



HIV, Stigma and Older Adults

HIV Treatment Education &
Integration for Service Providers
Serving Older Adults

Module 7

Modular Objectives

By the end of the module, participants will be able to:

- Define and identify HIV/AIDS-related stigma and discrimination.
- Clarify personal values and attitudes with regard to HIV/AIDS prevention and care.
- Know how to address stigma and discrimination in the context of providing services.
- Better understand how these issues inform/influence the quantity and quality of services older adults receive and pursue.

Examining Assumptions



On separate pieces of paper define the following terms:

- Senior
- Older
- Elder(ly)
- Mature
- (add special group after a review of each list)

Process Points

- Review each list, looking for any common themes.
- Was it difficult to think of each group as individuals?
- Were there any two groups that could be merged into one?

Process Points (2)

- Now add one new designation to each group – HIV +.
- What changed on the lists?
- Was the change an improvement?
- Overall how do you view the target population? Is it one needing services? Is it one who needs little assistance?

Context

- For the past several years, diverse and often confused concepts of stigma have been involved in the discussion on AIDS.
- This approach is grounded in a broad biosocial understanding of stigma and AIDS-related discrimination.
- The definition of stigma remains unclear.

Context (2)

- Stigma undoubtedly poses several challenges, but the mechanisms by which it is at the heart of the AIDS pandemic need to be explored.
- Stigma and discrimination are part of the complex systems of beliefs about illness and disease that are often grounded in social inequalities.

Epidemiological Facts

- Older adults represent a significant percentage of AIDS cases— 1 in 7 new cases in some areas
- Main risk behavior is older men having sex with men (but difficult to get current data!)
- Other transmission risks have increased
 - Heterosexual
 - Injection Drug Use
 - No identified Risk

Epidemiological Facts

- Transfusion risk has declined, but is still higher than other age groups
- **Women are particularly vulnerable in the later years.**
- The racial distribution parallels the epidemic— Blacks and Hispanics disproportionately represented

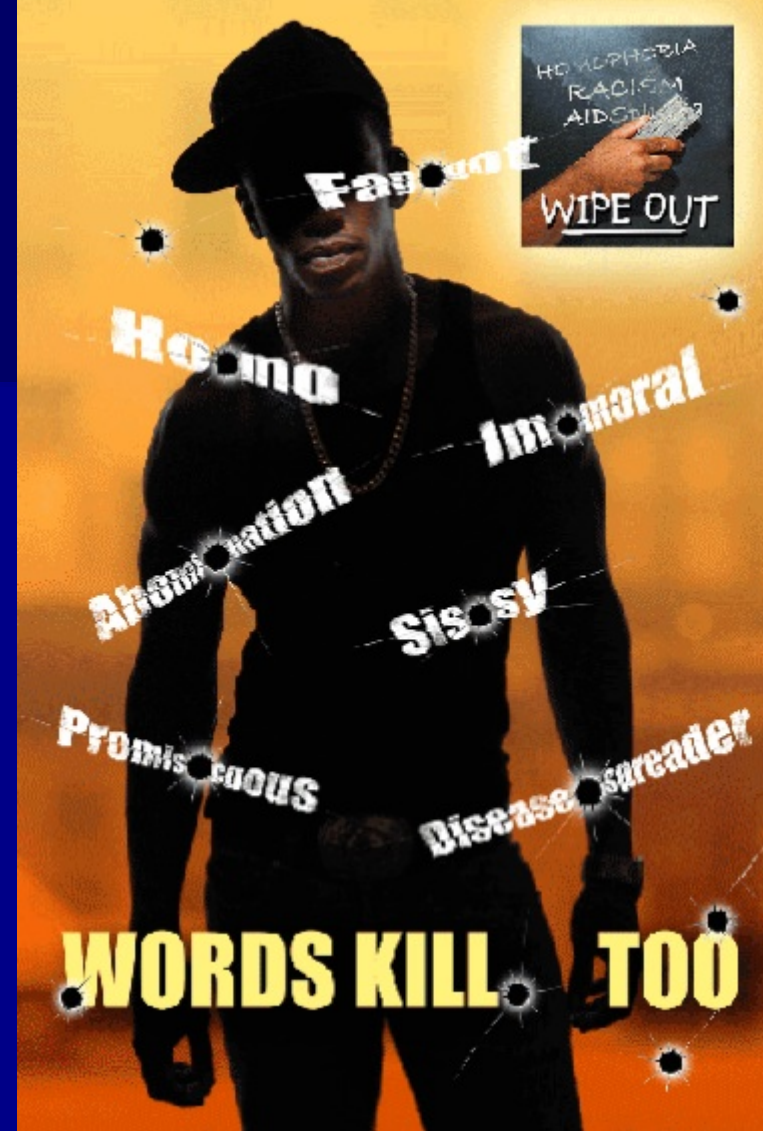
STIGMA

- theoretical work of Goffman (1963), and expanded by Herek and colleagues (1998) to define **HIV stigma as prejudice, discounting, discrediting and discrimination** that are directed at people perceived to have HIV or AIDS.
- Stigma has been recognized as a phenomenon that can be felt (internal) or enacted (external)

STIGMA

- From the beginning of the epidemic in 1981, AIDS was closely associated with disfavored minority groups, and culturally and historically taboo behaviors, such as homosexuality, drug use, and commercial sex work.

AIDS Community Research Initiative of America



STIGMA

- Although knowledge of HIV transmission has increased, more than **20** years later stigma still persists.
- Older adults also experience stigma and discrimination associated with ageism. For many, these challenges are compounded by living with **HIV/AIDS**.

- http://www.helpstartshere.org/health_and_wellness/hiv/aids/current_trends/hiv/aids_current_trends.html#stigma

STIGMA

- Older adults are members of communities that are increasingly affected and infected by HIV/AIDS, e.g., communities of color, poorer populations, and men who have sex with men. Being an older person with HIV is often coupled with dealing with the stigma and discrimination associated with sexism, classism, homophobia, and racism.

http://www.helpstartshere.org/health_and_wellness/hiv/aids/current_trends/hiv/aids_current_trends.html#stigma

Stigmas:

- Racism
- Heterosexism
- Ageism
- HIV Phobia

Stigma versus Discrimination

- Stigma refers to unfavorable attitudes and beliefs directed toward someone or something.
- Discrimination is the treatment of an individual or group with partiality or prejudice.

Stigma versus Discrimination

- Stigma reflects an attitude.
- Discrimination is an act or behaviour.

Themes Related to Stigma

- Attitudes and actions are stigmatising.
- Choice of language may express stigma.
- Lack of knowledge and fear foster stigma

Themes Related to Stigma

- Shame and blame are associated with stigma and HIV.
- Stigma makes disclosure more difficult.
- Stigma can exist, even in a caring environment.

What is Ageism?

- Any prejudice or discrimination against or in favor of an age group
- Prejudice against an age group: negative stereotype about that group, or a negative attitude based on a stereotype
- Discrimination against an age group: inappropriate negative treatment of members of that age group

Common

Stereotypes:

- Many live in nursing homes
- Most are unable to adapt to change
- Many are bored, lonely, live alone, live in poverty, and are often angry or irritated
- They have more injuries than younger persons
- They have higher rates of criminal victimization

9 Major Ageist Stereotypes:

1. **ILLNESS:** most are sick or disabled
2. **IMPOTENCY:** most no longer have any sexual activity or desire
3. **UGLINESS:** old people are ugly
4. **MENTAL DECLINE:** mental abilities tend to decline from middle age onward, especially the ability to learn/remember
5. **MENTAL ILLNESS:** many or most are senile; mental illness is common, inevitable and untreatable

9 Major Ageist Stereotypes:

- 6. USELESSNESS:** due to disability, most older adults are unable to continue to work, and those few that do continue to work are unproductive
- 7. ISOLATION:** the majority of old people are socially isolated, lonely, and live alone
- 8. POVERTY:** views about the economic status of older adults range from those who think most are poor to those who think most are rich
- 9. DEPRESSION:** because the typical older person is sick, impotent, senile, useless, lonely and in poverty, they must be miserable

Negative Ageism Words

Death/Dying

Dependent

Elderly

Frail

Geezer

Greedy/selfish

Homogenous

Helpless/victim

Ineffectual

Incapable

Neglected

Lonely/isolated

Old

Poor

Senile

Weak

Neutral Ageism

Words

Aged

Young Old

Aging

Old Old

Older *

Oldest Old

Retired

New Old

Senior

Positive Ageism Words

Alert

Involved

Autonomous

Productive/useful

Diverse

Life satisfaction

Dependable

Mentally active

Independent

Physically active

Can Names Portray an Image?

Younger adults consider themselves not “Senior” enough to attend programs at “Senior” centers...

Institutional names:

Congregate Meal Program
Elderly Nutrition Program
Senior Lunch Program
Senior Friendship Center

Other terms used:

Café
Friendship Meals
“Centro De Oro”

HIV/AIDS Phobia

- HIV disease is viewed as something for the young
- Older Adults are not considered to be those who have any risk behaviors.
- Few expect PLHA to have grey hair or wrinkles
- OA PLHA fear acts of discrimination on many fronts.

What we know

HIV is transmitted through:

- Unprotected sexual intercourse (vaginal, anal, oral)
- Shared needles or equipment for injecting drugs
- Unsterilized needles for tattooing, skin piercing or acupuncture
- Pregnancy, delivery and breastfeeding (from an HIV-infected mother to her infant)
- Occupational exposure in health care settings

What we know (2)

HIV CAN NOT be transmitted through:

- Casual, everyday contact
- Shaking hands, hugging, kissing
- Coughs, sneezes
- Giving blood
- Swimming pools, toilet seats
- Sharing eating utensils, water fountains
- Mosquitoes, other insects, or animals

“Vulnerable Groups”

- Older Adults
- People with limited English proficiency
- Aboriginal population
- Migrants & Refugees
- Women
- People with Low literacy
- People of Color
- Mentally Ill
- Homeless
- Sex trade Workers
- Intra-venous drug users (IVDUs)
- Men who have sex with men (MSM)
- Trauma Survivors

HIV-Related Stigma

- Fear of life-threatening illness
- Fear of infection (instrumental)
- Fear of “lifestyle” associated with “taboo behaviors” (ie. IDU, MSM)
- People being seen as (ir)responsible
- Religious/moral beliefs about punishment (shame & blame)
- Misperceptions of “other” groups

Consequences of HIV-related stigma

- Refusal to seek HIV testing or treatment
- Deterioration in personal, social and familial relations
- Negative emotions such as fear, guilt, grief, depression and anxiety
- Loss of support, SOCIAL ISOLATION
- Lack of trust in health care providers
- At the extreme discrimination, persecution, ostracism and violence

Secondary Consequences

- Restriction in one's rights
- Diminished capacity to advocate or negotiate for oneself
- Employment and housing problems
- Healthcare access issues
- Even, access to foreign countries
- Denial and avoidance of self-care and self-responsibility

The US vs. THEM dilemma

- HIV/AIDS is a global issue affecting millions of people largely for financial and social reasons
- Where consistent access to HAART is available, HIV-related stigma is reduced

The Power of Stereotypes

- act as short cuts for perceptual processing of categories of people
- blanket generalizations for *all* individuals
- exaggerate and homogenize traits held to be *characteristic* of particular categories
- maintain and produce 'norms' of behavior and impose order on the social world
- encourage a sense of continuity and certainty
- based on myths which are usually inaccurate, simplistic and rigid.

The 'Common Sense' Reality of Stereotypes

- signifies a set of unquestioned beliefs that enable people to make sense of everyday life
- operates in ways that legitimizes behaviors and limits the possibility for imagining and acting on alternative realities
- people are often unaware of the basis for their assumptions that inform their common sense reality
- combating ageism requires an understanding of the interests that are served by the common sense reality of

Conceptualizing Stigma

- Difficult, since it is complex and may seem amorphous
- Stigma is a social process and not just an individual one
- Reasons for stigma may vary
 - Fear of contagion or death
 - Prejudice against already stigmatized groups (compounded stigma)
 - Social norms about “bad” behavior
- <http://www.docstoc.com/docs/526751/HIV-Stigma-and-Discrimination>

WHO ARE WE TALKING ABOUT?

- How many older people are in this country?
- 1/4 of our population are people over fifty, 1/8 are over 60
- 2 million in NYC (1 million over 60)

- Why are they invisible?

➤ **AGEISM**

*Source: NYC Dept. of Health
HIV Training Institute*

Defining “Aging Adult”

- Older than 50
 - CDC groups all over 50 into one group
 - Significant biologic changes occur after age 50
- After 65, more hospital stays & longer stays
- Most are healthy

HIV and Elders: Myths

- People over 50
 - Not interested in sex
 - If sexually active, 3M only
 - Male/female
 - Monogamous
 - Missionary
- Don't use illegal drugs*
- Don't abuse drugs/alcohol*
 - **OK, if they did it was so long ago it doesn't matter*

Theories of Aging

- Homeostenosis (Wearing Out)
 - Gradual
 - Progressive
 - Each organ system independent
 - Evident by early 30s

Theories of Aging

- Disease (dis-ease)
 - Each person is an individual and becomes more so as they age
 - Abrupt decline in any system is due to disease
 - “Normal” aging is dependent on risk behaviors

AGEISM

- Discrimination against, and prejudicial stereotyping of older people
- Belief that a person's worth and ability are determined solely by chronological age
- Negative attitudes, biases, and myths attributed to people as they mature

*Source: NYC Dept. of Health HIV Training
Institute*

AGEIST MYTHS/FACTS



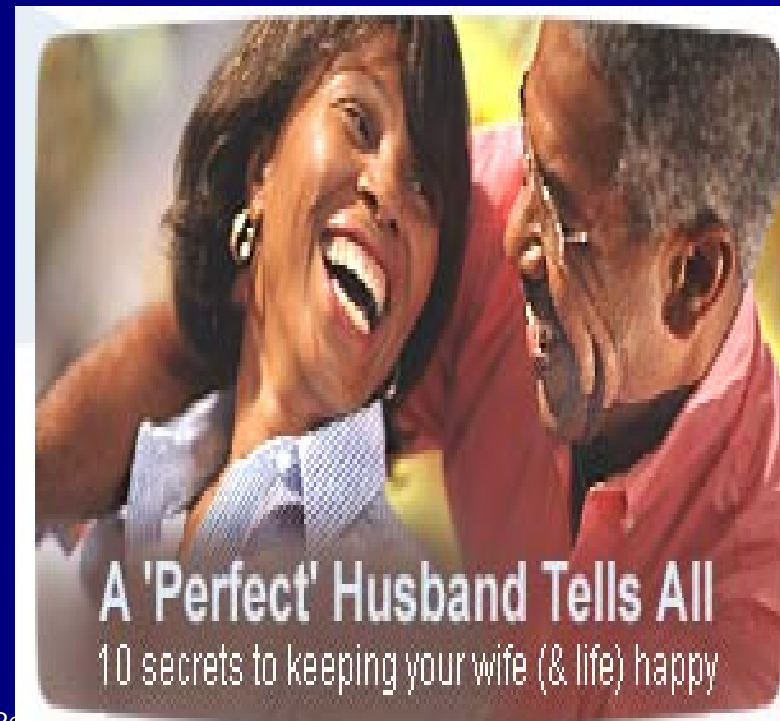
- Old people don't do drugs and
- If they did, it was so long ago that it doesn't matter
- Alcohol and Substance abuse are the third leading health problem among Americans aged 55 and over
- IVDU account for 17% of the cases of HIV among the elderly

Diagnosis and assessment of substance abuse in older adults: Current strategies and issues, King, Van Hasselt, Segal and Hersen Addictive behaviors, Vol. 19, No. 1 pp41-55

AGEIST MYTHS/FACTS

Senior Sexual Activity

- Old people are no longer interested in sex
- If they are, no one is interested in them



AGEIST MYTH/FACTS

➤ If Older Adults have sex, it's within a monogamous, heterosexual relationship

- Nearly 1/2 of the cases of 50+ HIV are men who have/had sex with other men.
- Many seniors, heterosexual, homosexual, or lesbian, enjoy and maintain multiple relationships.

AGEIST MYTH/FACTS



➤ Seniors do not practice any high risk sexual behaviors that would increase their risk for HIV infection

➤ Seniors are less likely to have protected sex

➤ People of varied ages enjoy a variety of sexual practices, including hiring sex workers, serial monogamy, and extra-marital affairs.

4 CHARACTERISTICS LINKED TO HIGHER LEVELS OF STIGMA WITH HIV/AIDS

- perceived to be bearer's fault/responsibility
- associated with degenerative conditions
- condition perceived to be contagious
- conditions that are readily apparent to others

RISK FACTORS

Age is significantly associated with progression to AIDS because of:

- Declining immune function
- Inadequate caloric intake
- Changes in mucosa
- Increased incidence of transfusion
- Low frequency of condom use, and HIV testing
- Lack of education from physicians concerning their risk behaviors

Helpful Provider Behaviors

- Be aware of HIV related risk among older adults
- Avoid assumptions about sexual activity and substance use
- Recognize the aging symptoms that are similar to HIV infection
- Look for opportunities to educate older adults

Recognizing Stigma

- “I felt blamed by others for my illness”
- “I feared that people would hurt my family if they knew my illness”
- “I avoided getting treatment because someone might find out about my illness”
- “I felt people would avoid me because of my illness”
- “I thought other people were uncomfortable being with me”

Unhelpful Provider Behaviors

- Avoiding the subject
- Responding in a stereotyped, hostile, or physically rough manner
- Using jargon
- Dismissing or failing to acknowledge older person's past
- forcing current and future technology
- placing barriers
- assuming older person is not interested in current and future technology

Asking about HIV Risk Safely

- Assure complete privacy
- Assure confidentiality
- Keep your questions short
- Avoid general, yes-or-no questions
- Put the question in context
- Ask direct, concrete, behavioral questions
 - Have you ever had sex with a man or woman without a condom?
- Don't ask: "Are gay?"

Avoid Heterosexual Assumptions

- **Avoid applying gender-specific pronouns to client's partner until the client uses them**
- **Say directly: 'I don't want to make assumptions about your partner's gender'**
- **Say 'partner' until you know what word the individual uses, then use that term**
- **Ask: "How long have you been together?" not "How long have you been *married*?"**
- **Ask about different relationship types**

Effects of Stigma

- Social isolation
- Limited rights and reduced access to services
- Secondary stigma (stigma by association)

Fear of . . .

- Illness
- Physical debilitation, losses, limitations
- Mental deterioration
- End of life suffering
- Rejection of support systems due to HIV
- Others??

Self Stigma

- HIV diminishes me
- I won't tell anyone to avoid stigma, embarrassment, humiliation
- Compounded for older adults due to less information and misunderstandings about HIV risk in elders
- Stigma threatens ego strength and self image, and the person may respond fatalistically, withdraw from support systems (Worth, 1990)

Stigma and Families

- Concern that HIV may bring shame on the family (Nichols, et al., in press)
- Telling part of the story—
 - Example: caregivers may indicate they are caring for someone with cancer
 - Work of maintaining the information

Service Providers and Stigma

- Believe older adults not vulnerable to HIV because they are not sexually active or are monogamous (Catania, et al., 1989; Pulio, 1996)
- Sex phobic with this population— relates to perceptions of own parents or grandparents?
- Provider resists making and HIV diagnosis – rule out all alternatives before testing (Gutheil & Chichin, 1991; Linsk, 1994)
- Reluctance to discuss HIV with their patients/clients (Feldman, 1994; Quam & Whitford, 1992; Zelenetz & Epstein, 1998)

Poverty and Income Changes

- HIV/AIDS and aging may each compound the economic losses of aging
- Racial differences: white versus African Americans (Speer, et al.)
 - Annual income for African Americans half that of whites
 - 68% of AA and 61% of whites reported marked decrease in income since diagnosis
- Financial conditions would have been better without HIV in lives (e.g. Nichols et al.)
 - Not having enough money to live on
 - Give up work earlier due to HIV

Impact of -isms

- *Often seen as a pseudonyms for:*
 - Poverty
 - Lower literacy levels
 - Risk promoting lifestyles
 - Dysfunctional health behaviors
 - Cultural biases
- Mistrust.
- Victimization by a social condition.
- Denial.
- Homogeneity of thought and action.
- “*hard to reach*” populations.

Interrelated components of stigma

- People label and distinguish differences
- Dominant cultural beliefs link labeled persons to undesirable characteristics – to negative stereotypes.
- Labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” and “them”
- Labeled persons experience status loss and discrimination that lead to unequal outcomes

Other factors

- Class
- Race
- Gender
- Sex/Sexuality
- These are influencing factors that inform the paradigms of our perception.

Conclusion

- Goffman defined stigma as the identification that a social group creates of a person (or group of people) based on some physical, behavioral, or social trait perceived as being divergent from group norms.

Conclusion (2)

- This socially constructed identification lays the groundwork for subsequent disqualification of membership from a group in which that person was originally included.

Conclusion (3)

- Stigmatization is entirely contingent on access to social, economic, and political power that allows identification of differences, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination.

Key Points

- While stigma reflects an attitude, discrimination is an act or behaviour.
- Discrimination is often defined in terms of human rights and entitlements in health care, employment, the legal system, social welfare, reproductive, and family life.
- Stigma and discrimination are often interlinked. Stigmatising thoughts can lead to discrimination.

Key Points

- HIV/AIDS-related stigma and discrimination may discourage PLWHA from accessing key HIV services.
- It may also:
 - **Discourage disclosure of HIV status**
 - **Limit access to education, counselling, and treatment even when services are available and affordable.**

Key Points: LABELS

- Labels are a general way of categorizing things that are too complex for the mind to see all at once.
- Using labels to describe a person completely underestimates an individual's sexual capacity for fantasy and experiences but also underestimates an individual's capacity to be something beyond their sexuality category.
- Once we label something we tend to forget about it, or at least to no longer endure the humiliating inconvenience of individual recognition.
- Identity is persistent and labile.