

Research Article

Developing a Sexuality Education Survey for Women Living with HIV

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Abstract

Background: Advances in antiretroviral therapy have transformed HIV into a chronic condition, shifting care priorities beyond viral suppression toward quality of life and well-being. Sexual health is a central component of health; however, sexuality education for women living with HIV (WLH) has historically emphasized risk reduction and fertility control, often neglecting pleasure, sexual agency, and reproductive autonomy. The absence of tools to assess sexuality education experiences among WLH limits the ability to identify gaps, evaluate interventions, and deliver equitable, patient-centered HIV care.

Objective: To describe the development of a sexuality education assessment tailored for women living with HIV, informed by women's lived experiences and grounded in sexual health and reproductive justice frameworks.

Methods: Between March and May 2024, two qualitative focus groups were conducted with WLH recruited from the Miami site of the Multicenter AIDS Cohort Study/Women's Interagency HIV Study Combined Cohort Study (MWCCS). Participants reviewed and provided feedback on two existing instruments: the HIV-Positive Primary Prevention (HIV-PPP) Survey and the Student Sex Survey. Guided discussions focused on item relevance, language appropriateness, and identification of missing content domains. Audio recordings were transcribed verbatim and reviewed for accuracy. A multidisciplinary research team used a consensus-based analytic approach to determine item retention, modification, removal, and addition.

Results: Participants identified substantial limitations in existing sexuality education measures, including stigmatizing language, heteronormative assumptions, and an overemphasis on risk. Assessment refinement resulted in expanded domains addressing sexual pleasure, desire, intimacy, HIV-related counseling experiences, disclosure, U=U education, aging and menopause, and relational and structural influences on sexual agency. Women emphasized the importance of evaluating not only whether sexuality education occurred, but how it was framed; specifically whether it supported autonomy, dignity, and informed choice.

Conclusions: This study addresses a critical measurement gap by developing a sexuality education assessment tailored to the experiences of women living with HIV. Grounded in reproductive justice principles, the assessment moves beyond behavior-focused metrics to capture empowerment, agency, and well-being. This tool has the potential to inform research, clinical practice, and interventions aimed at integrating comprehensive, rights-based sexual health education into HIV care for women.

Introduction

Advances in antiretroviral therapy have transformed HIV into a chronic, manageable condition, allowing women living with HIV to experience near-normal life expectancy [1,2]. As a result, HIV care has expanded beyond viral suppression to encompass quality of life, mental health, and overall well-being, consistent with World Health Organization definitions of sexual health as a fundamental aspect of human health and human rights [3]. Despite this shift, sexuality remains insufficiently addressed within HIV research and clinical care, particularly for women.

Women living with HIV (WLH) experience sexuality at the intersection of biomedical, psychosocial, relational, and structural

forces, including HIV-related stigma, gender norms, trauma histories, aging, and reproductive health transitions [4,5]. Historically, sexuality education for women with HIV has focused primarily on transmission prevention and fertility regulation, often excluding discussions of pleasure, desire, sexual functioning, intimacy, and sexual agency [6,7]. From a reproductive justice perspective, defined by the right to bodily autonomy, the right to have or not have children, and the right to parent and live with dignity in safe and sustainable communities, this narrow approach constrains women's ability to make fully informed and self-determined decisions about their sexual and reproductive lives [8,9].

Empirical evidence demonstrates that many WLH report unmet needs related to sexual functioning, body image, menopausal changes,

and communication with partners and healthcare providers [10,11]. Fear of HIV transmission and internalized stigma persist even in the context of robust evidence supporting Undetectable = Untransmittable (U=U), which has been shown to eliminate sexual transmission risk when viral suppression is maintained [12,13]. These challenges are disproportionately experienced by women who face intersecting structural inequities, including women of color, women aging with HIV, and women experiencing socioeconomic marginalization [14,15].

Despite increasing recognition of sexual well-being as integral to health, the extent to which WLH receive comprehensive, affirming, and rights-based sexuality education remains poorly characterized. This gap reflects, in part, the absence of assessment tools designed specifically for women living with HIV. Existing sexual health and HIV-related measures often prioritize risk behaviors and clinical outcomes, with limited attention to sexual pleasure, agency, power dynamics, reproductive decision-making, and trauma-informed care [16,17].

The lack of tools to assess sexuality education among WLH represents a critical limitation for advancing patient-centered, equity-oriented HIV care. Without such measures, it is difficult to identify educational gaps, evaluate interventions, train providers, or inform policy and program development. Importantly, assessment is a prerequisite for accountability and aligns with reproductive justice principles by centering bodily autonomy, informed choice, and dignity rather than fear-based or restrictive messaging [3,8].

The purpose of this study is to describe the development of a sexuality education assessment tailored for WLH. Grounded in women's lived experiences and informed by contemporary sexual health and reproductive justice frameworks, this research aims to provide a foundational measurement tool to support holistic HIV care, guide intervention development, and advance the equitable integration of sexual well-being into HIV services.

Methods

Study Design and Participants

This qualitative study employed focus group methodology to inform the development of a sexuality education assessment tailored for women living with HIV (WLH). The study was approved by the University of Miami Institutional Review Board. Between March and May 2024, two focus groups were conducted with WLH to review existing sexuality education assessments and provide feedback to ensure relevance, appropriateness, and cultural responsiveness for the target population.

Participants were recruited from the Miami site of the Multicenter AIDS Cohort Study/Women's Interagency HIV Study Combined Cohort Study (MWCCS), the largest and longest-running observational study of people living with HIV in the United States. Recruitment flyers were posted in areas where routine MWCCS study visits occurred. Interested individuals were referred to the study coordinator for screening and enrollment. Eligibility criteria included being an adult woman living with HIV and currently enrolled in MWCCS.

Instrument Identification and Review

A comprehensive review of the literature was conducted to identify existing sexuality education and sexual health assessments relevant to capturing women's educational experiences across the life course. Although no single validated instrument adequately captured sexuality education experiences among WLH, two complementary tools were identified by the Principal Investigator (PI) as foundational for adaptation:

1. **The HIV-Positive Primary Prevention (HIV-PPP) Survey**, which assesses HIV-related knowledge, sexual behaviors, and prevention practices before diagnosis, at the time of infection, and following diagnosis.
2. **The Student Sex Survey**, which assesses exposure to school-based sexuality education, including curriculum type, duration, and perceived adequacy.

Together, these tools provided a starting framework to capture both formal sexuality education and HIV-specific sexual health experiences.

Focus Group Procedures

Two in-person focus groups were conducted in a private conference room within the same facility where MWCCS study visits occurred, enhancing participant familiarity and comfort. All participants provided written informed consent prior to participation. Each focus group was audio recorded and facilitated by the PI, with a research associate present to take handwritten notes and observe group dynamics but not participate in discussion.

Each focus group lasted approximately 90 minutes. Participants were guided through a systematic, item-by-item review of both instruments. Consistent with the study's measurement development objectives, discussion focused narrowly on three domains:

1. **Relevance:** Whether each item was appropriate and meaningful for WLH.
2. **Language:** Whether wording was clear, respectful, inclusive, and non-stigmatizing.
3. **Content gaps:** Identification of missing domains or questions necessary to capture women's sexuality education experiences.

At the conclusion of each focus group, participants received \$25 compensation for their time. Audio files were uploaded to the University of Miami's secure, cloud-based server.

Analyses

Audio recordings were transcribed verbatim by two medical students completing a supervised research practicum. Following transcription, each medical student and a Master's-level clinical research coordinator independently reviewed the transcripts against the audio recordings to ensure accuracy and completeness.

Using a consensus-based analytic approach appropriate for instrument development, the research team reviewed transcripts and summary notes to evaluate each survey item. Discussions focused

on whether items should be retained, revised, or removed, and on identifying new items warranted based on participant feedback. The PI facilitated iterative team meetings to resolve discrepancies and finalize decisions regarding item inclusion and wording.

Rather than formal thematic coding, analyses emphasized pragmatic content validity, clarity, and alignment with reproductive justice and sexual health frameworks. This approach is consistent with early-phase measure development aimed at refining relevance and acceptability prior to psychometric testing.

Outcomes

Assessment Refinement and Content Expansion

Nine women participated across both focus groups (five in focus group #1, 4 in focus group #2). Focus group feedback resulted in substantial refinement of both source instruments. Participants consistently emphasized that sexuality education experiences extended far beyond school-based instruction and were shaped by healthcare encounters, HIV diagnosis, aging, relationships, and sociocultural context.

Key outcomes of the assessment development process included:

- Removal or revision of stigmatizing or heteronormative language, particularly terminology perceived as outdated, judgmental, or male-centered.
- Expansion of items addressing sexual pleasure, desire, and satisfaction, domains participants noted were rarely addressed in prior education yet central to quality of life.
- Inclusion of HIV-specific educational experiences, such as counseling received at diagnosis, discussions of U=U, disclosure guidance, and provider communication about intimacy.
- Addition of life-course perspectives, including menopause, aging, and changes in sexual identity or partnerships over time.
- Integration of relational and structural factors, including power dynamics, partner communication, and experiences of stigma within healthcare settings.

Participants strongly endorsed the importance of assessing not only whether education occurred, but how it was delivered, including tone, framing, and whether it supported autonomy versus fear.

Alignment with Reproductive Justice Principles

Across both focus groups, participants articulated themes closely aligned with reproductive justice, including bodily autonomy, informed choice, and dignity. Women emphasized the need for education that affirmed their right to desire, intimacy, and self-determination, regardless of HIV status. These perspectives directly informed the inclusion of items assessing whether sexuality education was empowering, neutral, or restrictive.

Discussion

This study describes the development of a sexuality education

assessment specifically tailored for women living with HIV, addressing a critical gap in HIV research and care. Although sexual well-being is widely recognized as integral to health, women's sexuality, particularly in the context of HIV, remains under-measured and under-prioritized. Findings from this qualitative assessment development process underscore the inadequacy of existing tools to capture the complexity of WLH's educational experiences.

Consistent with prior literature, participants reported that sexuality education was frequently framed through risk, fear, and restriction, rather than pleasure, agency, and well-being [10,16]. Importantly, women identified HIV diagnosis as a pivotal moment of sexuality education, yet noted substantial variability in the quality and content of counseling received. These findings highlight the need for tools that assess sexuality education across clinical, relational, and life-course contexts, not solely in adolescence or school settings.

By grounding assessment development in women's lived experiences and reproductive justice principles, this study advances a rights-based approach to sexual health measurement. The resulting assessment moves beyond behavior-focused metrics to capture autonomy, dignity, and empowerment, dimensions essential for equitable, patient-centered HIV care.

Limitations

Several limitations warrant consideration. First, participants were recruited from a single MWCCS site, which may limit generalizability to WLH not engaged in longitudinal research cohorts or HIV care. Second, the sample size was intentionally small, consistent with qualitative focus group methodology, but not intended to capture the full diversity of WLH experiences. Third, this study focused on content development rather than psychometric validation; reliability and validity testing are needed in future research.

Next Steps and Future Directions

The revised assessment is currently being piloted among 30 WLH. Future work will involve pilot testing the refined sexuality education assessment in a larger and more diverse sample of WLH to evaluate feasibility, reliability, and construct validity. Subsequent analyses will explore associations between sexuality education experiences and outcomes such as sexual satisfaction, stigma, mental health, relationship quality, and engagement in care.

Ultimately, this assessment has the potential to inform intervention development, provider training, and policy by making women's sexuality education experiences visible and measurable. Incorporating such tools into HIV research and clinical practice represents a critical step toward holistic, reproductive justice-aligned HIV care that affirms not only longevity, but pleasure, dignity, and self-determination.

Sexual Wellness, Education, Experiences, and Treatment in Positive Women (SWEET P)

Please fill out the below questions to the best of your ability. All answers are anonymous, so please be as honest as possible.

Demographics:

Age: _____

1. Are you Hispanic or Latino
 - A. Yes
 - B. No
2. Which one or more of the following would you say is your race? (Check all that apply)
 - A. White
 - B. Black or African American
 - C. Asian
 - D. Native Hawaiian or Other Pacific Islander
 - E. American Indian or Alaskan Native
 - F. Other
3. Which of the following best represents how you think of yourself
 - A. Straight
 - B. Gay or Lesbian
 - C. Bisexual
 - D. Other
4. What is your annual household income from all sources?
 - A. Less than \$10,000
 - B. \$10,000 - \$25,000
 - C. \$25,000 - \$35,000
 - D. \$35,000 - \$50,000
 - E. \$50,000 - \$75,000
 - F. \$75,000 - \$100,000
 - G. More than \$100,000
 - H. Don't Know/Unsure
5. What is your living situation today?
 - A. I have a steady place to live
 - B. I have a place to live today, but I am worried about losing it in the future
 - C. I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)
6. What is your highest level of school completed?
 - A. No schooling completed
 - B. Some school-no diploma
 - C. High School Diploma or GED

- D. Some college-no degree
- E. Trade/Technical School or Associates Degree
- F. Bachelor's Degree
- G. Advanced Degree (Masters, Doctorate, or Professional Degree)

About Your Sex Education:

Note: This survey uses the term "sex education" to mean instruction about anything relating to preventing pregnancy and sexually transmitted infections, HIV/AIDS, abstinence from sexual activity, healthy decision-making around sexuality, and other sexual health topics.

7. Did you receive your sex education before or after diagnosis
 - A. Before
 - B. After
 - C. Both
 - D. Don't Know/Unsure
8. Where were you first taught sex education (sex ed)?
 - A. School
 - B. Home
 - C. Community outreach/program
 - D. Healthcare setting (hospital, clinic, doctors office, etc.)
 - E. Other (personal experience, movie/media.....):
 - F. I have never learned about sex education
9. Were you ever taught sex education in school
 - A. Yes
 - B. No
 - C. Don't Know/ Unsure
10. If you didn't have sex education in school, why? (**Only answer if 9 is 'No' or 'Don't Know/Unsure'**)
 - A. Parents didn't want me to learn sex ed in school.
 - B. Parents forgot to sign the consent form.
 - C. Instructions were not offered.
 - D. Other _____
11. If you have been taught sex education in school, when did you have it?
 - A. Elementary school
 - B. Middle school
 - C. High school
 - D. College
 - E. Don't Know/Unsure

12. In what type of school system did you receive your sex education:

- A. Public school
- B. Private school
- C. Religious school
- D. Charter school
- E. Other: _____

13. Was the class mandatory?

- A. Yes
- B. No
- C. Don't Know/Unsure

14. How long did your instructor spend on sex ed in school?

- A. Less than a day
- B. 1 Day
- C. 3-4 Days
- D. 1 week
- E. More? Specify: _____

15. Which topics did the sex education instruction cover? (Choose all that apply)

- A. No Sex/Abstinence
- B. Condoms
- C. Contraception (birth control)
- D. How to make healthy decisions
- E. Body image
- F. Gender roles
- G. Gay and Lesbian relationships (LGBTQ+)
- H. Sexual abuse/Healthy Relationships
- I. Local resources for sexual health (where to get STI testing)
- J. Consent
- K. Reproductive health (menstrual cycle)
- L. Sexual pleasure
- M. Reproduction (how pregnancy happens)
- N. STI prevention
- O. How to approach conversations about safe sex with a partner
- P. Other: _____

16. Which of the following best describes what you were taught about preventing STD's and unintended pregnancy?

- A. Abstinence (don't have sex) was the only thing discussed.

B. Condoms and birth control mentioned, but most time was spent on abstinence.

C. Abstinence and condoms/birth control were both discussed fully.

D. Abstinence mentioned, but most time was spent on condoms/birth control.

E. Abstinence was not discussed.

17. Which statement most accurately reflects what you were taught about condoms?

A. "When used properly, condoms are effective in preventing unintended pregnancy, sexual transmitted infections (STDs), and HIV"

B. "Condoms are not effective in preventing unintended pregnancy, STDs, or HIV"

C. I was not taught about condoms.

18. In sex ed class, I generally felt: (Choose all that apply).

- A. Comfortable
- B. Uncomfortable
- C. Accepted for who I am
- D. Judged for who I am

19. To what extent were you satisfied with your sex ed class?

- A. Very satisfied
- B. Satisfied
- C. Neutral
- D. Dissatisfied
- E. Very dissatisfied

The Sex Education You Want:

20. Do you think your school should have spent more or less time on sex ed?

- A. More
- B. Less
- C. Fine how it is

21. At the time, did you feel comfortable asking your parent(s) or guardian(s) about these topics (e.g. safe sex, healthy relationships, etc.)?

- A. Yes
- B. No
- C. Sometimes
- D. Don't Know/Unsure

Factors in Becoming HIV Positive:

22. Check the MAJOR behavior(s) you believe led to you becoming HIV positive:

- A. Vaginal sex without a condom
- B. Vaginal sex with a condom
- C. Receptive anal-penis sex without a condom
- D. Anal-penis sex with a condom
- E. Oral (mouth-penis) sex
- F. Oral (mouth-vagina) sex
- G. Sharing needles
- H. Blood transfusion
- I. I do not know
- J. Other: _____

23. Please describe your relationship (*at the time of transmission*) to the person(s) who may have passed HIV to you:

- A. Spouse, husband/wife, life partner, significant other
- B. Non-spouse but longstanding friend and/or longstanding sex/needle partner
- C. Casual acquaintance, casual sex partner, and/or one-night stand
- D. Sex worker
- E. Blood transfusion
- F. Needle
- G. Mother-to-baby (born with it)
- H. Nonconsensual sex
- I. I have no idea who may have passed HIV to me
- J. Other: _____

24. Where do you think you became infected with HIV?

- A. In Miami-Dade County
- B. Outside of Miami-Dade County, but in Florida
- C. Outside of Florida, but in the US
- D. Outside of the US
- E. Don't Know/Unsure

25. When you became HIV positive, what was your living situation?

- A. I had a steady place to live
- B. I had a place to live, but was worried about losing it
- C. I did not have a steady place to live (I was temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station,

or in a park)

- D. Don't Know/Unsure

26. Which of the following statements, if any, were true for you when you became HIV positive?

- A. I didn't know the person was HIV positive
- B. I was feeling depressed, lonely, just not caring
- C. I was feeling like I really needed to have sex
- D. I was drunk or high at the time
- E. I didn't know about safer sex and/or safer needles
- F. I was feeling in love
- G. S/he was so good-looking, health-looking, clean-looking
- H. I did not like condoms, so I didn't use them
- I. Neither of us had condoms with us
- J. I didn't feel assertive enough to insist on safer sex
- K. I was trying to get or keep my partner
- L. I was sexually abused as a child/adolescent
- M. The person told me s/he was HIV negative
- N. I was feeling like I really needed to get high (inject drugs)
- O. I thought my partner was only having (unsafe) sex with me
- P. The condom broke
- Q. My partner(s) refused to practice safer sex
- R. I did not have access to clean needles
- S. I hated/was conflicted about my sexual attractions and desires
- T. I was feeling damned by God
- U. I needed money or other things
- V. I wanted to become infected
- W. My partner(s) refused to practice safer needles
- X. Other: _____

Concerns of Persons with HIV Postdiagnosis:

27. Since you were diagnosed with HIV, which of the following statements were true for you even once:

- A. I have engaged in safer sex (sex with condoms) with at least one other person
- B. I avoided sex, chose not to have sex, or shut down sexually
- C. I have had sexual contact with other(s) without disclosing my HIV status
- D. I have engaged in unprotected anal/vaginal sex (without condoms) with another person(s) who I knew was HIV positive

E. I have engaged in unprotected anal/vaginal sex (without condoms) with another person(s) who was HIV negative or whose HIV status I did not know

F. I have engaged in unprotected oral sex (mouth-penis/vagina without condoms) with another person(s) who was HIV negative or whose HIV status I did not know

G. I have shared needles with another person(s) who I knew was HIV positive

H. I have shared needles with another person(s) who was HIV negative or whose HIV status I did not know

I. I have engaged in other risk activities that could pass on HIV

J. I have given serious thought to having a baby

K. On at least one occasion, I have thought seriously about ending my life

L. On at least one occasion, I have tried to kill myself

28. Since you were diagnosed, which of the following issues, if any, have been problems or challenges for you:

A. Practicing/maintaining safer sex

B. Practicing/maintaining safer needle use

C. Alcohol and/or other drug use

D. Feeling confident that I will not infect others

E. Knowing how to tell potential sex partner(s) that I am HIV positive

F. Being intimate with other people

G. Experiencing sexual pleasure

29. Since being diagnosed, which, if any, of the following topics have you received education on (check all that apply):

A. Disclosing my HIV status to others

B. How to talk to a sex partner(s) about PrEP

C. How to experience sexual pleasure

D. How to practice safe sex

E. How to prevent HIV transmission (regarding sexual contact, sharing needles, mother to child, blood transfusion)

Future Sexual Education:

30. What topics, if any, do you think should be implemented in sex education classes in schools?

A. Abstinence

B. Condoms

C. Contraception (birth control)

D. How to make healthy decisions

E. Body image

F. Gender roles

G. Gay and Lesbian relationships (LGBTQ+)

H. Sexual abuse/Healthy relationships

I. Local resources for sexual health (where to get STI testing)

J. Consent

K. Reproductive health (menstrual cycle)

L. Sexual pleasure

M. Reproduction (how pregnancy happens)

N. STI prevention

O. How to approach conversations about safe sex with a partner

P. Sexual Pleasure

Q. Other: _____

31. Do you think adults could benefit from taking a sex education class?

A. Yes

B. No

C. Don't Know/Unsure

32. Do you think adults living HIV could benefit from taking a sex education class?

A. Yes

B. No

C. Don't Know/Unsure

Sexual Pleasure

33. Have you ever learned about sexual pleasure?

A. Yes

B. No

C. Don't Know/Unsure

34. If so, where did you learn about sexual pleasure

A. School

B. Personal experience

C. Media (movies, tv shows, social media, etc.)

D. Friends

E. Family

F. Other _____

35. Did you ever learn about the female sexual response cycle

A. Yes

B. No

C. Don't Know/Unsure

36. Have you ever learned about female sexual dysfunction (a persistent or recurrent problem with sexual response, desire, arousal, orgasm, or pain during intercourse that causes distress or interpersonal difficulty)

- A. Yes
- B. No
- C. Don't Know/Unsure

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