transmission for people over 50 is sexual behavior.
- New and more engaging messages should be developed for older MSM in order to overcome education fatigue.

2. Establish coalitions and encourage collaboration among agencies to develop and deliver HIV information and services for older adults.

- HIV and aging experts should work together to develop better health care services for seniors.
- Policy should focus on increasing awareness of HIV within all agencies that serve the aging.
- Groups and organizations such as the Prevention Planning Group, churches, and other community resources can be instrumental in increasing awareness of HIV and outreach to seniors.

3. Since older adults are less likely to be referred for HIV testing, make particular efforts to encourage the determination of HIV status and to integrate HIV testing into routine health care.

- Many factors can influence the decision to test, including depression, culture, and denial or ignorance of risk. Older women with HIV are especially unlikely to be diagnosed. It is important that providers assess and try to surmount barriers to testing.
- Older people are often preoccupied with other health problems, such as cardiovascular disease or cancer, which they consider more life threatening than HIV. They should be advised about the interaction among HIV and other diseases and the need for comprehensive treatment.

4. Ensure that clinical training for providers includes competence in HIV risk screening, testing, and provision of or referrals for appropriate treatment as standard components of care for older adults.

- Training for all primary care, HIV, and geriatrics services providers should include the skills required for HIV prevention counseling and risk assessment in older adults.
- Increased resources and non-categorical funding should be made available to promote provider attention to HIV status and access to care for seniors.
- Provider education should include the ways in which HIV interacts with other chronic diseases of aging.

Workshop #5 - Prevention

Sexuality and Sexual Health in an Aging Population

Panel Presentations (See also slide presentations.)

Moderator:

Karen Taylor

Director of Advocacy and Training

Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)

Red Ribbon, Silver Threads

Jennifer Hillman, PhD

Professor of Psychology

Penn State University, Berks College

Older people are a much more heterogeneous group than younger people. Although in the media only young beautiful people have sex, in fact people in hospice care, people with dementia, with debilitating illness, with colectomies, all sorts of people have sex. And there is a wide variety of sex, from penetration to masturbation and cuddling. Some make connections online, use Viagra, and engage in unsafe behavior. Providers must recognize the sexuality of older people in all types of settings, including institutions such as nursing homes and prisons (where, in some cases, men asking for pornography to masturbate were instead given chemical restraints).

Many people have misinformation or no information. Just as memory loss and dementia are not normal parts of aging, neither is painful intercourse. In one study, 68% of women interviewed had no experience at all with condoms, and only 63% thought condoms were effective at preventing HIV. Less than half knew you shouldn't use vaseline with condoms. (Astroglide, KY, or other water-based products should be used, but Vaseline or any oil-based products should not.)

Sexuality is a right, not a privilege. Communities should become more aware of the epidemiology and needs of older adults and the advantages of engaging them as full community participants. Instead, many elders encounter stigma and fear.

Many elders have misconceptions about HIV and their risk of infection. Even if they are not sexually active, many are affected by HIV as caregivers. Older people should have appropriate HIV education and products and materials adapted for them, such as thinner, easy to use condoms; educational handouts and computer pages with larger size text; and supportive discussion groups and counseling.

Barriers to HIV prevention include lack of familiarity with condoms and terminology, religious beliefs, culture, ethnicity, and a lack of provider training and clinical guidelines that include older adults. Often, clinicians do not consider an HIV test even when symptoms are evident. Older people do not see people who look like them in HIV education ads and materials, and many are embarrassed to take sexuality materials in front of peers. A range of strategies is required.

Sexuality in Older Adults

Gary Kennedy, MD

Director, Division of Geriatric Psychiatry

Montefiore Medical Center

Albert Einstein College of Medicine

Sexuality in older adults is a critical issue, but it is a provider problem, not a patient problem. Many patients welcome questions about sexuality. Older adults are sexual beings, and there is an increasing expectation that clinicians should be knowledgeable about sexual health. But there is a long way to go in training physicians about late life sexuality. And many people may have unrecognized acute infection, that is, they are viremic and infectious but not symptomatic. The population at risk for HIV will increase.

Older adults are healthier, better educated, and economically better off than ever before. Longevity has not increased recently, but we are adding substantial active lifespan years, so baby boomers will be sexually active much longer. The body retains the capacity for sex and orgasm long after the procreative years because it is important for bonding and intimacy. Women outlive men by five years, and men have disabling conditions five years earlier than women. So there are many more active older women.

In women, arousal can precede desire, whereas in men desire is first, but they can have difficulties with arousal. In post-menopausal women, the loss of estrogen results in vaginal thinning and less lubrication, but lack of sexual activity also promotes vaginal atrophy and loss of desire. As people age, the plateau phase of excitement is prolonged for both men and women. It takes longer, with more foreplay, to get to orgasm. But even after cardiovascular events, if someone can climb two flights of stairs, they can tolerate orgasm.

Predictors of active sexuality later in life are partner availability and life experience (those with previous high levels of sexual activity stay sexually active). Sexual inactivity for a prolonged period can lead to complete loss of desire, which may be an acceptable solution for people who do not have partners. For others, loss of desire may require therapeutic intervention, although for some who want to resume sexual activity, sexual health is gone and can't be restored. Depression also diminishes libido and sometimes the desire to do anything. But one way to counter depression is to reintroduce activities that provide enjoyment.

Older LGBT Adults and HIV

Karen Taylor

Director of Advocacy and Training

Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)

Most find it's easier to talk about housework than sex. As people age, they become sexually invisible. Young LGBT people are perceived as hypersexual, but neither their own communities nor the wider culture recognizes them as sexual when they age. Older people are not all the same, but most still have sex. So why is there an age cap on HIV testing?

The HIV information of older LGBT is often outdated. People retain assumptions about sex from when they were young, which for many is pre-AIDS. Some still think people can get AIDS from a doorknob, because no new information has been directed at them for 30 years, and no one is currently educating 70 year olds. They assume they can continue the behavior they are used to. Further, they are not worried about getting pregnant so don't use condoms. Many have used or are using paid sexual encounters. And language is an issue. Few older LGBT will use the term queer or call themselves lesbian, but rather say gay women.

The stigma of HIV affecting homosexuals and drug users is still very strong among older people. And many came of age prior to widespread public coming out. There is also such a thing as minority stress, the social burden of living as non-white or immigrant or LGBT. A 70 year old lesbian was 40 when homosexuality was taken off the list of mental health disorders. Gay behavior in the past was criminalized. The children of LGBT people were taken away, and parents were often institutionalized. It was socially inappropriate for two men to live together. Even today, many cohabitate as "cousins" or "uncle and nephew."

However, two thirds of older LGBT people live alone; 80% do not have a partner; 90% do not have children. The care giving system requires that either family members or paid employees take care of older people, so as they age with HIV they are even more alone.

Discussion

The goal of improved medicine is not just to extend an individual's lifespan, but to substantially extend an active, healthy lifespan, which includes sexual activity. It is important to define and learn to talk about sexual health, which involves intimacy and pleasure that may or may not include orgasm. If the therapeutic goal is defined as only orgasm, it is likely to fail. However, the sexuality of older and single people is often discounted or even ridiculed. HIV prevention messages are not delivered to nursing homes.

The focus should be not only on aging with HIV but on the risk of HIV transmission to seniors. Of the newly diagnosed, 15-17% (of 56,000 per year) are over 50. No one is even gathering data on risk factors in older adults.

Mainstream culture still does not really accept gay people, and most LGBT adults are alone and/or have lost partners. In recent NY City DOHMH data, about 39% of gay and bisexual men in NYC have not disclosed their sexual orientation to their doctors: 19% of whites, 48% of Hispanics, 47% of Asians, and 60% of black men. The frame for sexual health should not focus only on monogamous marriage.

While prevention with positives is a priority, it is also important to learn more about sexual compulsion, whether it is an addiction, whether the causes are the same in younger and older people, and what interventions are available. Sex is normally discussed the way people talk about potty training, helping people to gain control through shame and guilt. Talking about sexual health rather

than sexual pathology destigmatizes sexual behaviors. Harm reduction and prevention education require learning more about the range of older adult sexuality. Talking about sexual risk is different than talking about sexual health and pleasure. There is still no real sexuality education in schools or serious discussions about sex between HIV positive partners and sex among substance users.

Although bath houses used to be the high risk settings, now often the high risk environment is the home. Sex outside of a relationship puts a regular partner at risk. Older people find sex online or use prostitutes because of partner accessibility issues, or sex is exchanged for housing. Then people are reluctant to be tested for HIV. Other issues also create risk. Older men, especially those who drink, are sometimes targeted by younger women, many with HIV, especially at congregation sites when social security checks arrive. Some older people are multiply diagnosed with drug/alcohol use, HIV, hepatitis C, plus asthma, mental illness, disability, or other problems, so they are highly medicated and stigmatized. Yet in some countries, sex work is legal and, if person is handicapped, sexual services are even covered by health insurance.

Older people process drugs and alcohol differently. Renal and hepatic function, even body composition, is different. It takes less alcohol to impair judgment about condom use. But providers should understand that even brief interventions can reduce risk. Five minutes of discussion about safe alcohol limits, without preaching, can have great impact.

Provider education and appropriate reimbursement are critical. Currently, there is no discussion about sexuality in any medical setting. Sexual health conversations should be routinized. Failure to do this should be a deficiency in evaluations, like not doing a CD4 count. The best strategies may be to educate medical students and residents and offer grants to medical schools to establish centers of excellence. And individuals should be encouraged to initiate conversations about sexual health with providers. In the reimbursable, collaborative care model, the nurse, social worker, or psychologist helps with chronic illness management, which may work better than mandating another job for physicians. The NY State Long Term Care Ombudsman Program provides patient advocacy, but HIV and aging care are still not integrated.

HIV trainings do not mention talking to the elderly about sex. Current funding is for meals and case management, not discussion groups on conscious aging and sexuality. RFAs should address the sexual health needs of older people in a variety of environments. All aging services should include HIV prevention education, and all general clinical and HIV-specific services should include sexual health assessments and HIV information and care for older adults.

RECOMMENDATIONS

- 1. Train clinicians and other members of health care teams to have routine, knowledgeable, respectful conversations with older adults about sexuality and to provide sexual health care.**
 - Clinicians should allocate time during patient visits for assessment of sexual health, an important indicator of general health and well being. While sexuality is challenging for

many people to discuss candidly, seniors are often willing to talk in a safe, uncritical environment.

- Provider training about sexuality, aging, and HIV should begin early, in medical/nursing/social work/PA schools, and should be supported thereafter. Centers of excellence should be established to promote the education of physicians and other providers regarding sexuality and sexual health, with particular focus on aging patients. These centers should be funded with competitive grants.
 - A collaborative model of care should be promoted in which physicians are part of a team and the team collectively ensures that sexual health care is incorporated into routine health services.
 - Providers should recognize the great heterogeneity among older persons at any given age and base health assessments on individual presentation rather than age. They should be sensitive to cultural and generational assumptions about sexual behavior and language that may impede honest discussion. These include not only the familiar bias of ageism, but the presumption that those with physical or cognitive disabilities (dementia, wheelchair use, colostomy, multiple chronic conditions, frailty) or substance use are not sexually interested, sexually active, or at risk for HIV.
 - Providers should be aware of factors that increase the vulnerability of older people to HIV and other illnesses. These include social isolation and bereavement, poor nutrition, sedentary lifestyle, ignorance of condom use or the need for HIV/STI protection, sexual or other types of violence or abuse, depression, and the use of alcohol or other drugs and age-related changes in their effects. Victims of sexual assault should be evaluated with respect to HIV and STIs regardless of age.
 - Provider training should encompass other factors affecting sexual behavior, such changes in desire and arousal related to age or illness, male or female sexual dysfunction, increased time to orgasm, beliefs about sexual capacity following illness, sexual experience and knowledge, energy level, and the availability and attitude of partners. Just as depression and dementia are not natural inevitable consequences of aging, neither are vaginal dryness and erectile problems necessary and unavoidable conditions.
 - The upper limit of age 64 in CDC recommendations for routine HIV testing is a disservice to older adults. It discourages clinicians from discussing sex and HIV risk with their older patients and reinforces the assumptions that seniors do not have sex and are not at risk for sexually transmitted diseases.
- 2. Design public education about sexual health and HIV prevention and treatment specifically for older adults, with careful consideration of the most effective language, correction of possibly outdated information, and utilization of a variety of strategies and settings.**

- HIV prevention messages targeted to specific populations is a widely used public health strategy that should be employed for older adults. Messages for older people should address misperceptions and provide basic information about sexual health that may be outdated or not fully understood. Older people may underestimate their risk of HIV infection believing that HIV still primarily affects gay men or drug users or that menopause or Viagra protect against HIV. They may be unfamiliar with condoms and lubricants or believe that condoms are only for contraception. They may not be aware of the risk of other STIs. They may be insecure about the idea of sexual activity after long partnerships, periods of celibacy, or illness.
- Images should represent older people. However, while many adults may prefer to talk to peers about sexuality and HIV, others may prefer an intergenerational approach. Seniors should be encouraged to be active partners in their own health care.
- Novel and engaging strategies should be considered. For individuals with memory impairment, repeating information and use of memory aids may be helpful. For people with arthritic fingers or motion disorders, condom packaging that is more easily opened could be designed. Some older adults may be reached with HIV prevention information through sex workers.
- Choice of language with a focus on sexual health and pleasure is very important. Terms that are familiar to older people, such as “rubbers” rather than “condoms,” or “blow-job” rather than “going down on,” may make information more accessible. Messages should avoid the language of pathology in characterizing where and how individuals have sex.
- Locations and timing of targeted interventions should be creative. Although funding for services for the aging is limited, there are over 350 centers for older adults in NYC alone. Seniors there may be interested in talking about sex, while directors may not. Campaigns to reach older people should focus on all venues and at times at which seniors congregate. Computer instruction to enable online sexual health education would be useful.
- Specific attention should be devoted to HIV and sexual health education and prevention programs, including the provision of condoms, for older individuals in nursing homes, prisons, and jails. The inhumane practice of using chemical restraints on individuals in institutions who masturbate or use pornography should be discontinued unless another individual is placed at risk.
- More education should be provided about sex between members of HIV-positive seroconcordant couples.

3. Pay particular attention to issues concerning older lesbian, gay, bisexual, or transgender (LGBT) adults.

- LGBT persons are misperceived as hypersexualized when they are younger; yet many in these communities “disappear” from view as they get older, their sexuality and sex lives discounted.
- Providers should note that older gay men may be having sex in unconventional places. Home may never have been a safe place to have sex, so that bathhouses and parks, which are safer, became preferred venues.
- Stigma directed against LGBT people is a barrier to HIV prevention efforts and to sexual health. The social marginalization of lesbian, gay, bisexual, and transgender people is a source of chronic stress that may be added to that of being non-white, foreign born, and, perhaps, undocumented or HIV-infected. Campaigns and interventions to decrease stigma, homophobia, and heterosexism are important adjuncts to HIV prevention and health care for older LGBT adults.
- The language used with older LGBT people should reflect the language they use. Terms like “queer,” for example, are more likely to resonate with younger generations.

4. As resources permit, establish the provision of sexual health care as a billable service.

5. Collect and analyze data on HIV risk factors for older adults.

Workshop # 6 – Reimbursement/Financing

Funding Programs/Paying the Bills

Panel Presentations (See also full text narratives and slide presentations.)

Moderator:

Jacqueline Treanor
Division of HIV Health Care
New York State Department of Health AIDS Institute

HIV Medicaid Programs and Health Care Restructuring

Ira Feldman
HIV Medicaid Programs and Policy
Deputy Director, New York State Department of Health AIDS Institute

Medicaid programs serve as the primary payer of care for more than half of the population with HIV and AIDS in New York State. An HIV-specific regulatory framework includes a continuum of nine HIV models of care providing integrated primary, acute, and chronic care services. These programs are currently under evaluation as part of the State's multi-year health care restructuring. Medicaid reform is focused on creating an up-to-date, transparent system that recognizes the needs of complex illnesses, rewards quality, and creates incentives for efficiencies in care.

Health care restructuring includes an extensive redesign of Medicaid reimbursement across care settings. The State has begun to phase in Ambulatory Patient Groups (APGs) as the basis for medical service payments in hospital ambulatory care settings. Phase in for Diagnostic and Treatment Centers, when approved by the Centers for Medicaid and Medicare, will be retroactive to September 1, 2009.

Long-term care service delivery and payment structures are also being restructured to incentivize placement in home and community-based settings. The AIDS Institute is working within the Department of Health and with providers to evaluate the current AIDS nursing home and home care programs and identify the evolving long-term care needs of the HIV/AIDS population.

Given the interdisciplinary health care needs of older people, the AIDS Institute has informed Designated AIDS Center hospitals (DACs) of the opportunity to lead the Department of Health's patient-centered medical home program within their institutions.

Over the past year, the AIDS Institute has collaborated with federal, State, and NYC agencies to prepare a plan to phase in the removal of the HIV exemption from managed care for Medicaid-eligible individuals, starting with New York City.

HIV Special Needs Plans (SNPs) offer an integrated model of HIV care for the HIV-infected Medicaid managed care eligible population in New York City. HIV SNP networks are broadly composed, encompassing the full continuum of HIV services as well as comprehensive health care

services. HIV experienced providers enable SNPs to meet the complex medical and psychosocial needs of enrollees.

Meeting the Needs of Older Adults Living with HIV/AIDS

Emma DeVito, MBA

President and CEO

Village Care of New York

More than half (3,200) of VillageCare's HIV-positive clients are over age 50. They have more comorbidities and require substantially more complex care, with 50% more prescriptions (an average of 18 each) than non-HIV-positive older residents and six times the number of outside consultations. About 80% have high levels of pain; 60% smoke; and 75% have psychiatric problems other than dementia.

Programs to address the significant differences between the general nursing home and AIDS nursing home patients include interdisciplinary care teams, the extensive use of electronic medical records, on-site case management, and enhanced rehabilitation programs. Village Care has introduced a number of geriatric treatment modalities into HIV care programs, such as occupational therapy for frailty and memory exercises to address dementia. Other changes for older PLWHAs include diet planning and nutritional counseling, cross consultations (geriatric consults for PLWHAs and HIV specialist consults for the general nursing home population), support groups to address the psychosocial needs of older PLWHAs, and HIV 101 training for all staff to minimize discrimination.

The future model of care for older PLWHAs will have to manage this complexity across a continuum of services essentially in three categories:

- Primary and medical home care, consisting of multiple disease management, care coordination, and medication adherence, nutrition, and other support services;
- Home and community-based long-term care, consisting of primary care coordination, medication and pain management, and therapy for activities of daily living;
- Residential care, consisting of structured continuous clinical care in HIV/AIDS assisted living, skilled nursing, or hospice facilities.

A number of reforms are recommended. These include a departmental review of HIV regulatory standards that are outdated in comparison with those for geriatric care, a renewed focus on HIV training for all levels of staff in health and support organizations to minimize bias and provide education about older adults with HIV/AIDS, the integration of health information and use of standard health information technology among providers, and resolution of obstacles to the approved conversion of some nursing home beds to assisted living units.

HIV and Aging: Growing Shift to Medicare as Primary Payer

Christine Rivera

Director, Bureau of HIV Uninsured Care Programs

New York State Department of Health AIDS Institute

Changes in primary insurance payers will take place as people with HIV and AIDS age. Currently, about 13% of the 23,000 HIV Uninsured Care Program enrollees are also enrolled in Medicare. The Uninsured Care program covers premiums, deductibles, and co-payments for Medicare Part D for individuals eligible for both the Uninsured Care Programs and Medicare.

The HIV/AIDS population eligible for both Medicaid and Medicare is anticipated to grow. Of the 61,000 Medicaid enrollees identified from CY2007 data, 19% are eligible for both Medicaid and Medicare. The dual HIV Medicaid/Medicare population continues to use Medicaid for services not available on Medicare, such as COBRA case management, AIDS adult day care, medical transportation services, home health care and personal care services. For eligible individuals, Medicaid also covers the premiums, deductibles, and coinsurance associated with using Medicare for allowed health related services.

For many persons with complex care needs, Medicaid will remain the sole payer of care as they reach age 65 if the person does not have the required work history for Medicare eligibility. Other insurance sources, including private health insurance, the HIV Uninsured Care program, and veterans benefits will also play an important role in the continuum of insurance coverage available for people aging with HIV.

Discussion

Health care reform and reimbursement changes are having and will continue to have substantial impact on the continuum of HIV care, including acute care, ambulatory care, home care, long-term care, and managed care settings.

Reforming reimbursement for long-term Medicaid services, including nursing homes and home care, is a complex process with many vocal stakeholders. Technical advisory groups are important to ensure provider input in the process.

Medicare will become a more significant payer of HIV care as consumers either “age in” or become disabled.

HIV uninsured care programs, including ADAP, are facing flat funding with increased enrollment. More participants are assisted in obtaining and retaining public or private health insurance.

Providers request that State regulations and requirements become more flexible in adapting to a changing care delivery environment.

RECOMMENDATIONS

1. Review existing geriatric models of care to determine how they may be adapted or enhanced for use by aging PLWHAs.

- There are major differences between the general geriatric and HIV/AIDS nursing home populations. Issues that vary in type or degree include pain management, substance abuse history, smoking, psychiatric diagnoses, pill distribution, complexity of medication regimens, the frequency of outside health care consultations, and treatment education and adherence support.
- Current patient assessment tools for long-term care and home care do not recognize the complex needs of PLWHAs. The focus is on mobility impairment and Activities of Daily Living rather than HIV related issues of treatment adherence and co-occurring mental health and substance abuse issues.
- The AI should obtain input from providers and consumers of aging and HIV services on how best to adapt existing models of care.

2. Modify existing HIV program models, including COBRA case management and adult day care, to meet the health care, social support, and other needs of the aging HIV/AIDS population.

- The integration of HIV care and routine medical care is proceeding as a result of health care restructuring and changes in the epidemic. The goal is to retain successful features of HIV programs, such as those for treatment adherence, interdisciplinary care coordination, and co-occurring mental health and substance abuse issues.
- Components of successful care coordination for the older HIV population include electronic medical records, case management services, enhanced rehabilitation, nutrition, specialized support groups, and cross consultations.
- HIV Special Needs Plans (SNPs) offer a responsive, integrated model of HIV care for the Medicaid managed care eligible population. As the State moves toward mandatory enrollment of persons with HIV, more public education is needed about SNPs and mainstream managed care plans in New York City.
- Expanded support services should address the continuing social isolation and stigma many PLWHAs experience. A new type of case management could also offer less intensive services but still provide psychosocial support.
- There is a lack of dedicated funding streams to cover many holistic health services, such as acupuncture for pain management.

- 3. Nurture intra-agency and interagency collaboration among the DOH/AI, Department of Aging, OMH, OASAS, and other agencies to develop program models.**
- 4. Provide provider education and workforce training at all levels about HIV and aging.**
 - Strategies should be developed to educate service providers to meet the needs of aging PLWHAs.
 - The AIDS Institute should collaborate with higher learning institutions to address workforce development and training of physicians, mental health practitioners, and dentists to treat older people living with HIV/AIDS.
- 5. Develop an expanded continuum of residential care options such as supportive housing, naturally occurring retirement communities, and assisted living programs for persons aging with HIV.**
 - There continues to be a high risk of overt discrimination, especially in residential settings, if a service provider is not designated and reimbursed for HIV care.
 - Assisted living programs for seniors with HIV/AIDS would provide more services than current HIV/AIDS supportive housing programs, including 24 hour nursing staff, medication management, and personal care.
 - NORC's (Naturally Occurring Retirement Communities) may serve as an adaptable model for PLWAs striving to age in place in supportive and community based housing.
- 6. Reform state regulations and advocate for other changes to enable provider flexibility in designing innovative programs.**
 - A review of regulations and requirements pertaining to HIV providers should be conducted to remove rules that are outdated or excessive in comparison with regulatory requirements for geriatric service providers. Education should be undertaken to encourage Ryan White funding to allow greater flexibility for services such as transportation, psychosocial support, and holistic therapies.

Workshop #7 - Education

Educating the Workforce, the Community, and the Individual

Panel Presentations (See also slide presentations.)

Moderator:

Terry Hamilton, MA
Director of HIV Services
Office of Planning and HIV Services
New York City Health and Hospitals Corporation

HIV and Aging: How do we prepare for a "new" phenomenon?

Roseanne Leipzig, MD
Vice Chair, Brookdale Department of Geriatrics and Palliative Medicine
Gerald and May Ellen Ritter Professor of Geriatrics and Adult Development
Mount Sinai School of Medicine

There is great variability among older adults of the same age, and between younger and older seniors, so rather than make assumptions based on age, it is more useful to ask at what age medical needs change. The interaction of aging, disease, lifestyle, and genetics produces physiological changes, like decreased blood oxygen, kidney function, and T cell response and increased co-morbidities leading to frailty, although increased wisdom is a more positive consequence of aging.

The normal goals for healthy aging – good nutrition, exercise, prevention screening, and social connections – become complicated by the need to manage chronic diseases and possibly by increased impairment, loss of social and financial supports, and depression, all of which can decrease the ability to perform essential and functional activities of daily living. PLWHAs have increased risk of geriatric diseases and syndromes like polypharmacy, sleep disorders, malnutrition, and frailty. They must also manage the short and long term effects of HIV disease and treatment, including chronic inflammation.

The specialty of geriatrics developed because most clinicians did not recognize and were not adept at handling the special needs of older patients. These include medication management, atypical presentation of disease, cognitive and behavioral issues, care transitions, end of life care, and others. Geriatric and HIV care have a number of elements in common, like the need for co-location of services and coordination and continuity of care, but also differ in that older adults need greater focus on quality of life and on dispelling the myths of ageism.

Barriers to care center on the fact that both HIV and geriatric care providers have a clinical focus that is too narrow. Neither consider factors related to the other field when assessing patient symptoms; neither recognize that older adults may be sexually active and using drugs or have in the past; and neither they nor their non-professional staff are very comfortable managing disorders of the other discipline. There is also a lack of data concerning the interaction of HIV and aging.

Cross fertilization of the HIV and aging fields, increasing knowledge and clinical comfort with diagnosis and services, together with public education about HIV risk in older adults are important educational opportunities.

HIV and Aging

Joseph R. Masci, MD

Medical Director of HIV/AIDS Services, Queens Health Network

Professor of Medicine, Professor of Preventive Medicine

Mount Sinai School of Medicine

Many people with HIV on effective therapy are living far beyond age 50. Remarkably, the life expectancy for PLWHAs who begin therapy at age 20 with a CD4 count of at least 200 is 50 years greater than that for untreated people. However, unless CD4 can be maintained above 500, life spans are still not normal, and there is an increased risk for age-associated conditions such as cardiovascular disease, osteoporosis, and dementia. Some of these risks can be modified, although in many people inflammation remains high despite suppression of viral load and recovery of CD4 levels.

Further, older adults are also at risk for HIV transmission. Expanded testing will identify more older adults with HIV, so it is important to determine if HIV services meet their needs. HIV specialty care, developed to meet the needs of young and middle aged patients with life threatening illness in an environment in which HIV was highly stigmatized, provides little focus on care of the elderly. Care of aging PLWHAs elicits uncertainty about the role of specialty care, the changing needs of patients, and the comfort of HIV providers with geriatric care and of non-HIV providers with HIV care.

Education of healthcare professionals must improve training in elder care and understanding of the aging of the HIV-positive population. HIV specialists must learn to focus on quality as well as length of life. Public education should focus on earlier HIV diagnosis. PLWHAs can help providers improve services for older adults.

Information and Support for Older Adults

Minister Christine Walker

Chair of the HIV Ministry

Christ the Rock Church

Older adults have been ignored for a long time, and now HIV is an important problem for them. Older adults have sex without fear of pregnancy and take risks. Viagra and similar drugs encourage older people to have sex with younger people. There is a lot of abuse in nursing homes, and many seniors with HIV don't know how they were infected.

It's hard to tell older people what to do, but seniors have a lot of wisdom. They also have a lot of misinformation. They need support from medical providers, from families, and from faith communities. It's not useful to just say don't have sex.

Providers cannot talk to all patients the same way. Some are celibate, some not. Different people have different beliefs and different side effects from medications.

People must have information to make choices. They can choose to protect themselves and prevent HIV. They can take their medications and live. They must choose life.

Discussion

Young counselors often still have critical attitudes about HIV and about drug use. Stigma is still very high in upstate rural communities. People travel to see providers elsewhere because they don't want to see a community provider or there is none in the area. Patients and providers must work together to combat stigma.

There is not much information about HIV for seniors. There are ads for Viagra but not for HIV risk. There should be an ongoing public education campaign about HIV over 50 with literature and ways to stay up to date. But HIV education at 50 is too late. AIDS education should take place in every school, according to the law, and in general health settings or health vans, not HIV vans.

Providers do not take sexual histories, offer HIV tests, or provide resources. However, some people do not want to discuss their sexuality with doctors or anyone else. Young people don't want to talk to a grandmother about sex, and clinicians and providers still find it hard to talk about drug use or sexuality and want more training. There are cultural privacy issues, but it should still be possible to document in the medical record that providers made repeated efforts to have a careful, respectful conversation to identify sexual issues. But no matter how routine testing becomes, counseling of some kind will still be necessary.

Providers must learn to recognize the great differences among people at the same ages, at different ages, and among cultural backgrounds, which has been a significant focus within the geriatrics provider community. With 180 different languages in the Queens communities around Elmhurst Hospital, for example, it is an enormous problem. Cultural competence training should include care for transgender people.

There are not enough HIV specialists, geriatricians, or primary care providers. HIV specialists cannot provide all HIV care. Primary care doctors can provide basic care, monitor medications, and consult with HIV specialists as needed, just as they manage other chronic conditions with specialty consults. Electronic medical records may help in tracking care.

Presentations at senior centers are very valuable community education. Many people shop around for different ways that care is delivered. Good information should be available wherever and however care is provided.

RECOMMENDATIONS

1. Routinize HIV testing in healthcare.

- There should be greater emphasis on HIV testing and the availability of testing services in all health settings.
- Routinization will help to increase individual education about HIV and decrease stigma.

2. Develop and implement an HIV public education campaign for and about people over 50.

- Strategies should be designed to increase public understanding of healthy aging, of aging and HIV risk, and of the importance of HIV testing and treatment.
- State regulations should be enforced regarding HIV/AIDS education in public schools, and education should be undertaken in other venues to improve community understanding of HIV prevention for people of all ages.
- Other strategies should be developed to decrease stigma concerning both HIV and aging.

3. Institute older adult peer education and training, programs in which seniors train seniors, and increase the participation of older adults in designing services.

- A senior Consumer Advisory Board (CAB) should be established.

4. Increase the competence of physicians, case managers, and other providers concerning HIV and older adults.

- It is essential that providers improve coordination of care and collaboration in providing services.
- Training should address the cultural and linguistic competence of providers in dealing with the diverse backgrounds, expectations, and needs of seniors and with the process of aging.
- Newly evolving care models that address co-morbidities and the course of HIV in older adults should be developed and disseminated.
- Physicians should avoid assumptions about sexual activity in older people and be advised to regularly ask about sexual history and discuss sexual health.
- Medical education should be revised to address aging and cultural issues.

- Differences in professional settings and geographic areas should be examined for impact on the provision of care to older adults.

5. Re-evaluate the balance of funding for medical and support services to ensure that the full range of care is available to seniors.

V. Access to Additional Forum Materials

This document offers summaries of slides and oral presentations submitted by forum speakers. Text included here should not be construed as a transcript of the live presentation.

The slide presentations of plenary and workshop panel speakers, the forum agenda, a webcast of the morning plenaries, a resource list of websites and articles, the full text of some publications, and other materials and links are available online at:

<http://www.health.state.ny.us/diseases/aids/conference/index.htm>

The recommendations listed in this report represent the opinions and ideas of Forum participants, not necessarily those of the New York State Department of Health. Moreover, many of the activities recommended have already been undertaken and are ongoing within the Department.

Acknowledgments

The AIDS Institute of the New York State Department of Health is grateful to the many staff members who planned and facilitated this forum; to the speakers, moderators, and participants who so generously shared their expertise, experience, and ideas; and to the organizations who donated materials and support.

Humberto Cruz
Director of the AIDS Institute
New York State Department of Health

2010