HIV-related stigma and operationalising universal testing and treatment for HIV in sub-Saharan Africa

PROSPECTIVE STUDY DESIGN NESTED WITHIN THE HPTN071 (POPART) CLUSTER RANDOMISED TRIAL
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Stigma ancillary: Study Team

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with
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and
the PopART and Stigma Ancillary Protocol Teams
GETTING TO ZERO

ZERO NEW HIV INFECTIONS
ZERO DISCRIMINATION
ZERO AIDS RELATED DEATHS
What is stigma?

• “the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised”

  Link & Phelan

• Discrimination is a constitutive feature of stigma
  – Individual level: unequal treatment that arises from membership in a particular social group
  – Structural level: societal conditions that constrain an individual’s opportunities, resources, and well-being
HIV-related stigma in sub-Saharan Africa

- HIV (label)
  - Linked to sexual deviancy, badness (negative stereotyping – status loss)
  - Feared, avoided, self isolation (separation)
  - Gossip, insult, physical assault (individual discrimination)
  - Travel restrictions, labour market / health service exclusion, criminalisation (structural discrimination)

- Power-relations: “sanctioned” sexual norms.

- Power relations: “Health systems”
  - Stigma can include neglect of patients, differential treatment, disclosure without consent, gossip, abuse and separating HIV-positive patients
  - Health workers are themselves vulnerable to stigma and job-stress
• The presence of stigma can also lead to
  – Anticipation of negative consequences of (rightly or wrongly) being labelled
  – Internalisation among those with stigmatised traits
• Which in turn can influence
  – Mental health
  – Health-seeking behaviour
  – Physical Health
Key areas for intervention development, scale-up and measurement

Stigma "marking"
- HIV Stigma
- Intersecting Stigmas
- Other stigmas

Actionable drivers and facilitators

Stigma manifestations

Stigma outcomes

Stigma Impacts

Individual
Interpersonal
Organization
Community
Public Policy
Stigma measurement

- Complex, multi-domain, relational phenomenon
- The DHS 4 common items
- Enormous heterogeneity in practice (Mahajan)
  - Stangl 2013: 47 quant studies of stigma reduction initiatives
  - No. of items varied 1-61
- Harmonisation process
  - Global Stigma and Discrimination Indicators Working Group
  - 2010 Consultation, ongoing process, MERG approval 2013
- Measurement tool for assessing stigma among health care providers validated in 6 countries
Prevalence and trends in HIV-related stigma
PLHIV Stigma Index, South Africa

486 respondents living with HIV, recruited in clinics in 4 provinces

<table>
<thead>
<tr>
<th>Experience of stigma and discrimination</th>
<th>N=486</th>
<th>Never Experienced (%)</th>
<th>Experienced (Once to Often) (%)</th>
<th>Not indicated (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being gossiped about</td>
<td>215 (44.2)</td>
<td>254 (52.3)</td>
<td>17 (3.5)</td>
<td></td>
</tr>
<tr>
<td>Verbally insulted/harassed, threatened</td>
<td>339 (69.8)</td>
<td>138 (28.3)</td>
<td>9 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Husband/spouse/other household member have been discriminated against</td>
<td>358 (73.7)</td>
<td>116 (23.8)</td>
<td>12 (2.5)</td>
<td></td>
</tr>
<tr>
<td>Sexual rejection</td>
<td>368 (75.7)</td>
<td>101 (20.8)</td>
<td>17 (3.5)</td>
<td></td>
</tr>
<tr>
<td>Manipulation by partner</td>
<td>373 (96.7)</td>
<td>101 (20.8)</td>
<td>12 (2.5)</td>
<td></td>
</tr>
<tr>
<td>Excluded from social gatherings</td>
<td>399 (80)</td>
<td>91 (18.8)</td>
<td>6 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Physically assaulted</td>
<td>400 (82.3)</td>
<td>78 (16.1)</td>
<td>8 (1.6)</td>
<td></td>
</tr>
<tr>
<td>Excluded from family activities</td>
<td>406 (83.5)</td>
<td>75 (15.5)</td>
<td>5 (1)</td>
<td></td>
</tr>
<tr>
<td>Physically harassed</td>
<td>387 (79.6)</td>
<td>75 (15.5)</td>
<td>24 (4.9)</td>
<td></td>
</tr>
<tr>
<td>Discriminated against by other PLHIV</td>
<td>404 (83.1)</td>
<td>71 (14.6)</td>
<td>11 (2.3)</td>
<td></td>
</tr>
<tr>
<td>Excluded from religious activities</td>
<td>417 (85.8)</td>
<td>50 (10.3)</td>
<td>19 (3.9)</td>
<td></td>
</tr>
</tbody>
</table>

*Questions relate to the previous 12 months.*
HIV-related stigma, testing and treatment

- HIV-related stigma creates barriers to:
  - Testing
    - Anticipation of negative social consequences of a positive HIV test associated with refusal to test among antenatal clinic attenders (Turan 2012)
  - HIV Status Disclosure
  - PLWH Retention in care
  - ARV adherence
    - Review of 75 studies (0 RCTs) suggests HIV stigma compromises clients’ ability to adhere to treatment (Katz et al. 2013)
Objectives

Within the context of PopART HPTN071 trial:

Collect mixed-method data on the domains of HIV-related stigma, and how this changes over time

Analyse data to investigate how HIV-related stigma affects and is affected by the PopART intervention, integrating data from multiple sources and methods
PopART intervention package

- Annual rounds of Home Based Voluntary HIV Testing by Community HIV-care Providers (CHiPs)
- Health promotion, Active Referral and/or Retention in Care support by CHiPs for the following:
  - Voluntary Medical Male Circumcision (VMMC) for HIV negative men
  - Prevention of Mother to Child Transmission (PMCT) for HIV positive women
  - HIV treatment and care for all HIV positive individuals
  - Promotion of sexual health and TB services
  - Condom provision
- ART irrespective of CD4-count provided at the local health centre in Arm A, or at national guidelines (Arm B)

No other intensive stigma reduction or social-group targeted interventions
A 3-arm cluster-randomised trial with 21 communities:

- **Arm A**: Full PopART intervention including immediate ART irrespective of CD4 count.
- **Arm B**: PopART intervention except ART initiation according to current national guidelines.
- **Arm C**: Standard of care at current service provision levels including ART initiation according to current national guidelines.

Each arm has 7 communities (N=21). PopART intervention package includes:

- 2,500 random sample from each community: Population Cohort N = 52,500
- 12 in Zambia, 9 in S. Africa

Primary outcome: HIV incidence at 36 months.

*CD4-count <350 cells/mm³

[Link to website](http://www.hptn.org/research_studies/hptn071.asp)
### Competing hypotheses

<table>
<thead>
<tr>
<th>PopART may reduce stigma</th>
<th>PopART may increase stigma</th>
<th>Stigma may limit PopART effectiveness</th>
</tr>
</thead>
</table>
| “because the main intervention in HPTN 071 is universal and is offered to the entire community, it will obviate the need for specially-targeted interventions for different risk groups, should help to avoid stigmatization, and should encourage community-wide support for HIV prevention and care” | HIV-infected individuals becomes more visible as many more people know their HIV status and start ART  
Growing visibility is accompanied by increased stigma and discrimination | HIV-related stigma may undermine the acceptability of regular HIV testing, early ART initiation and lifelong treatment adherence  
UTT may fail unless HIV-related stigma is addressed |

| UTT is a stigma reduction intervention | Complementary, effective stigma reduction efforts an integral component of UTT |
Stigma Ancillary: Methods

- Nested evaluation
- Mixed-methods
- Implementation Science
- Prospective data collection throughout PopART
- Measurement
  - Ancillary Specific: Health workers, Key populations
  - Nested within PopART: PC, CC, Social science
- Parallel assessments using harmonisation indicators
Implementation Science

- The study of methods to promote the integration of research findings and evidence into healthcare policy and practice.

  “seeks to understand the behavior of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption, and implementation of evidence-based interventions”

- Investigate and address major bottlenecks (e.g. social, behavioral, economic, management) that impede effective implementation ...
# Data Collection

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Source</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-workers (CHIPS and HFW)</td>
<td>Attitudes and Experiences, job-stresses</td>
<td>HW</td>
<td>SocSci Aim 1 + Observations and longitudinal case-studies</td>
</tr>
<tr>
<td>Community Members</td>
<td>Attitudes</td>
<td>PC</td>
<td>SocSci Aim 1 (interviews) + SocSci Aim 3 (ethnography)</td>
</tr>
<tr>
<td>Testers / Non-Testers</td>
<td>Attitudes, anticipation</td>
<td>CC1</td>
<td>SocSci Aim 2 (quali. case-studies)</td>
</tr>
<tr>
<td>Early ARV initiators / non initiators</td>
<td>Attitudes, anticipation</td>
<td>CC2</td>
<td>SocSci Aim 2 (quali. case-studies)</td>
</tr>
<tr>
<td>Key populations</td>
<td>tbd</td>
<td>-</td>
<td>Longitudinal case-studies</td>
</tr>
<tr>
<td>Stigma-reduction efforts (context)</td>
<td>Register of stigma-reduction events</td>
<td>-</td>
<td>SocSci Aim 3 Document review, participant and non-participant observation</td>
</tr>
</tbody>
</table>
Objectives

- Describe, develop scales to measure, and explore determinants of HIV-related stigma among health facility staff and CHiPs involved in the delivery of PopART, and how these change over time.
- Evaluate whether health facility staff randomized to the different arms of the trial report different levels of HIV-related stigma after three years.
- Evaluate whether higher levels of HIV-related stigma among health-workers are associated with less successful uptake of UTT.
- Contextualise findings through longitudinal qualitative and participatory research with a focus on understanding interactions between CHiPs, health facility staff and potential clients of HIV-related services.
Study design and sample

• In all 21 clusters
  – CHiPs
  – Health facility staff
  – n=1240

• Data collection
  – electronic data capture
  – self-interview
  – years 1, 2 and endline
Data Collection Tool

- Sociodemographic Information (8 questions)
- Employment details (8 questions)
- Knowledge of and proximity to HIV & TB (5 questions)
- Training at work (6 questions)
- Safety at work (4 questions)
- Policies at work (4 questions)
- Participation in stigma-reduction activities (3 questions)
- Personal experience of HIV testing & own HIV status (5 questions)
- Experience of stigma and discrimination for People living with HIV only (15 questions)
- Experience of stigma and discrimination for providing care to People Living with HIV (3 questions)
- Perspectives (63 questions)
- Job-stress (24 questions)
- Study participation (1 question)
Parallel item examples

- People living with or thought to be living with HIV are **talked badly about**
- My co-workers sometimes **talk badly about** women who are or are thought to be women who exchange sex for money, gifts or drinks

- People living with or thought to be living with HIV are **verbally insulted, harassed and/or threatened**
- Young women who become pregnant before marriage are **verbally insulted, harassed and/or threatened**

- People living with or thought to be living with HIV **lose respect or standing**
Qualitative research

- In situ key informant interviews and observations
- N=40
  - 15 CHiPS
  - 15 Health Facility Staff
  - 10 Supervisors
- Annual interviews

- Context Description
  - Diaries and registers of stigma-reduction events monthly in all sites

- Preliminary qualitative interviews with key populations
- Followed by more detailed description of in-depth work
Ethical Issues

• Benefits
  – Perspectives of those delivering interventions often poorly documented
  – Studies of intervention delivery
    • Recommended as part of implementation science, process evaluation for complex interventions
    • Several studies on HIV-related stigma

• Risks
  – Juridic Vulnerability
  – Deferential vulnerability
  – Pay check vulnerability
Minimising risks

- Robust and transparent procedures for fully-informed consent
- Maintaining confidentiality of individual responses at all stages
- Referral of participants-in-need to support or counseling services
- Not using data acquired through this study for M&E purposes
- Monitoring participants’ experiences of participation
- Independent Ethical Review
Submission Preparation

Negotiating Access
- Clarifying study process & manager’s role
- General data collection schedule

First Visit
- Introducing study process & roles of persons of interest
- Give participant IDs
- General data collection schedule

Individual Consent
- Individual summarizes study in their own words
- Study team member highlights key points
- Verbal consent

Group Informing for consent
- Study team member highlights key points
- Signed individual consent

Complete Questionnaire

Opt out
Parallel data collection
PopART Social Science

- Qualitative work on community members, PLWH
- Stigma ancillary team involved in
  - Design of data collection
  - Prioritisation and conduct of analysis
Community

- Nested within PC
- Random 20% of all PC members asked stigma questions
- n=500 per cluster (N=10,500)
- 4-item Likert (Strongly Agree, Agree, Disagree, Strongly Disagree)
12 Items, for example

People sometimes talk badly about people living with or thought to be living with HIV to others.

Health workers sometimes talk badly about people living with or thought to be living with HIV to others.

People living with or thought to be living with HIV lose respect or standing.

People living with or thought to be living with HIV are verbally insulted, harassed and/or threatened.
PLWH

- Nested within PC
- All self-identified PLWH asked experience of stigma and discrimination questions
- Expected n based on HIV prevalence, self-report=150-200 per cluster (N=3150-4200)
- 4-item Likert (Strongly Agree, Agree, Disagree, Strongly Disagree)
- Or 4-item frequency Likert (Never, Once, A few times, often)
I have lost respect or standing in the community because of my HIV status.

People have talked badly about me because of my HIV status.

Healthcare workers talked badly about me because of my HIV status.

I have been verbally insulted, harassed and/or threatened because of my HIV status.
Case-control Studies

- Those who do / do not accept testing (Arm A and B)
- PLWH who do / do not accept early ARV (Arm A)

- Parallel data collection
  - Attitudes
  - Anticipation as a barrier
The remaining pieces

- We are still discussing potential more focused, or additional work with key populations
  - Quantitative
    - Key populations
      - Enumeration?
      - RDS in some sites?
    - Adolescents
  - Qualitative Case Studies
(i) compare stigma indicators between the trial arms
(ii) use adjusted, non-randomised comparisons to assess whether and how stigma acts as a barrier to the implementation of the PopART intervention package
(iii) integrate quantitative and qualitative approaches
Project Status

- Study protocol registered with HPTN
- Questionnaire development for year 1
  - complete (community members, including self-identified PLWH)
  - nearly complete (health-workers)
- Data collection
  - Is underway (community-surveys)
  - June 2014 (health-workers)
- Future work on key populations – under discussion
Conclusions

• The stigma ancillary study aims to strengthen the capacity of the HPTN071 (PopART) trial to meet its objectives by addressing how stigma intersects with the interventions under study
• The success of the PopART intervention will rest on the efforts of health workers based in facilities and in the community
• Data collection will be complementary to main trial data and data analysis will be integrated with the main trial analysis
• We will assess how HIV-related stigma influences, and is influenced by, the delivery and uptake of the HIV-related interventions that comprise PopART
• The work is linked to the broader social science and social epidemiology agenda within HPTN071 which includes research on a range of structural drivers and social inequalities and HIV infection within the context of the PopART trial