

Early Stage Investigator Lecture

Misperceived Social Norms as Drivers of HIV Prevention: Exploring Opportunities for Individual and Social Change



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The Big Questions

01

What factors drive human behavior, health outcomes, and health disparities?

02

Where and how can we intervene and improve prevention?

03

What doesn't work?
What might work?
How can we adapt or improve what we know works?

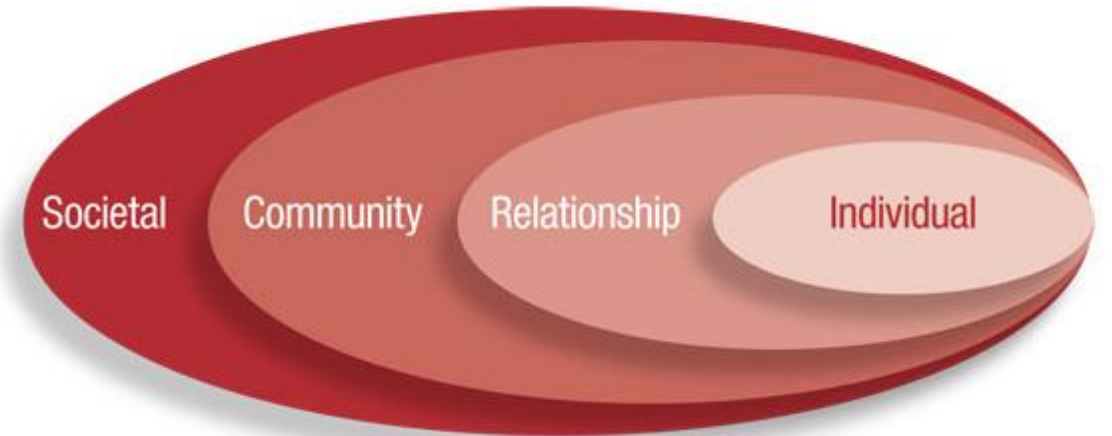
My background

- Bachelor of Science in Psychology
- Master of Science Population and International Health
- Doctoral degree in Health Policy
- Postdoctoral work in Population and Global Health
- Assistant Professor in Department of Human and Organizational Development at VU & Core Faculty at Vanderbilt Institute of Global Health



Why I study social norms and health

We are inherently connected to a vast network of people from which social norms arise and drive our attitudes, intentions, and behaviors. These networks and norms influence us across multiple levels whether we are consciously aware of it or not.



Socio-ecological Model: A Framework for prevention

Today

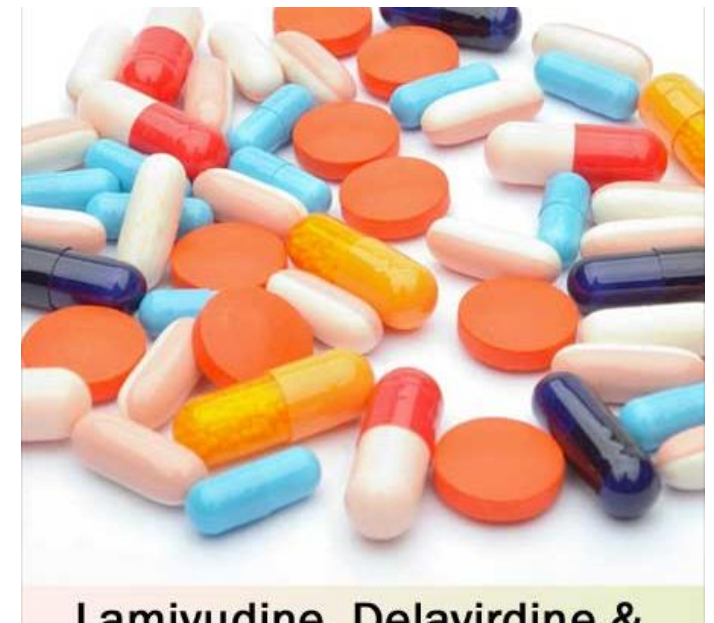
- Current context of HIV/AIDS globally
- Social norms as root causes
- Empirical evidence about misperceived norms as drivers of HIV related behavior
- Addressing misperceived norms as part of prevention programs and future directions



Current Context

Where do we stand in terms of HIV prevention and progress?

We have great primary prevention and treatment interventions. Many of them are accessible and affordable to some degree.



Lamivudine, Delavirdine &

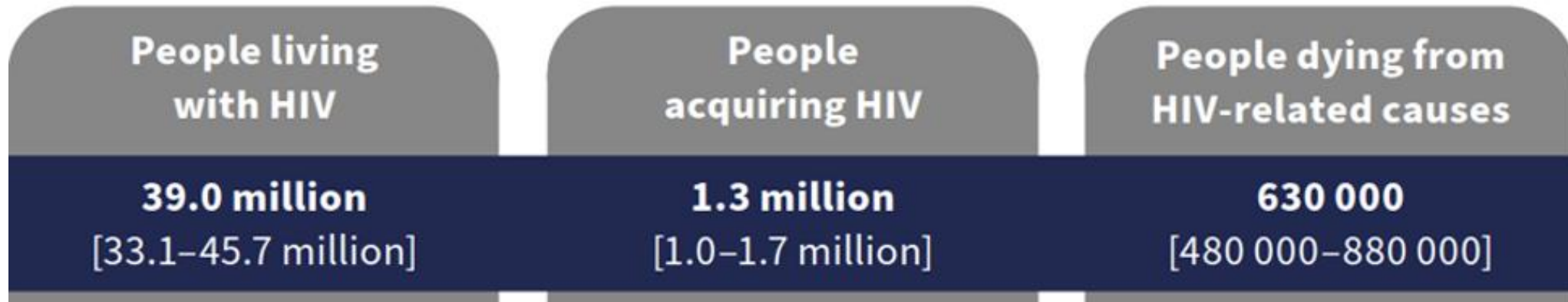
In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 95-95-95 targets.



However, ~25% of people with HIV are either unaware of their status or are not taking treatment regularly.



In 2023, more than one million individuals acquiring HIV and more than half a million dying from HIV.



- Challenges in hitting thresholds to end the epidemic suggest that behavior matters.
- “Individuals are not calculating automatons. Rather, **people are malleable and emotional actors** whose decision making is influenced by **contextual cues, local social networks and social norms, and shared mental models.**”
- In addition to addressing critical structural and social determinants of health, innovative to end the epidemic, behaviorally informed, evidence-based programs are also needed.

*Thirumurthy et al. 2023. The Lancet;
Andraweis et al. 2022. Current HIV/AIDS Reports
World Development Report, 2015*



Ending The HIV Epidemic

Social Norms as Root Causes of Attitudes & Behavior

A Conceptual Framework

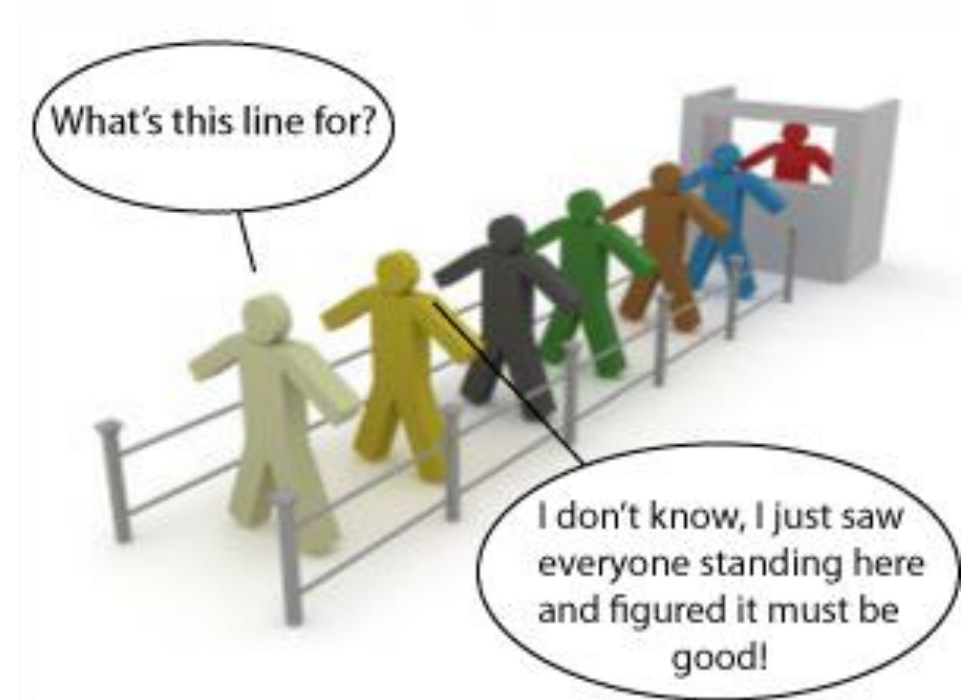
Social Norms are generally understood as **unspoken rules** in our community about how people should **behave** in any given **situation**

We know that social norms affect us.

But how do we know what the norms are?



Often, we look to others and around us to know how to act.



Many kinds of cues in the environment contribute to our understanding of social norms.



~~stigma~~



1) Does our understanding of local social norms represent reality?

Perceived Norm

**What an individual thinks
most people in a group
do or support**

?

=

Actual Norm

**What do most people
in that group do
support**

2) Do misperceived norms matter?

Misperceived Norm

**I think most people do X
when in reality most do
not do X**

?



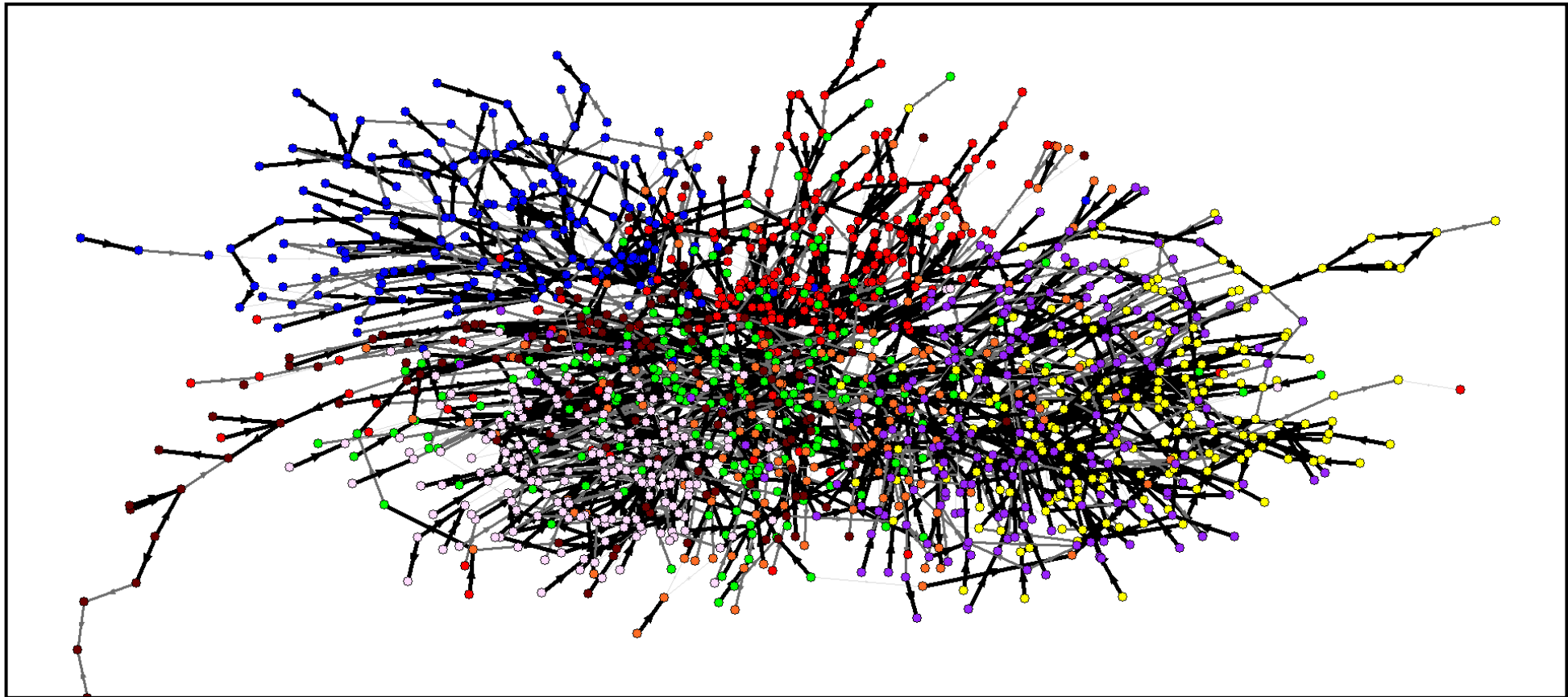
Personal Outcome

**Do I do X?
Do I support X?
Do I tolerate X?**

Misperceived Norms and HIV-Related Transmission Risk and Prevention Behaviors

Empirical evidence from whole-population
network studies of adults (≥ 18 years) in rural
Uganda





Started a longitudinal cohort of 18+ adults in 8 villages in southwest Uganda in 2010

Q1: Do misperceived norms around HIV related behaviors exist?

Perceived Norm
How many men/women
in your own village do X
(or support X)?

?
=

Actual Norm
What is the prevalence
of X in each village?



We have found pervasive underestimates of existing positive local norms for **HIV testing, ART adherence, male circumcision uptake, and willingness to talk about and take PrEP.**

- 2/3 of adults incorrectly thought most of their male and female village peers had never been tested for HIV even though most had been tested in their lifetime and in the past few years
- 19% of circumcised men, 43% of uncircumcised men, and 47% of women underestimated the male circumcision prevalence in their village or had no idea even though almost half of young men are circumcised
- 1/3 of adults thought most men and women were not willing to talk about PrEP with a provider even though 75% of adults in their village were willing to do so



We also have found misperceived norms around issues linked to HIV risk, such as **alcohol use, violence when finding out about partner PrEP use, and perpetration of intimate partner violence** in general.

- 81% of adults mistakenly thought that most men in their villages drank heavily even though only 25% did so
- 39% of adults mistakenly thought that the majority of men would react violently to partner if partner took PrEP even though 2/3 would not
- 45% of men mistakenly thought that most men endorsed IPV and 48% of men mistakenly thought that most other men perpetrate IPV at least monthly even though only 25% endorsed the use of IPV and 17% perpetrated at least one act of IPV at least monthly

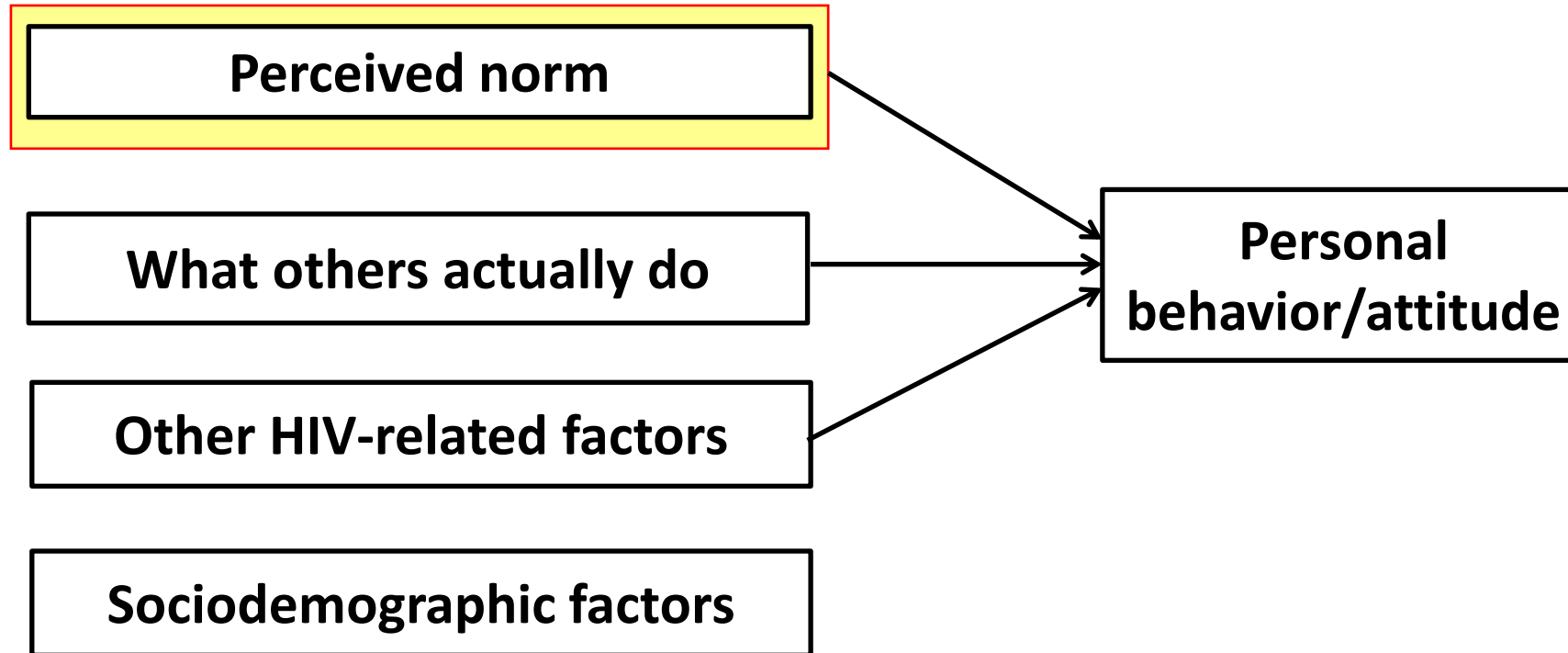


Misperceived Norms Exist

People tend to incorrectly think that negative, unhealthy, and risk behavior and attitudes are common when, in fact, positive, healthy, and protective behavior and attitudes represent the majority.



Q2: Do misperceived norms matter?



Adults who misperceive positive local norms are less likely to engage in prevention behavior (aORs ranged from 0.25-0.80) and more likely to engage in transmission risk behavior (aORs 1.49-4.75)

Perkins JM et al. Actual versus perceived HIV testing norms, and personal HIV testing uptake: A cross-sectional, population-based study in rural Uganda. *AIDS Behav.* 2018;22:616–628



Perkins JM et al. Perceptions about local ART adherence norms and personal adherence behavior among adults living with HIV in rural Uganda. *AIDS Behav.* 2022;26:1892–1904.

Tsai AC et al. Normative vs personal attitudes toward persons with HIV, and the mediating role of perceived HIV stigma in rural Uganda. *J Glob Health.* 2021 Sep 15;11:04956.

journal of **global** health

Perkins JM et al. Male circumcision uptake and misperceived norms about male circumcision: Cross-sectional, population-based study in rural Uganda. *J Glob Health.* 2023 Dec 20;13:04149.

Perkins JM et al. Overestimation of alcohol consumption norms as a driver of alcohol consumption: a whole-population network study of men across eight villages in rural, southwestern Uganda. *Addiction.* 2022;117:68-81.



Perkins JM et al. Misperception of norms about intimate partner violence as a driver of personal IPV attitudes and perpetration: A population-based study of men in rural Uganda. *J Interpers Violence.* in press.

Preliminary work with youth

Up to 75% thought health risk behaviors (e.g., condomless sex, transactional sex) are common among peers, when in fact they are not

AYA who misperceived these norms were more likely to engage in risk behaviors (e.g., aOR=1.94 for transactional sex; 95% CI, 1.13-3.36)



Preliminary work with role models

Parents: “I think out of 100% of the unmarried youth, maybe only like 20% [others said 10%] of them have tested... They fear testing and how society will treat them.”

Community health workers and other leaders also misperceive norms about HIV related behavior in their community

How these adults about what they perceive as social norms around HIV could affect youth’s decisions or contribute to stigma



Builds on findings about perceived peer norms and other behaviors in other contexts



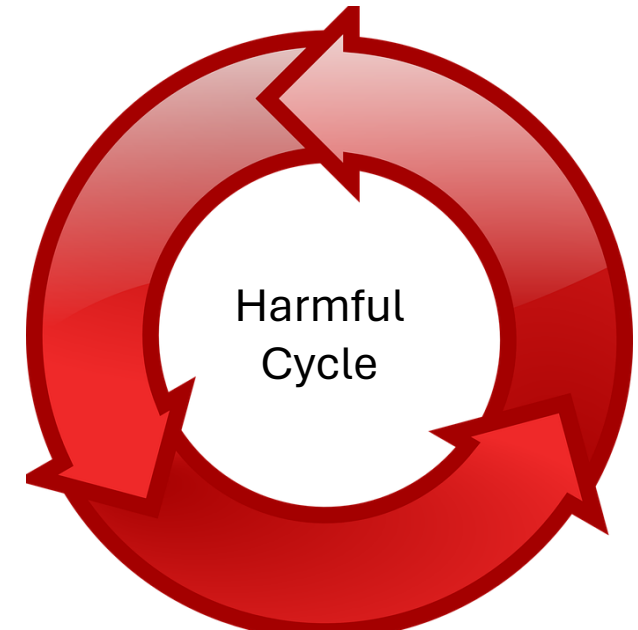
Perkins JM et al.. J Stud Alcohol Drugs. 2019;80:659-68.



Perkins JM et al. Youth Soc. 2019;51:814-39.

Taken together, misperceived norms matter

1. When people think a risk behavior is the norm instead of a prevention behavior, they are likely to make choices that align with that misperception and engage in risk behavior
2. People are then also likely to hide or diminish their own healthy and protective choices, attitudes, and behaviors because they think they are atypical, which then become invisible to others.
3. People are less likely to speak up when they witness others engaging in a risk behavior and more likely to tolerate or even support it



We know that perceptions are malleable, and that changing perceptions can change individual and population behavior.


Addressing misperceived norms that drive HIV related behavior represents an area for growth and innovation in HIV prevention work, an opportunity to promote uptake of effective interventions.

Few behaviorally informed interventions like changing perceived norms are utilized for HIV prevention, especially in HIV-endemic contexts.



Addressing Misperceived Norms Related to HIV Prevention

Future directions



If we know that
misperceived norms
are pervasive,

and we know that
perceived norms
matter,

then how can we
change misperceived
norms about HIV
related behavior?

Changing Perceptions to Change Personal and Collective Outcomes

Social Norms Approach

Norms-Based Approach

Norms Correction Approach

Norming Intervention

Positive Community Norms

Make positive local norms
more visible and salient in
the local environment



➤ Less exaggerated
misperceptions of
norms or total
correction of
misperceived norms

➤ Uptake of healthier
behavior or attitude
and increased
support for health-
promoting behavior

Message characteristics

POSITIVE

INCLUSIVE

EMPOWERING

CREDIBLE

LOCAL

SUFFICIENT

Messages do not prescriptively say what is good or bad or what people should or shouldn't do, and they are not pared with scare statistics or fear-based imagery.

Delivery of actual norms information

Social norms marketing

Edu-entertainment

Small group discussion

Seed messages within a network

Gamify learning about local norms

Give visuals with messaging to trusted role models

Text messages

75% of men and women in your village have been tested for HIV in the past few years.

Most men/women in your village would not beat their wife if they found out that she/he was taking PrEP.

Personalized normative feedback

- You thought 40% of people in your village had ever been tested for HIV.
- In reality, 85% of people in your village have been tested for HIV and have done so in the last few years.
- You last got tested more than 5 years ago. Would you like to get tested today?

(Data from the village survey last year)

Trending norms



Emphasize increasing prevalence of a health-promoting behavior

The number of young men choosing to get **circumcised** here increases every year and have support from their partners to do so. Now almost half of men aged 18 to 35 in your village are circumcised.

Free male circumcision services are available here.

More than 70% of married and single men and women in this village are willing to talk with a health provider about **PrEP**. More and more people in your social network every year are willing to take PrEP and think it would help them fulfill life dreams.

Limited examples in HIV scholarship

- Visual image about ART adherence norm outside adult clinic in Tanzania (McCoy et al. 2017. PlosOne)
- Text messages with young adult group ART adherence norms in Uganda (MacCarthy et al. 2020. BMC Infect Dis)
- PNF intervention about HIV stigma and testing among adults in Mozambique (Yu J. 2023. Dev Econ)
- Social norms marketing posters and other formats about IPV perpetration and bystander norms targeting in-school boys in South Africa (PIs: Cuo, Matthews, Harrison)



Potential effects of interventions that highlight actual positive norms and reduce misperceived norms

Individual effects
Motivates uptake of prevention behavior
Maintains prevention behavior
Inhibits development of misperceptions
May push individuals to seek ways around barriers to engaging in prevention behavior.

Potential effects of interventions that highlight actual positive norms and reduce misperceived norms

Individual effects	Collective effects
Motivates uptake of prevention behavior	<ul style="list-style-type: none">• Reduces stigma that may be associated with prevention behavior.• Increases willingness to be vocal about engaging in prevention behavior.• Increases willingness to help others engage in prevention behavior.• Inhibits spread of misperceptions <p>These effects may grow stronger as actual prevalence of (and collective awareness of) health behavior increases</p>
Maintains prevention behavior	
Inhibits development of misperceptions	
May push individuals to seek ways around barriers to engaging in prevention behavior.	

Changing misperceived norms as part of a comprehensive HIV prevention approach

COMBINE

- Use targeted & universal prevention norms-change strategies to change individual behavior and attitudes and lead to collective change

LEAD

- Change perceptions about local norms among key leaders, change makers, role models, key network connections, etc. and how they talk about local norms to combat the spread of misperceptions

COMPLEMENT

- Partner positive actual norms messaging ahead of or alongside policy changes, structural changes, and provision of services

Additional Future Directions

- Mixed methods research
- Methodological innovation
- Novel strategy designs
- Multi-norm messaging
- Implementation research on strategy adaptation
- Complement to other programs
- HIV vaccine



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Questions?

Misperceived Norms about HIV Prevention and Treatment as Opportunities for Individual and Social Change

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