


HIV In Older Adults: Engaged

A stylized, high-contrast portrait of an older man and woman. The image is rendered in a limited color palette of oranges, browns, and greys, giving it a graphic, almost woodcut-like appearance. The man is on the right, looking slightly to the left with a gentle smile. The woman is on the left, looking towards the camera. The background is dark, making the subjects stand out.

acRIA

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ACRIA – Who we are, what we do

ACRIA, the AIDS Community Research Initiative of America, conducts a comprehensive HIV Health Literacy Program that offers a diverse roster of services for people with HIV. ACRIA is an independent, not-for-profit community-based AIDS research and education organization committed to improving the length and quality of life for people living with HIV disease through medical research and HIV health literacy.

Disclaimers

The information in this Discussion Guide is presented for educational and informational purposes only and is not intended as medical advice. All decisions regarding a patient's personal treatment and therapy choices should be made in consultation with a physician.

The stories featured are factual or based on fact. The interviews combine actual subjects and dramatizations by professional actors. This is no indication of their sexual orientation or medical status.

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Introduction

Understanding the Challenges of HIV Prevention

Far too few people over 50 are protecting themselves and their loved ones from HIV. One national survey found that people over 50 are six times less likely to use condoms and five times less likely to get tested for HIV than people in their 20s. The troubling reality is that older adults who are sexually active or who use drugs aren't doing as much to prevent HIV infection as younger people. Yet, more than a quarter of people with HIV in the U.S. are over 50 years old.

So why don't older adults do more to protect themselves? The short answer is that they don't realize they're at risk and don't know how to protect themselves. Health professionals often don't give older adults the information they need. This is due in part to the general perception that older adults are not at risk for HIV, and to society's reluctance to discuss the sexual and drug-taking behaviors that increase HIV risk among older adults.

A study of doctors in Texas found that a shocking number of doctors "rarely" or "never" ask patients older than 50 about HIV or discuss how to prevent it. Almost 40% "rarely" or "never" asked their patients over 50



about HIV, compared to 6.8% of their patients under 30.

Another challenge is that many older adults live in nursing homes and other assisted living communities, where there is still great stigma attached to HIV, often linking it to homosexuality or substance use. The management of some facilities may prevent HIV materials and presentations from reaching residents.

Older adults need support and education to ensure that their sex lives continue to be rewarding and safe. This will not only help them stay healthy, but will empower them as leaders and teachers of younger generations.



What is ACRiA doing?

"The most comprehensive research has come from the AIDS Community Research Initiative of America."
–The New York Times

In conjunction with its groundbreaking ROAH study (Research on Older Adults with HIV), ACRiA presented a comprehensive series of policy recommendations in the areas of healthcare, social policy, and research. Two key recommendations were:

- Target tailored prevention messages to older HIV-positive adults; develop public education outreach campaigns on ageism and HIV stigma in healthcare, including mental health services and social care agencies.
- Encourage and solicit community-based organizations and AIDS service organizations to apply for funding to train those who provide services to older adults with HIV to ensure responsiveness to their needs.

Why we made this DVD

“Engaged” is our second DVD targeting older adults. It reinforces the need to address HIV for adults 50 and older and offers new strategies for doing so. Most scenes take place in a community center, where a group of friends is planning a surprise engagement party.

Characters discuss their own stories. Some disclose their HIV status; some do not. The story, using fictional characters, presents the conflicts and turmoil that can result from openly discussing HIV. It’s a sobering representation of the urgency of addressing HIV prevention, testing, and education in older adults.

This guide will assist you in starting thought-provoking discussions about HIV prevention among older adults. People who watch the video are encouraged to share their reactions, feelings, and viewpoints.

How to use this guide

This guide will:

- Help those who are facilitating discussion groups or trainings that utilize the “Engaged” DVD.
- Present factual information and talking points that can be helpful in a focused and respectful exchange.
- Encourage integration of prior knowledge, learning styles, strengths, and needs of participants.
- Cultivate critical thought and leadership skills to deal with controversial topics.
- Encourage long-term commitment to behavior change instead of short-term information retention.
- Help viewers understand the need for HIV prevention interventions for older adults.
- Allow participants to discuss the Stages of Change Model as it applies to the characters in the story.
- Encourage facilitators to participate as both guides and co-learners.

Suggested discussion format

It is best to show the DVD at least a week prior to the group discussion. Encourage participants to take notes while watching, and allow at least 45 minutes for the discussion. It may be helpful to note the best ideas raised in the discussion, for follow-up meetings or action steps.

We encourage facilitators to be creative in adapting the materials to fit each discussion, audience, and time available. But it may be convenient simply to follow this guide’s sequence.

The guide can be used in a variety of formats to ensure a dynamic interaction, rather than a one-way transfer of information to passive learners.

Participants can simply follow the outlined sequence in the guide.

They can also be divided into small groups, with each group assigned

one portion of the DVD. After 5 to 10 minutes, each group can report back to the entire group and the facilitator can encourage questions and comments from everyone.

Participants who wish to practice staging using the Stages of Change Model will have a chance to do so in the “Provider’s Corner.”

The principles of adult learning can help further the discussion of HIV prevention among people 50 and older. For example, adults have a foundation of experience and knowledge, such as work-related activities, family responsibilities, and previous education. They need to connect new learning to this knowledge and experience base. It’s important to draw out the experience and knowledge they have that is relevant to this topic.

Why is this important to older adults?

Older adults are often excluded or ignored by HIV education and prevention programs, probably because of widespread myths and biases. False assumptions that older adults are not sexually active or involved in other risk activities may have discouraged prevention efforts. Sadly, many older adults may have internalized ageist attitudes as well.

The sexual lives of older adults are often minimized, ignored, or even ridiculed. In the media, sexual activity between older adults is portrayed as infrequent and undesirable. A news article reporting on a comprehensive study of sexual behavior among older adults was met with complaints that an accompanying picture of two older adults kissing was “disgusting” and “nauseating.” In the face of such negative stereotypes and ageist messages about their sexuality, older adults may experience conflict about their sexual desire and expression. They may feel embarrassed about a continued interest in sex, and may avoid the information and support they need to reduce the risks associated with it.

Over 65% of ROAH participants reported that they were infected through vaginal or anal sex. Among participants infected over ten years earlier, roughly equal numbers (28%) reported being infected through anal sex, vaginal sex, and sharing needles.

But almost half of those infected in the preceding five years reported unprotected vaginal sex as the route of infection. The growing number of people being infected through vaginal sex – especially among black and Latino older adults – will continue to be a factor in the rising infection rates among older adults.

With HIV infection rates staying level, the HIV-positive population is both graying and growing. Almost 27% of all people living with AIDS in the U.S. are over 50 years old. In New York City, 30% of the over 100,000 people living with HIV are over age 50 and 73% are over age 40. By 2015, it is probable that the majority of people with HIV in New York City will be over age 50.

Since physicians often do not perceive older adults to be at risk for HIV, they may not recommend HIV testing. Consequently, many HIV infections in older adults are detected late. One study of people aged 60 to 79 who had died in a long-term healthcare facility found that 5%, unknown to them, had HIV.

There is a need to:

- Create awareness about stigma and stereotypes that exist when dealing with older adults and sexual risk.
- Increase the awareness of HIV risk for older adults, and the related risk of other sexually transmitted infections (STIs) and viral hepatitis.
- Increase HIV testing efforts in senior and older adult communities.
- Increase targeted HIV prevention efforts for all older adults – those with HIV and those at risk
- Increase cultural competency among service providers.
- Increase awareness of groups within the older adult community at higher risk for HIV, such as men who have sex with men, addressing stereotypes and homophobia.
- Improve cooperation between HIV service providers and senior service providers.
- Increase the continuity of HIV prevention and access to care.

Effective Behavioral Interventions:

Effective prevention efforts targeted to older adults must be tailored to their culture, environment, beliefs, and attitudes. Some effective behavioral interventions already exist, however none are specifically designed to reach older adults.

The goal of behavioral interventions is to reduce the risk of behaviors related to HIV, drug use, and STIs. In general, these interventions seek to delay the onset of sexual intercourse, reduce the number of sexual partners, promote condom use, and reduce or eliminate drug injecting and the sharing of needles and other drug equipment. True reductions in such risks – particularly if adopted widely and sustained over time – translate into decreased HIV transmission.

The “Diffusion of Effective Behavioral Interventions” (DEBI) was designed by the Centers for Diseases and Control (CDC), to bring science-based community, group, and individual HIV prevention interventions to community-based service providers and health departments. The goal is to implement interventions at the state and local levels, to reduce the spread of HIV and STIs, and to promote healthy behaviors.

The Stages of Change Model

The Stages of Change Model (SCM) was originally developed in the late 1970s by James Prochaska and Carlo DiClemente at the University of Rhode Island, as they studied smokers who were able to quit.

The SCM has been applied to a broad range of behaviors including weight loss, injury prevention, alcoholism, and drug problems. The idea behind the SCM is that behavior change does not happen in one step. Rather, people progress through different stages on their way to successful change. Also, each of us progresses through the stages at our own rate.

The stages of change are:

- Pre-contemplation:** Not yet acknowledging that there is problem behavior that needs to be changed.
- Contemplation:** Acknowledging that there is a problem, but not yet ready or sure of wanting to make a change.
- Preparation/determination:** Getting ready to change.
- Action/willpower:** Changing behavior.
- Maintenance:** Maintaining the behavior change.
- Relapse:** Returning to older behaviors and abandoning the new changes.
- Stable behavior:** Maintaining healthy behavior.

Telling an alcoholic who is still in the “pre-contemplation” stage to attend a certain number of AA meetings in a certain time period will most likely not be useful (and perhaps counterproductive) because the individual is not ready to change.

Each person must decide when a stage is completed and when it is time to move on to the next stage. Moreover, this decision must come from inside – stable, long-term change cannot be externally imposed.

In each of the stages, a person has to grapple with a different set of issues and tasks that relate to changing behavior.



Characters' Profiles

Mateo

Mateo is a Latino male who has never been tested. He was married for 15 years, but now enjoys life as a single man. His friend Marlon confronts him, saying that he needs to get tested because of his “womanizing lifestyle.”



Marlon

Marlon, an HIV-positive African-American male, was in a committed relationship with another man and was very careful. His partner was quite afraid of HIV and pleaded, “Just don’t kill me.” His partner later died from cancer. He urges Mateo to get tested.

Iris

Iris is a Latina of unknown HIV status. She was married to a man who often left her home alone. They finally separated and she became a single parent of two kids, both of whom are in college. She now lives with her childhood sweetheart. During a conversation with Mateo, HIV comes up. She feels HIV is not a concern for her – she never used condoms with her husband. She considers it an issue for younger people.

Note: The stories on the DVD are real. Some are enacted by actors.



Karen

Karen is an African-American woman with HIV who believes she got the virus by sharing needles. She and her husband used to get high together. After he got sick, she began to regret spending so much time with him and not with her son, who died of sickle cell disease. Watching him die motivated her to seek medical care for herself, despite her earlier fears about the side effects of HIV drugs. She attends workshops and seminars to learn how to take care of herself. She also shares the challenges of disclosing her HIV status to her family.

Marisol

Marisol expresses deep concerns about the engaged couple, Clarita and Toño. Her greatest fear is that Toño will “kill Clarita.” When Iris asks what she means, Marisol responds that Toño has HIV and could infect Clarita.





Mateo

Since Mateo had never contracted HIV or an STI, he probably holds the common belief that he isn't at risk for either. The women in his life probably also share this belief.

Discussion

Why do you suppose Mateo chooses to stay single and become a “womanizer” after 15 years of marriage?

How did you feel about Marlon calling Mateo a “playa”?

It appears that Marlon's urging Mateo to get tested may have had an impact. Did you see any evidence of this?

Provider's corner

In the video, Mateo appeared to listen to Marlon about getting tested. Based on what you saw, where would you place him in the Stages of Change Model?

Character's Challenges

Marlon

Marlon shared his experience of losing his partner with Marisol. This was a challenge to her concerns about people with HIV being in relationships. He said to her, "Because I'm HIV-positive, I should spend the rest of my life alone?"

Discussion

How do you imagine it feels to be "careful" with sex and yet lose your partner to another disease (in this case, cancer)?

Was Marlon's urging Mateo to get tested an intrusion or reaching out to a friend? Please explain your answer.

Was his talk with Marisol effective? If so, why?

Provider's corner

As you listened to Marlon share his story, can you identify challenges he may have encountered in his journey from the "pre-contemplation" to the "maintenance" stage?

In your experience as a service provider, have you ever encountered someone like Marlon, who is very literate in HIV prevention but who may have relapsed into old risk behaviors? What counseling issues would you focus on to help such a client regain control?





Iris

Like so many women over 50 who are or were married, the thought of HIV is the furthest thing from Iris's mind. She believed that since she and her husband didn't use condoms, everything was all right.

Discussion

What came up for you when Iris said that her ex-husband often left her alone at home and that they had unprotected sex?

Iris is part of a generation that often used condoms only to avoid pregnancy, not HIV. How would you introduce condom use to someone like her?

Did you personally identify with any part of her story?

What new insights did you gain about the role of trust in relationships?

Provider's corner

During a brief conversation with Mateo, Iris was confronted with the idea that even at her age and with her history she could still be at risk for HIV. It may have been the first time she'd ever considered that. Where would you place her on the Stages of Change Model?

Character's Challenges

Karen

Karen said that she didn't take HIV medications because she had seen them not work for other people. But watching her son die gave her the motivation to start them and take care of herself.

Discussion

What thoughts or emotions came up when Karen shared her regret for not spending as much time with her dying son as she did with her husband?

Like Karen, many people with HIV hesitate to disclose their status because of the stigma and discrimination. What are your feelings on disclosure? Are people with HIV responsible for disclosing their status even if there's no sex or needle-sharing involved?

Karen was emphatic about using condoms each and every time. What does this say about her HIV health literacy?

What do you think she meant by "friends with benefits"?

Provider's corner

Based on what you know about Karen, where would you place her on the Stages of Change cycle?





Marisol

Marlon shared his experience of losing his partner with Marisol. This was a challenge to her concerns about people with HIV being in relationships. He said to her, "Because I'm HIV-positive, I should spend the rest of my life alone?"

Discussion

What came up for you when Marisol said that?

She stated that her husband treated her like a princess, but that their sex life consisted of her lying next to him and him forcing himself on her. She appeared unhappy and helpless. What do you make of that?

After Marlon had his chat with her, she appeared calm and centered. What made the difference?

Provider's corner

Based on what you know about Marisol, where would you place her in the Stages of Change Model?

Older Adults and HIV: The Facts

- People over 50 may have the same risk factors for HIV that younger people have.
- Many older people are sexually active but may not be practicing safer sex. Older women may be especially at risk because age-related vaginal thinning and dryness can cause tears in the vagina.
- Some older people inject drugs or smoke crack cocaine, which can put them at risk for HIV. HIV transmission through injection drug use accounts for more than 16% of AIDS cases among people over 50.
- Some older people may be less knowledgeable about HIV than younger people and therefore less likely to protect themselves. Many do not perceive themselves as at risk for HIV, do not use condoms, and do not get tested for HIV.
- The stigma of HIV may be severe among older people, leading them to hide their diagnosis from family and friends. Failure to disclose one's HIV status limits emotional and practical support.
- Older people of color and immigrants may find it difficult to overcome discrimination and stigma. They can be more vulnerable to rejection from the broader communities they depend upon for support, and thus are at risk for later testing, diagnosis, and reluctance to seek services.
- Health care professionals may underestimate their older patients' risk for HIV and so may miss opportunities to deliver prevention messages, offer HIV testing, or make an early diagnosis that could help their patients get early care.
- Physicians may miss an HIV diagnosis because some symptoms can mimic those of normal aging, such as fatigue, weight loss, and mental confusion. Early diagnosis can improve a person's chances of living a longer and healthier life.

Get tested

- If you are sexually active, you should get tested for HIV and all other STDs regularly—at least once a year. You owe it to yourself and your partners.
- It's particularly important to get tested if you have ever engaged in high-risk sexual behavior or drug use (shared needles, etc.). Also be sure to talk to your health care provider about your sexual and drug-using practices when you get tested.
- If you or your partner had a blood transfusion between 1978 and 1985, or an operation or blood transfusion in a developing country at any time, you should get an HIV test.
- If you have a partner, both of you should be tested for HIV and other STDs.

Tips for talking to Your Doctor about Sex

You can take an active role when it comes to your health. Doctors can be one of your best sources of support and information, so here are some tips for talking to them:

Before your appointment, take some time to think about what you want to discuss. Having a clear agenda will help you and your doctor make the most of your visit. This can include questions about your sexual practices.

Write down your questions before you go. A trip to the doctor may make you feel anxious or nervous, and you might forget your questions. Having them in writing can help you remember.

If you want to talk about sexual concerns, set the agenda for that visit right at the start. You might say, "I have some concerns about my sex life. Could we take some time today to discuss them?" Your initiative can guide your doctor to prioritize your sexual concerns.

Share your life's realities with your doctor. This may mean opening up to your doctor about the people around you who make it tough to stay safe. Naming your obstacles will help your doctor better support you in staying healthy.

Your doctor may overlook your successes. If you've cut back on your drinking, drug use, or the number of your sexual partners, share that. Knowing you are making a change will help your doctor think of ways to support you further.

If you hear your doctor repeat the same advice time after time, consider it proof that she or he cares about you. Such words of concern can make a big difference.

Do your own research on the Internet or in the library to learn more about what sexual practices are considered safe and unsafe, and what you can do to protect yourself and others. After the research, you may have more questions for your doctor.

Keep the door open for further discussions. Ask your doctor if she or he is willing to take more time to discuss safer sex with you at your next appointment or whether there is another member of the health care team who can help you develop a safer sex plan.

If your doctor dances around the topic of sex, you can steer the conversation so that it meets your needs. You can say, "How can I stay healthy and have sex?"

If you have HIV, let your doctor know that you do not want to pass it on to others. You can ask for suggestions on how to disclose your HIV status and how to negotiate safer sex. Ask about the risk of re-infection with a different strain of HIV, and the risk of getting other sexually transmitted infections.

If you find that your doctor is not receptive to talking about sex and drug use, it might be time to think about changing doctors.

Resources

**AIDS Community Research Initiative of America (ACRIA),
Center of HIV and Aging**

www.acria.org, 212-924-3934

American Association of Retired Persons

www.aarp.org

The Body: An AIDS and HIV Information Resource

www.thebody.com

Centers for Disease Control and Prevention

www.cdc.gov

Copasetic Women Over 50

212-864-6978

Council of Senior Centers and Services of New York City

www.cscs-ny.org 212-398-6565

Gay Men's Health Crisis (GMHC)

www.gmhc.org 212-367-1000

Gay Men of African Descent, Inc. (GMAD)

www.gmad.org 212-828-1697

GRIOT Circle, Inc.

www.griotcircle.org 718-246-2775

Hispanic AIDS Forum (HAF)

www.hafnyc.org 212 868-6230

New York Association on HIV Over 50 (NYAHOF)

www.nyahof.org 212-367-1009

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

www.sageusa.org 212-741-2247

Sexuality Information and Education Council of the U.S.

www.siecus.org

**UCSF Center for AIDS Prevention Studies "What Are the
HIV Prevention Needs of Adults Over 50?"**

www.caps.ucsf.edu/pubs/FS/over50.php

DVD missing?

Call 212-924-3934 x129 for a free copy.



ACRIA is an independent, not-for-profit community-based AIDS research and education organization committed to improving the length and quality of life for people with HIV through medical research and health literacy.

ACRIA conducts an HIV Health Literacy Program to offer people with HIV and their care providers the tools and information they need to make informed treatment decisions. Health Literacy Program services include: workshops conducted at community-based groups throughout the New York City area in English and Spanish; technical assistance trainings for staff of AIDS service organizations; individual treatment counseling; and publications, including a quarterly treatment periodical and booklets in English and Spanish on treatment-related topics. TrialSearch is our online, searchable database of HIV clinical trials enrolling throughout the United States. ACRIA's National Training and Technical Assistance Program offers training and ongoing support to help non-medical service providers and community members in various parts of the country acquire the skills and information needed to provide HIV treatment education in their communities. The Older Adults Training and Technical Assistance Program offers similar services locally and nationally with a focus on the needs of middle-aged and older adults.

To learn more about ACRIA's research studies or the HIV Health Literacy Program, please call or email us at treatmented@acria.org. Information about our programs and copies of all of our publications are also available on our website.

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