Efficacy is not the only HIV prevention attribute that matters – lessons learned from contraception

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We finally have HIV prevention choices, with more on the horizon.
Contraception: more choices → greater use

Modern Contraceptive Prevalence Rate (%)

y = 9.816x + 0.831
R² = 0.369
So, have we arrived? Do more methods guarantee choice?
Lessons learned from long-acting reversible contraception (LARC): (not) a public health panacea.

• Highly effective
• Don’t require daily/weekly/monthly maintenance ➔ near-perfect adherence
• Acceptable, sometimes desirable, side effect profile
• Reversible
• Cost effective
LARC campaigns focused on people who can’t reliably take a daily pill

Unintended consequences of implicit pressure:
- dissatisfaction with method
- discontinuation
- negative impact on future healthcare interactions

Pressured LARC use: placement

• Providers recommend LARC more frequently to poor women of color than to poor white women and to poor white women more than middle-class women

• Young women more likely to report providers expressed a preference about contraceptive methods; perceived provider preference associated with decreased method satisfaction

• Qualitative studies: young Black and Hispanic women perceive subtle provider preferences, negatively affecting contraceptive use & future interactions with providers

Implicit pressure in tiered-effectiveness counseling

<table>
<thead>
<tr>
<th>More effective</th>
<th>Less than 1 pregnancy per 100 women each year</th>
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<tr>
<td>Less than 1 per 100</td>
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<tr>
<td>Vasectomy</td>
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<td>Female Sterilization</td>
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<td>IUD</td>
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<td>Implant</td>
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<td>2-8 per 100</td>
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<td>LAM (Breastfeeding)</td>
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<td>Shot</td>
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<td>Pill</td>
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<td>Ring</td>
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<td>Patch</td>
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<td>15-24 per 100</td>
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<tr>
<td>Diaphragm</td>
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<td>Mole Condom</td>
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<tr>
<td>Female Condom</td>
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<tr>
<td>Withdrawal</td>
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<td>Sponge</td>
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<td>Cervical Cap</td>
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<td>About 25 per 100</td>
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<td>Spermicide</td>
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<td>Fertility-Awareness Based Methods</td>
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<tr>
<td>Less effective</td>
<td>About 25 pregnancies per 100 women each year</td>
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Pressured LARC use: refusing removal

My provider was really hesitant to remove the [IUD]. She kept telling me, “Well, we should wait 3 months and see if your symptoms have worsened.” And I waited 3 months and she’s like “Well, you should wait some more.” And I’m like “No. So take it out or I’m going to a different doctor.”

I don’t know if it makes them [providers] look bad if you have an IUD removed … I don’t know if they have some chart somewhere, like a contest board in the breakroom…

Higgins AJPH 2016.
LARC demonstrated effectiveness is important, but not the only variable; REACH showed just that for PrEP.

Ngure, Choice and Adherence to Dapivirine Ring or Oral PrEP by Young African Women in REACH, CROI 2022.
How can we incorporate these lessons into care?
Counseling approaches

- **Informed Choice**
  - Only provide objective information; counselor does not participate in method/treatment selection itself

- **Method Promotion**
  - Examples: Tiered-effectiveness; “LARC first”; motivational interviewing
  - Rooted in the healthcare provider’s preferences and/or assumptions about patient priorities
Counseling approaches

Best method for an individual depends on their preferences
- Individuals will weigh effectiveness differently relative to other characteristics

Associated with higher satisfaction with decision-making

May not be best for everyone, but provides starting point for counseling

Dehlendorf: Contraception, 2013
Dehlendorf: AJOG 2016
Shared decision making

Develop trust

Leave an open door
- Flexibility for change
- Contingency planning

Facilitate decision-making

Elicit preferences
- Pregnancy intentions
- Method-related

Offer information
- Risks/benefits
- Side effects

Reproductive justice

The right to maintain personal bodily autonomy, have children, not have children, and parent in safe and sustainable communities

- SisterSong
Sexual & reproductive justice

Broadening the reproductive justice framework to include sexual justice – the right to sexual health and well-being. –SisterLove

- Specifically includes HIV prevention & PrEP

- Specifically includes the right to sex and sexual pleasure, free from stigma, shame, and the “risk narrative”
A sexual & reproductive justice lens applied to PrEP

- Acknowledge historical & social context – leaving out pregnant/lactating people, trans people, youth from trials
- Acknowledge individuals’ lived experience
- Eliminate barriers to access
- Describe what PrEP is (and what it is not)
- Make HIV prevention methods readily available to those who want them
- Respect the decision of those who chose not to use PrEP
- Respect the decision of those who chose to discontinue PrEP
- Maintain focus on whether an HIV prevention method meets the individual’s needs, rather than a public health goal.
Taking a step back: what do people bring into their health care visits for HIV prevention?

Types of trauma

- Racism
- Transphobia
- Domestic Violence
- Homophobia
- Islamophobia
- Ableism
- Ageism
- Bullying
- Sexism
- Xenophobia
- Unconscious Bias
- Sexual Violence
- Adverse Childhood Experiences - ACES

Historical and Structural Traumas
- Political / Economic Trauma
- Community Violence
- War and Combat
- Sexual Harassment
- Micro-aggressions
- Human Trafficking
- Immigration Policies
- Anti-Semitism
- Domestic Terrorism
- Abuse of Power and Control
- Social and Behavioral Determinants of Health
Health care experiences can cause trauma; medical settings can be a trigger.

Physical triggers
- Touch
- Removal of clothing
- Invasive procedures/tests/exams
- Vulnerable positions
- Closed spaces

Emotional triggers
- Personal, invasive questions
- Power dynamics/loss of power
- Loss of privacy
- Coercive or stigmatizing language
- Lack of choice
Advice to healthcare providers from a pregnant person who was unsheltered and had a substance use disorder in San Francisco:

“Don’t try and push anything …if someone doesn’t agree (and you push it), they will completely shut down about anything you have to say afterwards.”
How can we respond?

Overarching principles of trauma-informed care

- Use universal precautions
  - Healthcare may be particularly triggering
- Welcome people into care
  - Reframe: Where have you been? → Welcome back. We’re glad you’re here.
- Goal is to have a trauma-informed system, starting the moment people walk in
Trauma-informed care → healing centered engagement

• “I am more than the worst thing that happened to me”
  • Trauma-informed care can be a slippery slope to deficit-based thinking

• Healing centered engagement – developed by Dr. Shawn Gingwright
  • Highlights importance of collective trauma and therefore need for a collective response
  • Only treating individuals → miss opportunities for advocacy & structural change
  • Suppressing symptoms of trauma is limiting; also need to focus on healing, strengths, and wellness

Ginwright, Medium, 2018.
The PrEP journey: if we get it wrong, that journey can end abruptly.
What could a *PrEP journey* look like?

- **Activities**
  - Community & clinic-based universal HIV prevention education
  - Community & clinic-based universal education about HIV vulnerabilities

- **Ongoing conversation, rumination**
  - Access to healing-centered clinic that provides HIV prevention services
  - Shared decision-making about HIV prevention

- **Reevaluation of preferences & needs; discontinuation**
  - Initiate method that best meets their needs
  - Continuation & adherence to method
  - Retention in sexual & reproductive healthcare

- **Metrics**
  - Clinic environment & care experience metrics
  - Informed decision-making, person-centered care metrics
  - Method initiation; patient satisfaction metrics
  - Contextualized continuation, discontinuation, re-initiation metrics
  - Retention in care metrics
Acknowledging social context: social & structural determinants of health drive so many HIV diagnoses. Therefore, addressing health determinants remains a critical form of HIV prevention.

Social Determinants of Health

Structural forms of HIV prevention
- Housing
- Food
- Transportation
- Education / job training

Ensuring our research reflects our values

How do we measure success?
  - HIV cases prevented?
  - PrEP initiation?
  - PrEP continuation / discontinuation?
Patient-reported performance measures

<table>
<thead>
<tr>
<th>Please rate the provider you saw with respect to:</th>
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<tbody>
<tr>
<td>Respecting me as a person</td>
<td>PrEP</td>
</tr>
<tr>
<td>Letting me say what mattered to me about my birth control method</td>
<td>PrEP</td>
</tr>
<tr>
<td>Taking my preferences about my birth control seriously</td>
<td>PrEP</td>
</tr>
<tr>
<td>Giving me enough information to make the best decision about my birth control method</td>
<td>PrEP</td>
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</tbody>
</table>
Acknowledgements

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Family planning researchers, advocates & providers
Thank you!

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