Methods for Understanding and Addressing Stigma to Prevent Common Risk Factors for Disease

Valerie A. Earnshaw, Ph.D.
Mind the Gap Webinar Series
NIH Office of Disease Prevention
December 11, 2019
Acknowledgments and Conflicts

2017-2021
Understanding and Addressing Disclosure to Members of Social Networks among People Recovering from Substance Use Disorders (K01DA042881; PI Earnshaw)

2016-2020
Novel Stigma/Structural Interventions for Increasing HIV/STI Testing from BMSM (R01MH109409; PI Eaton)

2017-2021
The Role of Resilience in Addressing Racial Disparities in Adverse HIV-Related Outcomes (R01MH112386; PIs Howe + Keita)

2018-2021
IMPART: A Provider-Assisted HIV Partner Notification & Testing Intervention for Prisoners in Indonesia (R34MH115779; PI Culbert)

No conflicts of interest to disclose.
Presentations Aims

Stigma Overview
- Stigma Definition
- Key Concepts
- Conceptual Framework

Understanding Stigma: Common Critiques
- Conflate Manifestations
- Ignore Sources
- Silo Lived Experiences
- Disregard Context

Addressing Stigma: Intervention Toolkit
- Resilience Tools
- Reduction Tools
- Implementation
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Stigma Defined

- **Social** devaluation and discrediting associated with a mark or characteristic\(^1\)

\(^1\)Goffman, 1963; \(^2\)Link & Phelan, 2001
### Stigma Defined

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Stigma Defined

• **Social** devaluation and discrediting associated with a mark or characteristic\(^1\)
• Stigma results from a **social** process\(^2,3\)
  – Co-occurrence of labeling, stereotyping, separation, status loss + discrimination within a context wherein power is exercised
  – Marks constructed as indicators of tarnished character
  – Used to justify discrimination toward and power loss of people with mark

\(^1\)Goffman, 1963; \(^2\)Link & Phelan, 2001
Three Fundamental Functions of Stigma

- Keep people down
- Keep people away
- Keep people in

Phelan, Link, & Dovidio (2008)
Three Fundamental Functions of Stigma

Examples:
Racism + Sexism

Keep people down

Keep people away

Keep people in

Phelan, Link, & Dovidio (2008)
Three Fundamental Functions of Stigma

- Keep people down
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Examples: HIV + Ebola Stigma

Phelan, Link, & Dovidio (2008)
Three Fundamental Functions of Stigma

- Keep people down
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Examples: SUD + LGBTQ Stigma

Phelan, Link, & Dovidio (2008)
Cross-Cutting Approach
Cross-Cutting Approach
Cross-Cutting Conceptual Framework

Social Process

Stigma

Stigma Manifestations

Internalized Stigma
Enacted Stigma
Anticipated Stigma

Mediating Mechanisms

Access to Resources
Health Behaviors
Stress

Health Outcomes

Mental Health
Physical Health

# Stigma Manifestations

## Internalized Stigma
- Endorsement of negative beliefs/feelings, applying them to the self
- E.g., "I'm a bad person", feelings of shame

## Enacted Stigma
- Experiences of stigma from others in the past or present
- E.g., Job or housing loss, poor or disrespectful treatment

## Anticipated Stigma
- Expectations of stigma from others in the future
- E.g., Worry about job loss, housing loss, poor or disrespectful treatment in future
Cross-Cutting Conceptual Framework

SOCIAL PROCESS

STIGMA MANIFESTATIONS

Internalized Stigma
Enacted Stigma
Anticipated Stigma

MEDIATING MECHANISMS

Access to Resources
Health Behaviors
Stress

HEALTH OUTCOMES

Mental Health
Physical Health

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- Conflates Manifestations
- Ignore Sources
- Silo Lived Experiences
- Disregard Context

Addressing Stigma: Intervention Toolkit
- Resilience Tools
- Reduction Tools
- Implementation
Common Critiques

- Ignore Sources
- Silo Lived Experiences
- Conflate Manifestations
- Disregard Context
Common Critiques

Ignore Sources
Silo Lived Experiences

Conflate Manifestations
Disregard Context

Common Critiques
Critique: Conflate Manifestations

- Stigma scales often mix questions for different stigma manifestations
- Problem because impossible to know which stigma manifestation:
  - Participants are having more of
  - Is leading to bad health outcomes

Earnshaw & Chaudoir (2009); Fox, Earnshaw, Taverna, & Vogt (2018)
### Table 3.
Structural validity: five-factor SU-stigma Mechanism model standardized estimates \((N = 178)\)

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Solution: Measure Manifestations Independently

1. Use different scales
2. Use one scale, with subscales, example:
   - Substance Use Stigma Mechanism Scale\(^1\)
   - Subscales:
     - Enacted stigma
     - Anticipated stigma
     - Internalized stigma

\(^1\)Smith, Earnshaw, Copenhaver, & Cunningham (2016)
Table 3. Structural validity: five-factor SU-stigma Mechanism model standardized estimates ($N = 178$)

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Stigma Manifestations

Internalized HIV Stigma

Anticipated HIV Stigma

Enacted HIV Stigma

Health and Well-Being

Affective

Behavioral

Physical

Earnshaw, Smith, Chaudoir, Amico, & Copenhaver (2013)
Common Critiques

- Ignore Sources
- Silo Lived Experiences
- Conflate Manifestations
- Disregard Context

Common Critiques
Critique: Ignore Sources

• From whom?
  – Stigma scales often don’t ask about sources of stigma
  – Sources: family, friend, employer, healthcare provider
Critique: Ignore Sources

Family: “They’re like the big people that hurt you.”
“They just didn’t trust me in the house.”

Employers: “I’m sure that if they did find out I might be fired, and that’s what I’m worried about.”

Healthcare Workers: “Any time I need anything for pain, I can tell that they don’t want to give it to me or they think I’m lying to get it.”

Earnshaw, Smith, & Copenhaver (2013)
| Perception                                                                 | Often |   |   | Sometimes |   |   |   | Rarely |   |   |   | Not at all |   |   |   |
|                                                                           | n     | %  | n | %         | n | %  | n | %     | n | %  | n | %         | n | %  | n | %     |
| Felt blamed by others for illness                                         | 6     | 7.3| 18| 22.0      | 3 | 3.6| 55| 67.1  |    |     |    |            |    |     |    |       |
| Felt ashamed of illness                                                    | 23    | 28.0| 25| 30.5      | 6 | 7.3| 28| 34.1  |    |     |    |            |    |     |    |       |
| Thought illness was punishment for things done in past                     | 19    | 23.2| 22| 26.8      | 3 | 3.7| 38| 46.3  |    |     |    |            |    |     |    |       |
| Feared I would lose my job if someone found out a                          | 16    | 28.1| 8 | 14.0      | 1 | 1.8| 32| 56.1  |    |     |    |            |    |     |    |       |
| Felt compelled to change my residence because of illness                   | 14    | 17.1| 6 | 7.3       | 5 | 6.1| 57| 69.5  |    |     |    |            |    |     |    |       |
| Avoided getting treatment because someone might find out                  | 6     | 7.3| 6 | 7.3       | 3 | 3.7| 67| 81.7  |    |     |    |            |    |     |    |       |
| Feared people would hurt my family if they learned about my illness       | 20    | 24.4| 14| 17.1      | 8 | 9.8| 40| 48.8  |    |     |    |            |    |     |    |       |
| Thought other people were uncomfortable being with me b                   | 19    | 23.5| 26| 32.1      | 10| 12.3| 26| 32.1  |    |     |    |            |    |     |    |       |
| Felt people avoiding me because of my illness c                            | 16    | 20.3| 13| 16.5      | 9 | 11.4| 41| 51.9  |    |     |    |            |    |     |    |       |
| Feared I would lose my friends if they learned about my illness           | 26    | 32.1| 18| 22.2      | 4 | 4.9| 33| 40.7  |    |     |    |            |    |     |    |       |
| Feared my family would reject me if they learned about my illness         | 16    | 19.5| 12| 14.6      | 4 | 4.9| 50| 61.0  |    |     |    |            |    |     |    |       |
| Felt I wouldn’t get as good health care if people learned about my illness| 9     | 11.0| 10| 12.2      | 3 | 3.7| 60| 73.2  |    |     |    |            |    |     |    |       |
| People who know I am HIV positive treat me with kid gloves d              | 12    | 15.0| 8 | 10.0      | 5 | 6.2| 55| 68.8  |    |     |    |            |    |     |    |       |

a Twenty-five respondents responded “not applicable” (n = 57). b One response missing (n = 81). c Three responses missing (n = 79). d Two responses missing (n = 80).
Solution: Measure Sources Independently

1. Use subscales to measure enacted + anticipated stigma from different sources
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Solution: Measure Sources Independently

1. Use subscales to measure enacted + anticipated stigma from different sources
2. Use methods that better account for relationship factors
Solution: Egocentric Social Network Methods

K01DA042881 (PI Earnshaw); Valente (2010)
Common Critiques

- Ignore Sources
- Conflate Manifestations
- Silo Lived Experiences
- Disregard Context
Critique: Silo Lived Experiences

- Intersecting characteristics and identities lead to unique experiences of stigma...

Slide Credit: Lisa Rosenthal, Ph.D.
Critique: Silo Lived Experiences

- ...that must be studied simultaneously to understand how they are experienced and affect health outcomes

Slide Credit: Lisa Rosenthal, Ph.D.
Challenges and opportunities in examining and addressing intersectional stigma and health

Janet M. Turan¹⁺, Melissa A. Elafros²⁺, Carmen H. Logie³⁴, Swagata Banik⁵, Bulent Turan⁶, Kaylee B. Crockett⁶, Bernice Pescosolido⁷ and Sarah M. Murray⁸
Solution: Measurement Approaches

Generalist

- Measure experiences of stigma in general, participants make attributions
- E.g., Everyday Discrimination Scale

# Generalist: Everyday Discrimination Scale

Table 1  
**Loadings From A Four-Factor Exploratory Factor Analysis With Oblique Oblimin Rotation and WLSMV Estimation In The Educational Diversity Project**

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<thead>
<tr>
<th>Item</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>You are treated with less courtesy than others</td>
<td>1.02</td>
</tr>
<tr>
<td>You are treated with less respect than others</td>
<td>0.81</td>
</tr>
<tr>
<td>You receive poorer service in restaurants or in stores</td>
<td>0.45</td>
</tr>
<tr>
<td>People act like you are not as smart</td>
<td>0.01</td>
</tr>
<tr>
<td>Act as if they are afraid of you</td>
<td>0.01</td>
</tr>
<tr>
<td>People act as if they think you are dishonest</td>
<td>0.00</td>
</tr>
<tr>
<td>People act like they think they are better than you</td>
<td>0.28</td>
</tr>
<tr>
<td>You are called names or insulted</td>
<td>0.06</td>
</tr>
<tr>
<td>You are threatened or harassed</td>
<td>0.06</td>
</tr>
</tbody>
</table>

*Note.* Factor loadings in bold represent locally dependent subsets of items (i.e., method factors) resulting from context effects (e.g., item location, item content, and item wording). Factor intercorrelations ranged from *r* = .41 to .71.
Solution: Measurement Approaches

**Generalist**
- Measure experiences of stigma in general, participants make attributions
- E.g., Everyday Discrimination Scale

**Parallel**
- Measure experiences of stigma in relation to several attributions
- E.g., Multiple Discrimination Scale

---

## Parallel: Multiple Discrimination Scale

Table 2 Multiple Discrimination Scale (MDS) item endorsement, descriptive statistics, and reliability coefficients for 181 Black and 167 Latino MSM

<table>
<thead>
<tr>
<th>Item</th>
<th>Blacks MOS-Race</th>
<th>Blacks MOS-HIV</th>
<th>Blacks MOS-Gay</th>
<th>Latinos MOS-Race</th>
<th>Latinos MDS-HIV</th>
<th>Latinos MOS-Gay</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In past year:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treated with hostility/coldness by strangers</td>
<td>28%</td>
<td>15%</td>
<td>28%</td>
<td>22%</td>
<td>16%</td>
<td>1A%</td>
</tr>
<tr>
<td>Ignored/excluded/avoided by people close to you</td>
<td>18%</td>
<td>17%</td>
<td>19%</td>
<td>14%</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td>Rejected by a potential sexual/romantic partner</td>
<td>15%</td>
<td>29%</td>
<td>13%</td>
<td>8%</td>
<td>25%</td>
<td>1%</td>
</tr>
<tr>
<td>Someone acted as if you could not be trusted</td>
<td>36%</td>
<td>15%</td>
<td>16%</td>
<td>19%</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>Denied a place to live/lost a place to live</td>
<td>10%</td>
<td>9%</td>
<td>9%</td>
<td>6%</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Treated poorly/made to feel inferior when receiving health care</td>
<td>10%</td>
<td>8%</td>
<td>6%</td>
<td>7%</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>Denied a job/lost a job</td>
<td>1%</td>
<td>3%</td>
<td>6%</td>
<td>14%</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Someone insulted/made fun of you</td>
<td>17%</td>
<td>18%</td>
<td>34%</td>
<td>T1%</td>
<td>15%</td>
<td>32%</td>
</tr>
<tr>
<td>Personal property damaged/stolen</td>
<td>7%</td>
<td>6%</td>
<td>11%</td>
<td>7%</td>
<td>6%</td>
<td>10%</td>
</tr>
<tr>
<td>Physically assaulted/beaten up</td>
<td>6%</td>
<td>5%</td>
<td>6%</td>
<td>6%</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Sum (M, SD)</td>
<td>15 (2.2)</td>
<td>1.2 (2.1)</td>
<td>15 (2.2)</td>
<td>1.3 (22)</td>
<td>1.2 (2.2)</td>
<td>1.5 (2.3)</td>
</tr>
<tr>
<td>Range</td>
<td>0–10</td>
<td>0–10</td>
<td>0–10</td>
<td>0–10</td>
<td>0–10</td>
<td>0–10</td>
</tr>
</tbody>
</table>
**Solution: Measurement Approaches**

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
<th>Example Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalist</td>
<td>Measure experiences of stigma in general, participants make attributions</td>
<td>E.g., Everyday Discrimination Scale²</td>
</tr>
<tr>
<td>Parallel</td>
<td>Measure experiences of stigma in relation to several attributions</td>
<td>E.g., Multiple Discrimination Scale³</td>
</tr>
<tr>
<td>Tailored</td>
<td>Measure unique experiences of stigma at the intersection of attributions</td>
<td>E.g., Gendered Racism Scale⁴</td>
</tr>
</tbody>
</table>

Tailored: Gendered Racism Scale

• 15 Likert-type items, anchors reflect frequency [1 (never) – 4 (all the time)]

• Examples
  – “How often do you feel that people make negative assumptions about how many sexual partners you have, based on being a woman of your racial/ethnic background?”
  – “During your most recent pregnancy, how worried were you that people were making assumptions about whether the father of the child would play a role in raising the child, based on being a women of your racial/ethnic background?”
Solution: Analytic Approaches

- Explore stigma → outcome association among separate samples
- Answer exploratory questions, such as who experiences more stigma?

Turan et al. (2019)
Solution: Analytic Approaches

**Stratified**
- Explore stigma → outcome association among separate samples
- Answer exploratory questions, such as who experiences more stigma?

**Moderation**
- Examine main effects + product within analysis
- Examine if effect of 1st stigma experience depends on a 2nd or another identity

Turan et al. (2019)
Moderation: SU Stigma X HIV Stigma

Figure 1. Line graph representing interaction between internalized HIV stigma and internalized substance use stigma on depressive symptoms.

* $p \leq .05$.
Solution: Analytic Approaches

- **Stratified**
  - Explore stigma → outcome association among separate samples
  - Answer exploratory questions, such as who experiences more stigma?

- **Moderation**
  - Examine main effects + product within analysis
  - Examine if effect of 1st stigma experience depends on a 2nd or another identity

- **Latent Class**
  - Identify subpopulations of individuals based on stigma experiences
  - With generalist measures

Turan et al. (2019)
Latent Class Analysis: Everyday Discrimination Scale

![Graph showing probability of select discrimination attribution across different categories.]

**FIGURE I** Latent class profiles for four-class model

Earnshaw et al. (2017)
Solutions: Takeaways

• Approaches to studying intersectionality have strengths + weaknesses
• Choose approach based on your research question + study design
Common Critiques

Ignore Sources

Silo Lived Experiences

Conflate Manifestations

Disregard Context

Common Critiques
Critique: Disregard Context

**SOCIAL PROCESS**

Stigma

**STIGMA MANIFESTATIONS**

Internalized Stigma

Enacted Stigma

Anticipated Stigma

**MEDIATING MECHANISMS**

Access to Resources

Health Behaviors

Stress

**HEALTH OUTCOMES**

Mental Health

Physical Health

**STRUCTURAL CONTEXTS**: Institutions, Communities, Societies

Introduction

Introduction to the special issue on structural stigma and health
Solutions: Consider Structural Stigma

• Operationalization: “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and well-being of the stigmatized”
• Examples of indicators of structural stigma:
  – Federal, state, local laws
  – Community-level social norms + attitudes
  – Contextual events
  – Area-level hate crimes
  – Disparities in judicial treatment, political participation
Solutions: Consider Structural Stigma

Methodological Approaches

Hatzenbuehler (2017)
Structural Stigma + Enacted Stigma

FIGURE 1
The moderating role of school GSA on rates of homophobic bullying in California schools before and after the vote on Proposition 8. Rates of homophobic bullying were estimated on the basis of the aggregated school-level data (n = 5121). The vertical line indicates when Proposition 8 voting took place (November of the 2008–2009 academic year).

Hatzenbuehler et al. (2019)
Presentations Aims

Stigma Overview
- Stigma Definition
- Key Concepts
- Conceptual Framework

Understanding Stigma: Common Critiques
- Conflate Manifestations
- Ignore Sources
- Silo Lived Experiences
- Disregard Context

Addressing Stigma: Intervention Toolkit
- Resilience Tools
- Reduction Tools
- Implementation
Stigma Intervention Toolkit

Counseling

Expressive Writing

Intergroup Contact

Legal + Policy Changes

Cognitive Dissonance

Values Affirmation

Communicating Diversity Values

Intersectional

Longitudinal

Multilevel

Chaudoir et al. (2017); Cook et al. (2014); Livingston et al. (2013); Rao et al. (2019); Stangl et al (2013)
Stigma Intervention Toolkit: Resilience

- Protect people from stigma
- Resilience resources = Modifiable, strengths-based buffers
- Examples:
  - Empowerment
  - Expressive writing
  - Social support
  - Adaptive coping

Chaudoir et al. (2017); Cook et al. (2014); Earnshaw, Bogart, Dovidio, & Williams (2013)
Stigma Intervention Toolkit: Resilience

• UNITY Trial
  – Population: African American women living with HIV
  – Multicomponent + intersectional stigma-reduction workshop, incorporating:
    • Education
    • Contact with affected persons
    • Counseling strategies
    • Training in coping skills
  – Among women with PTSD or clinically significant depressive symptoms at baseline, UNITY was associated with greater engagement in care

Fabian et al. (2019); Rao et al (2018); Rao et al. (2012)
Stigma Intervention Toolkit: Reduction

- Reduce stigma among general public + in structures
- Examples:
  - Contact
  - Education
  - Policy change
  - Communicate diversity values

Chaudoir et al. (2017); Cook et al. (2014); Rao et al. (2019); Stangl et al (2013)
Stigma Intervention Toolkit: Reduction

Contact
- In-person interactions
- Vicarious interactions: TV, radio/podcast, books

Mediators
- Increased empathy and perspective taking
- Enhanced knowledge (question stereotypes)
- Reduced anxiety about interactions

Outcome
- Lower Prejudice
- Less Discrimination

Pettigrew & Tropp (2006, 2008)
Stigma Intervention Toolkit: Implementation

Multilevel / Multicomponent

Intersectional / Cross-cutting

Longitudinal

Stigma Intervention Toolkit: **Implementation**

- Multilevel / Multicomponent
- Intersectional / Cross-cutting
- Longitudinal

Stigma Intervention Toolkit: **Implementation**

- Multilevel / Multicomponent
- Intersectional / Cross-cutting
- Longitudinal

Stigma Intervention Toolkit: Implementation

Multilevel / Multicomponent

Intersectional / Cross-cutting

Longitudinal

Thank you!

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