

# A CRITICAL FEMINIST SCOPING REVIEW OF 20 YEARS OF EPIDEMIOLOGICAL RESEARCH ON SEXUAL ACTIVITY, SEXUAL FUNCTION, AND SEXUAL SATISFACTION AMONG WOMEN LIVING WITH HIV

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## INTRODUCTION

When it comes to sex for women with HIV, discourses of risk have long-framed research and practice. To counter this narrative, we conducted a scoping review of quantitative research on sexual activity, function, and satisfaction among women with HIV globally using a critical feminist framework.

### Central characteristics:<sup>1</sup>

- 1) Conceptual analysis
- 2) Attention to diversity of experience (esp. marginalized bodies) & socio-political forces
- 3) Subversion of research assumptions (esp. re: heterosexuality & heteronormativity)

### Key conceptual underpinnings:

- 1) Sexuality is diverse & socially constructed (vs. normative & biologically determined)
- 2) Sexual response is context-sensitive & many factors can inhibit or enhance arousal
  - Including **social statuses** (e.g., gender), **structural inequities** (e.g., the law), & **cultural discourses** (e.g., HIV as 'dirty', women with HIV as 'irresponsible', female sexual passivity, wanting/having sex as 'normal/healthy', penetration as the 'natural' way to have sex & 'completion' defined by male ejaculation, etc.)



## METHODS

We synthesized the literature using scoping review methodology, with five stages.<sup>2</sup>

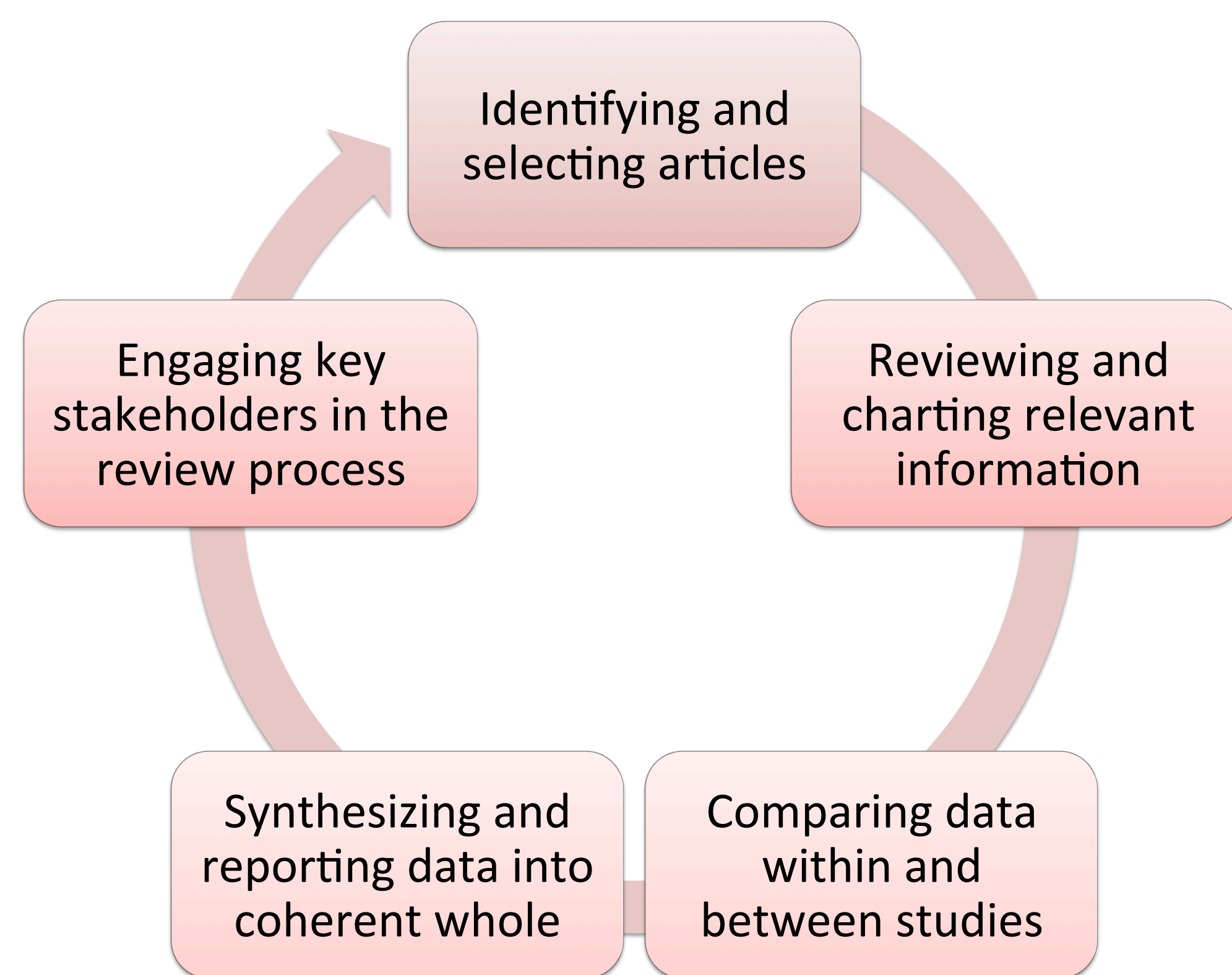


Figure 1. Stages of scoping review

- Six databases searched Oct 2015 – Dec 2016: CINAHL, Medline, PsycInfo, Web of Science, ProQuest, Cochrane Database of Systematic Reviews
- MeSH terms (or key words) of this generic formula were used: “HIV” and “women” and “sexuality” and “relationships”
- Articles in English from all geographic locations from 1996 onwards were included, including gender-mixed studies
- Review process was dynamic, iterative, and non-linear, and feminist theory and practice informed all stages.

## RESULTS

### The studies

- 29 studies involving 10,035 women with HIV were found (median sample size=167; interquartile range=74–459; range=9–1,927).
- Articles spanned 25 countries, though most (69%, n=20) were conducted within North America and Europe. Only 5 studies were in Africa where HIV burden is highest.
- 48% were mixed-gender cohorts, with women comprising 15% to 75% of the samples. Only 5 disaggregated data by gender.
- All but 2 analyses were cross-sectional, and 38% provided only bivariable results.

### The women

- Samples were diverse in age and ethnicity but mostly cis gender and heterosexual
- Education and employment status varied significantly, but low incomes were common (though not universal) across studies
- Health status also varied but in recent years, many women were on cART (80–100%) with undetectable viral loads (76–91%)

## RESULTS (CONTINUED)

### Studies' conceptualizations of women's sexuality: Negative physical outcomes

- Most researched sexual inactivity (n=10) and “dysfunction” (n=16).
- Few theories & many assumptions: e.g., sex as penetration, abstinence as problematic.
- Framed as individual “problems” versus resulting from relational and social contexts.
- Protecting others from HIV underpinned many inquiries versus women's own wellbeing.

### Women have a variety of experiences with sexuality following HIV diagnosis

- 84%** - Many women experience a sexual adjustment period, where discomfort with sex is high.
- 49-93%** - Some continue to be sexually active, with estimates ranging by country and sample demographics.
- 18-23%** - Others decide to give up sex altogether, at least for some period (range: 2 months to 24 years).
- 25-34%** - About one-third report difficulties with sexual response, including low desire (9-43%) and orgasm (61%).
- 61-64%** - Many are satisfied with their sex life, including those not having sex (50%), while others are not.
- Satisfaction levels can change, from low (immediately after diagnosis) to high (after more time living with HIV).

### Women's sexuality – whether it's interest in sex, arousal, orgasm, or satisfaction – is deeply connected to context.

- Women's own view on the factors underlying changes in sexuality are diverse:*
- **Fear of disclosure**
  - **Fear of transmission**
  - **Sex as a reminder of HIV**
  - **Feelings of guilt**
  - **No interest in sex**
  - **Depression**
  - **Religious taboos**
  - **Dislike condoms**
  - **Painful intercourse**
  - **Concerns about pregnancy**

*In analyses exploring the association between various factors in women's lives AND sexual activity, response, and satisfaction:*

1. Clinical markers of HIV (e.g., viral load, CD4 count) poorly predicted sexual outcomes.

2. Depression and anxiety were associated with decreases in interest in sex and overall sexual functioning, consistent with women's own views. Women were also affected by various forms of violence; this was associated with increased pain.

4. Social stigma of various kinds had a powerful effect on women's sexual wellbeing. For example:

- Women who contracted HIV through sex were 5x more likely to lose interest in it.
- Women experiencing high HIV stigma were 2x more likely to not have sex.
- Sexual dissatisfaction was linked to: discrimination, internalized stigma, and sex-negative attitudes. (all gender-mixed cohorts)
- Poor body image was associated with lower sexual functioning.
- Lower socio-economic status was associated with lower satisfaction.
- Older age was associated with lower sexual activity.

3. Women who were married, common law, or dating were more likely to be sexually active. Having a new regular partner since diagnosis was associated with more frequent sex but fewer orgasms. Women with HIV-negative partners reported higher sexual satisfaction.

## CONCLUSIONS

Efforts are needed to de-stigmatize and de-criminalize HIV, and affirm women's sexual identities, normalize their experiences of sexuality, and support them in leading a fulfilling sexual life, however that may look.

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