Sexual Health and Aging Program (SHAPE): A Feasibility Pilot Study

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ENDING AIDS BY 2020

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The Graying of the HIV Epidemic in the US

CDC Surveillance Data

<table>
<thead>
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<th>Number of people living with HIV</th>
<th>1.25 Million</th>
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<tr>
<td>Over age 50 in 2011</td>
<td>37%</td>
</tr>
<tr>
<td>Over age 50 in 2015</td>
<td>50%</td>
</tr>
<tr>
<td>Over age 50 in 2020</td>
<td>70%</td>
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Neglected area of research

The sexual risk behaviors of older adults is a neglected area of research in part due to the assumptions that they no longer engage in sexual activity, especially with new partners.
Background

• Current studies found that older PLWH reported between 33% and 42% unprotected sex, and many (18%) with serodiscordant partners.
  (ROAH Study – Karpiak et al, 2006; Golub et al, 2010).

• Risk factors for unprotected sex among PLWH include:
  – Low levels of knowledge about HIV transmission,
  – Recent substance use,
  – Poor physical health,
  – And poor psychological well-being.

• PLWH might abandon safer sex practices due to the belief that they are protected by treatment adherence and low viral loads.
What are the prevention needs of older women with HIV?

Little is known about how gender and age-related physical and psychosocial changes impact sexual health and sexual risk behavior.

Urgent attention is needed to understand how biologic events such as menopause and other life course changes affect the wellbeing of older women with HIV.
5 year KO1 grant:
Prevention Needs of Older women with HIV

Aims 1: Longitudinal analysis of sexual activity (SA) and unprotected anal and vaginal intercourse (UAVI) using extant data from the WIHS

Aims 2: Prospective cross-sectional survey to assess the impact of certain psychosocial and interpersonal variables on SA and UAVI

Aims 3: Utilize information from Aim 1 and 2 to develop and pilot test an intervention to address sexual risk behaviors among older women with HIV.
Women’s Interagency HIV Study (WIHS)

- The largest longitudinal cohort study of HIV-infected women in the United States
- Six sites (Washington, DC; San Francisco; Los Angeles; Brooklyn; Bronx; and Chicago).
- Enrollments in 1994-95, 2001-02.
- Semiannual study visits include:
  - Standardized, interviewer-administered questionnaires
  - Physical and gynecological examinations and biosamples
Aim 3: SHAPE Development

**Intervention Mapping (IM) protocol** (Bartholomew, 2011) that has 6 program planning steps:

1. Conduct a needs assessment;
2. Define the performance and change objectives;
3. Select theory-based intervention methods and practical applications to change (determinants of) health-related behavior;
4. Design and produce program components;
5. Develop protocol for the program adoption, implementation and sustainability; and
6. Develop a process for program monitoring and evaluation.
Needs Assessment

Findings from Aims 1& 2

• More than 2/3 of the HIV-infected women in the WIHS were sexually active, and **22-25% engaged in UAVI** over 13 years of follow-up

• Survey trends suggest that increased *isolation, loneliness, non-disclosure, depression, current drug use, history of physical or sexual abuse* are associated with UAVI

• Self-reported (Interviews) UAVI was associated with:
  - **Partnership characteristics** (trust, refuses condoms; knows risk and still no condom; sexual dysfunction)
  - **Low perception of risk** of HIV transmission (due to gender or TaP)
  - **Non-disclosure** due to fear of partner loss and negative retribution.
Logic Model of the Problem:
UAVI and non-disclosure among older women with HIV

Personal Determinants
- Belief: harder to give to a man
- Belief: harder to give if VL
- Chronic mental health or substance use
- Health status
- Viral load status
- Low perception of risk
- Low knowledge of risk with aging
- Fear of disclosure
- Gender/aging norms
- Fewer partners
- Need for intimacy
- Partner's sexual dysfunction
- Younger partner
- Partner reluctant to use condoms
- Menopause

Risk Behaviors
- Inconsistent condom use
- UAVI
- Non-disclosure

HIV Transmission
- New STI or HIV strain

Interpersonal/Environmental Conditions
- Ageism
- HIV stigma
- Social isolation
- Loneliness

Diminished treatment efficacy with new HIV strain

Increased risk of AIDS for newly infected
(Due to advanced age at time of new infection)
Performance and Change Objectives

Performance objectives

1. Use condoms consistently and correctly during vaginal and anal sex with all sexual partner(s)
2. Safely disclose HIV status to new and old partners, friends and family
3. Increase understanding of successful aging and good sexual health with HIV

Change objectives

1. To minimize HIV risk behaviors (unprotected anal and vaginal intercourse) among heterosexual, HIV-infected women aged 45 years and older.
2. Increase self-efficacy to safely disclose HIV status to friends, family and new sexual partner
Theoretical orientations

Social Cognitive Theory (SCT) that includes determinants of behaviors and a process of behavior change (Bandura, 1997)

- **Determinants of behaviors**, the SCT model posits a reciprocal triadic relationship between behavioral, cognitive, and environmental factors.

- **Behavior change framework** SCT uses the following four core concepts: observational learning/modeling, outcome expectations, self-efficacy, and goal setting and self-regulation.
Theoretical orientations

**Motivational Enhancement** (ME) encourages favorable group processes by actively involving participants in the behavior change process and in developing risk reduction strategies that are suited to their own circumstances (Miller, 1994 & 2002).

SHAPE program also utilizes perspectives from **Feminist gerontology** to broaden our understanding of aging for women with multiple aspects of diversity, including privilege, inequality, and interdependence (Calasanti, 2004; Garner, 1999; Hooyman, 2002; Ray, 1996; Ray, 2004).
SHAPE: Sexual Health and Aging Program

SHAPE is a peer-led program for older women with HIV to promote satisfying and safe sexual health as we get older and help those who want to learn how to disclose safely.

The main goal of the group is to learn something new and have fun doing it!
SHAPE Overview

SHAPE is a small-group, skills-based behavioral intervention for older women living with HIV derived from three evidence-based interventions

1. Healthy Relationships (Kalichman 2005)
2. WiLLOW (Wingood, 2004)
3. ROADMAP (Illa, 2010)

The SHAPE program is gendered and generationally tailored and focuses on skills building, self-efficacy, and positive expectations for new behaviors.

We used the concept of a metamorphosis with butterflies as a metaphor for the life course, optimally aging and personal transformation.
SHAPE Procedures and Objectives

The SHAPE program has 4, 2-hourlong group session.

Each session provides opportunities for skills building and feedback and includes written support materials.

Through interactive group discussions, role plays, videos and skill-building exercises, within groups of 5-8 women.

The intervention helps older women living with HIV to develop knowledge and skills to:

- age successfully with HIV
- enhance coping and decision-making skills for HIV disclosure to family, friends and new sex partners
- help participants to maintain safer sex practices as they age
Feasibility Pilot Study

Participants

- 60 women recruited in STAR and WIHS
- Eligibility: 45 years old and older and report UAVI
- 2 arms (RX and SOC)
  - RX arm is exposed to SHAPE
  - SOC receives brief MI intervention with provider + optimal aging overview with PI

4 components:
1. Survey (baseline, 3 and 6 month follow-up)
2. Program (SHAPE or optimal aging)
3. Interview
4. Support group
Survey Measures

- The HIV Disclosure and Safer Sex Self-Efficacy Scale
- Perceived Stress Scale (PSS)
- Coping Self-Efficacy Scale (CSES)
- The Female Sexual Function Index (FSFI)
- Brief UCLA Loneliness Scale (Version 3)
- Lubben Social Network Scale-6 (LSNS-6)
- Older People’s Quality of Life Questionnaire (OPQOL-brief)
- Geriatric Depression Scale (GDS, Short Form)
Today’s Presentation

Overview of the SHAPE core components

• Content
• Activities
• Exercises
• Prompts
Sexual Health and Aging Program
Session 1

Aging, Stress & Coping

• Introduce the “Graying of HIV”
  – Group rules
  – Introductions
  – Icebreaker

• The Life cycle and Metamorphosis
  – Our butterfly tales of transformation

• Healthy Aging with HIV

• Stress & HIV and the 5 SHAPE Coping Skills
The Graying of HIV

By 2015, 50% of all HIV-infected individuals in the US will be over 50
– 70% are long-term survivors

Women and minority groups will be disproportionately affected.
Video#1

HIV and Aging
Talking about My Generation
1960s & 1970s

Let’s get into groups of 2s.
Make a list of one of the following:

- Top 10 songs
- Top 10 movies
- Top 10 TV shows
- Top 10 events
- Top 10 fashion trends

(3-5 minutes to write list)

(5 minutes to discuss)
Metamorphosis: Butterfly Tales of Transformation
The Life Cycle of Women
Butterfly Life Cycle

- **Egg or Ova**
- **Caterpillar or Larva**
- **Pupa or Chrysalis**
- **Adult or Imago**
One butterfly’s Tale of Transformation
What’s your story of transformation?

• Now, let’s each of us think about how certain events in our lives helped shape us into the women that we are today.
  
  – What you write down is just for you.
  – You don’t have to share if you don’t want to

**Remember**: what we share here today is private; we must respect each other’s confidentiality

5 minutes

30 minutes to discuss
Healthy Aging with HIV
Risky Lifestyle behaviors & Older Adults
Lifestyle behaviors

**Alcohol**
According to one study, "2.5 million older adults and 21% of older hospital patients had alcohol-related problems."

**Smoking**
Older Americans, (The Vets & Boomer generations), had smoking rates among the highest of any U.S. generation.
Lifestyle behaviors

Illicit drug use

By 2020, sources estimated that there will be 4.4 million older adults struggling with addiction.

Prescription medication misuse and abuse

Older women take an average of 5 prescription drugs at a time.
Mental Health and Social Support

Social isolation and loneliness

One study found that only 1/3 of older adults with HIV had partners and 71% lived by themselves.

Depression and Anxiety

One study in NYC found that depression among older adults with HIV was almost 13 times higher than among the general population.
Overview
Stress and
5 Coping Skills
Stress

Some stressors are minor and easy to deal with, while other stressors are significant (major) and can be overwhelming.
Five Coping Skills

1. Awareness
2. Identifying triggers and barriers
3. Problem-solving
4. Effective Decision-making
5. Taking action
Hypothetical Situation/Problem

• You live alone
• No friends and family around
• Increasing health needs
• Might need help in the future
• There is a nice neighbor but....I’m afraid to tell her

PROBLEM:
I am socially isolated and afraid to disclose
Session 2: HIV Disclosure

Overview on Stress and HIV Disclosure to Friends, Family and New Sex partner (video 2&3)

Personal Feedback Report 1 & 2

Banner Activity

Video 4 (high & low risk with friends):
  – Discussion and Role-play

Video 5 (disclosure to a new partner):
  – Discussion and Role-play
Stress and Disclosure

As we all know, disclosure or telling someone that you are living with HIV can be very stressful.

People might
- Love and accept us
- Reject and treat us badly
- Embrace and support us
- Be Afraid or angry
Video#2
Everyone Has a Story: Stigma, Shame and Disclosure
Disclosure is an ongoing process

• Disclosure is not a one-time event, it happens over and over again as new people come into our lives.

• One of the goals of the SHAPE program is to help older women with HIV safely disclose if they want to.

• There is no one best way to tell someone. Similarly, there is no sure way to know how those you tell will react or whom they may choose to tell.
Disclosure with Sex Partner

- Perhaps the most stressful of all possible disclosure situations because not only can we be rejected (which is never nice) but for some there is the very real fear of physical retaliation.
  - As a result, many of us chose not to disclose.
- This section of the program focuses on how to identify when it is safe or not to disclose and how to do so in the most effective way possible.
Video #3
How Do You Tell Somebody That You're HIV+?: Haneffa’s story
PFRs (Personal Feedback Reports)

• Purpose: This activity is designed to build motivation for change by having participants reflect on their experiences and behaviors.

• This is our starting point for thinking about how stressful (how personally risky) disclosure to family, friends and new sex partners can be

• This report is only for the PARTICIPANT to help THEM set goals at the end of the program
Video#4

“He could kill her”
Session 3: Sexual Health & Safer Sex

1. Sexual Health overview
2. Family Feud game
3. Sexual Risk among Older Adults overview
4. Personal feedback report 3
5. Banner Activity: safer sex/risk reduction
6. Condom use with older partners
7. Skills building: T.A.L.K
Video#6

Adult Sex is... HOT!
Sexual Health

Older adults continue to engage in sexual activity, which contributes to general well-being and fulfills social, emotional and psychological needs.

— *Sex and sexuality is not just about the physical; its also about intimacy.*

A satisfying sex life for older adults can:
— Add years to their lives
— Improve mental and physical well being
— Alleviate stress and anxiety
— And solidify interpersonal relationship

“*sexuality and its expression as an activity of daily living that is significant for many older people*”
Video #7
Still Doing It: the intimate lives of women over 65
It's time to play Family Feud.
What are some of the benefits of having a healthy sex life as we age?

1.)

2.)

3.)

4.)

Total Points: 40

Score

Try Again
Benefits of having a healthy sex life as we age

1. Improve mental and physical well being
2. It can alleviate stress and anxiety
3. Increase lifespan
4. Makes you feel good about yourself
5. Happier mood
6. Give you a Stronger Immune System
7. Glowing Skin
8. Better sleep
9. A Stronger Relationship
10. Fast Relief from Aches and Pains
11. Stay mentally sharp
Challenges of Sex after 50

Some might turn away from sex because they think that they are too old.

Some lose interest in sex because of illness or the loss of a partner.

Some of us might feel embarrassed by changes in
- our aging bodies,
- our sexual performance
- or the sexual “performance” of our partners.

But these problems are not unbeatable.
Take a stroll down Menopause Lane
What things can you do to spice up your sex life?

• Change routine

• Be playful

• Foreplay

• Increase activity – just do it!
Video#8
How to Put a Condom on with Your Mouth
Video#9
PSA Safe Sex for Seniors
Video# 10
STI/HIV Risk among Older Adults
Estimated Diagnoses of HIV Infection among Adults Aged 50 and Older by Gender and Transmission Category 
2010, 46 States

- Male-to-male sexual contact/IDU: 3%
- IDU: 14%
- Heterosexual contact: 23%
- Male-to-male sexual contact: 60%
- Other*: <1%

Males (N=5,726)

- Heterosexual contact: 82%
- IDU: 18%
- Other*: <1%

Females (N=2,072)

*Injection drug use.
*Other transmission risk factors include hemophilia, blood transfusion, & risk factors not reported or identified.
*Heterosexual contact with a person known to have, or be at high risk for, HIV infection.
*Due to rounding, percentages may not add up to 100%.
Challenges with condom use as we get older
Reasons why some men don’t want to use condoms:

1. Sexual dysfunction (I don’t want to hurt his feelings)
2. Menopause (“you can’t get pregnant, so why?”)
3. He doesn’t want to wear it (even though he knows I’m positive) because he thinks it wouldn’t be bad if he got it
Reasons why some women do not use condoms:

1. “It’s harder to give it to a man”

2. “It’s harder to give it to him if I’m undetectable”

3. “He’s still negative after lots of unprotected sex”
Treatment as Prevention (TaP)

Suppressing viral replication among HIV+ persons in order to reduce the likelihood of sexual transmission

- Early initiation of HAART
- Adherence support
- Test and treat

Is PrEP as solution?

- PrEP means Pre-Exposure Prophylaxis, and it’s the use of anti-HIV medication that keeps HIV negative people from becoming infected.

- **What does it do?:** The medication interferes with HIV’s ability to copy itself in your body after you’ve been exposed. This prevents it from establishing an infection and making you sick.
PEP: Post Exposure Prophylaxis

- PEP is the use of antiretroviral drugs after a single high-risk event to stop HIV from making copies of itself and spreading through your body.

- PEP must be started as soon as possible to be effective—and always within 3 days of a possible exposure.

- If you think you may have been exposed to HIV very recently, see a doctor as soon as possible to find out if PEP is right for you.
Personal Feedback Report 3:

• Purpose: This activity is designed to build motivation for change of risky sexual behaviors and continued use of safer sex practices by having you reflect on your experiences and behaviors.

• It is a starting point for thinking about how stressful (how personally risky) it might be to try to consistently use condoms.

• This report is only for **YOU** to help you set goals at the end of the program.
Banner Activity:
Safer Sex and Risk Reduction

Think about each type of sexual activity listed on their card(s) and the level of risk involved.

– Which types of sexual behavior would be “High Risk”? 
– Which types of sexual behavior would be “Moderate Risk”? 
– Which types of sexual behavior would be “No/Low Risk”?

Place your card(s) on the Banner and Discuss
T.A.L.K
Communication Skills for Safer Sex

**T**iming is everything - Pick the right time & place

**A**ssert what you want

**L**ist your reasons for being safe

**K**now your bottom tine
Video#11
Let’s try something new
Scenario 1: Steady Partner

Frank: You and Susan have been together for 12 years. He knows your status. He hates using condoms and sometimes you have had unprotected sex with him. He is still negative.

Susan: You are HIV + older woman

Prompt: Why do we have to use those again? You are undetectable? We’ve have not used condoms many times and I’m still negative. I trust you. If I get HIV it won’t be so bad.
Session 4: Goal Setting
The Colors of My Wings

We are going to create a visual representation of the butterflies we want to be.

Think about the following

• What color or colors do you want to be?
• Will your wings have a pattern? A texture?
• Will your wings be large or small?
• Will they have different shapes?
• Will they have lines? Circles? Other shapes?
• What color will your body be?
Debriefing & Evaluation

• Are there any questions?

• Please fill out the following evaluation form
Partner Characteristics and Disclosure

Baseline vs. 3MFU (n=24)

- HIV-Partner: 79 (Baseline), 48 (3MFU)
- Don't know partner's status: 13 (Baseline), 8 (3MFU)
- No disclosure: 8 (Baseline), 8 (3MFU)
Preliminary Data (2)

Risk Behaviors

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<tr>
<th></th>
<th>Baseline</th>
<th>3MFU (n=24)</th>
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<tbody>
<tr>
<td>UVI</td>
<td>92</td>
<td>75</td>
</tr>
<tr>
<td>UAI</td>
<td>15</td>
<td>0</td>
</tr>
<tr>
<td>NO DISCLOSURE NO CONDOM</td>
<td>12</td>
<td>4</td>
</tr>
</tbody>
</table>
Here are some Butterfly Inspired Life Lessons
We delight in the beauty of the butterfly, but rarely admit the changes it has gone through to achieve that beauty.

~Maya Angelou
Life is a process of becoming... and it isn’t always pretty.
Like the Butterfly,
I have the strength & the hope
to believe,
In time
I will emerge from my cocoon...
Transformed.
There is power in going “inside” oneself... and then choosing to come out again.
We are like butterflies who flutter for a day and think it is forever.
~Carl Sagan

The butterfly counts not months but moments, and has time enough.
~Rabindranath Tagore
Enjoy the moment!
There is nothing in a caterpillar that tells you it's going to be a butterfly.

~Richard Buckminster Fuller
Never give up!
But, unlike the butterfly, we continue to transform and develop new and even more beautiful wings!
So what will the next phase of your life look like?
Where will your wings take you?
What life lessons learned will help you fly?
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Thank you
Videos
Video#1

HIV and Aging
Video#2

Everyone Has a Story: Stigma, Shame and Disclosure
Video #3
How Do You Tell Somebody That You're HIV+?: Haneffa’s story
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Let’s try something new
Video #12

Aging with HIV