Socio-Cultural Research on Tuberculosis

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Major foci of research
- Adherence
- Cultural diversity
- Cultural beliefs and practices
- Stigma
- Gender
- Organization of services

Stigma and Health
- Increased interest in impact of social stigma on health problems
- Social determinants of health, socio-cultural context, structural influences
- Stigma and Global Health Research Program, NIH Fogarty International Center (FIC)
- 19 projects funded in 2003

2001 Pilot Study in South Florida
(Coreil, Lauzardo & Heurtelou, 2004)
- Social stigma important deterrent to screening and treatment
- Sensitivity within Haitian community about ethnic labeling and discrimination
- Structural barriers: confidentiality, cultural competence, public-private collaboration
- Recommendations: Avoid targeting Haitians; reorganize and improve services

FIC Study 2003-08
- Two country study of impact of stigma on psychosocial response, help-seeking and treatment adherence for tuberculosis among Haitians in Haiti and the U.S.
- Approach considers tuberculosis within a transnational framework of understanding

Study Objectives
- Determine influence of sociocultural context on TB-related stigma (Haiti and US)
- Compare dimensions of TB-related stigma among community residents, clinic staff and TB patients
- Test hypothesis that perceived stigma negatively associated with adherence to preventive therapy for latent TB in Florida
Study Design

- Phase I: Ethnographic Study
- Phase II: Cultural Epidemiologic Study
- Phase III: Adherence Cohort Study

- Two field sites:
  - Leogane, Haiti
  - Broward & Palm Beach Counties
Ethnographic Phase

- 60 hours observation in 3 clinics
- 192 in-depth interviews with patients, staff and community residents
- 12 focus group discussions with above groups
- Media monitoring and local context
- Results help design structured EMIC instrument for Phase II

Structural Stigma

- Institutional policies and practices that reinforce negative stereotypes and stigma
- Organization of services
- Lack of protection for confidentiality
- Targeted programs label certain groups
- Media images and reporting
- Government policies

Cultural Epidemiologic Study

- Distribution of cultural models of tuberculosis across groups
- Haiti and Florida
- Community residents, providers, patients
- Six comparison groups
- Total sample: 475

EMIC Sample

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<thead>
<tr>
<th></th>
<th>HAITI</th>
<th>FLORIDA</th>
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<tbody>
<tr>
<td>Community</td>
<td>100</td>
<td>98</td>
</tr>
<tr>
<td>Healthcare provider</td>
<td>39</td>
<td>48</td>
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<tr>
<td>Patient</td>
<td>100</td>
<td>90</td>
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Theoretical Model

(Weiss, 2001)

- Illness
  - Experience
  - Meaning
  - Behavior
Operational Formulation

Explanatory Model of Illness

Patterns of Distress (PD)
Perceived Causes (PC)
Help-Seeking (HS)

Cross-National Differences

• Haiti: Economic Issues
  – Associated with poverty and malnutrition
  – Reflects on family’s ability to provide for its members’ needs, especially food

• Florida: Political Issues
  – Linked to discrimination, immigration, racism, socio-cultural marginality

Items Related to Discrimination

• “Is it more embarrassing for you to have a TB related condition because you are Haitian than it would be for other people in Florida?”
• “Because you are Haitian, will people think worse of you than others with the same TB condition?”

Immigration Policy

• “In your opinion has U.S. immigration policy discriminated against Haitians?”
• “As a group, have Haitians been treated badly in American society?”

Community Samples

• Recruited from 5 organizational types
• Churches, Schools, Businesses, Civic organizations
• Total sample: 198
  • Haiti: 100
  • Florida: 98
  • Broward (57); Palm Beach (41)

Demographic Profile

<table>
<thead>
<tr>
<th></th>
<th>FLORIDA</th>
<th>HAITI</th>
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<tbody>
<tr>
<td>Age</td>
<td>40.7</td>
<td>35.9</td>
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<tr>
<td>Education</td>
<td>12.5</td>
<td>10.5</td>
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<tr>
<td>Literacy</td>
<td>92.7</td>
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<tr>
<td>Female</td>
<td>46.9</td>
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<tr>
<td>Income</td>
<td>15,243</td>
<td>3,596</td>
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Patterns of Distress

- Physical
- Social
- Stigma
- Financial
- Psychological
- Other

Stigma Scale

- 24 item Likert-type index (α > .80)
- Cognitive and emotional responses
- Reactions of others and community
- Disclosure of diagnosis to others
- Impact on self and family
- Attractions associated with diagnosis
- Social identity associations

Perceived Causes

- Ingestion
- Health-related
- Heredity
- Environmental
- Moral/supernatural
- Psychological
- Other

Patterns of Distress

- Florida respondents higher on:
  - Medication side effects, isolation from family, social isolation
- Haiti respondents higher on:
  - Physical symptoms, marital problems, sadness, stress, anxiety about job, finances, family

Stigma Components

- Florida higher on:
  - worry about being sent to sanatorium, others refuse to visit, problems for children
- Haiti higher on:
  - loss of respect, verbal abuse, assoc. with HIV, fear of disclosure
Factor Analysis – Haiti

- 5 factor model:
  - Disclosure
  - Internal shame
  - Family reputation
  - External problems
  - Other illnesses

Factor Analysis – Florida

- 4 factor model:
  - Internal shame
  - Disclosure
  - External problems
  - Communicability

Implications

- Highlights influence of sociopolitical context on disease-related stigma
- Public health problems must be addressed within this larger context
- Interventions to reduce stigma must go beyond clinical and community settings
- Lessons from transnational research

Adherence Study – Florida

<table>
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<tr>
<th></th>
<th>COMPLETE TREATMENT</th>
<th>MEDICAL ADVICE</th>
<th>MOVED</th>
<th>NON-ADHERENT</th>
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<tr>
<td>Number</td>
<td>67</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<td>Stigma score</td>
<td>24.9</td>
<td>22.3</td>
<td>36.3</td>
<td>21.2</td>
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Challenges

- Complexity of study design
- Political situation in Haiti
- 2004 hurricane season
- Loss of Haitian clinic
- Staff turnover
- Bilingual project
- Patient recruitment

Collaboration

- Haiti: St. Croix Hospital
- Broward, Palm Beach Health Departments
- TDR four-country study (Weiss)
- FWA for foreign institutions
- Challenge of IRB training
Funding - international

- TDR – Tropical Diseases Research
- Global Fund to Fight AIDS, Tuberculosis and Malaria
- NIH: Fogarty International Center; NIAID, NHLBI, other institutes/centers

Gender and tuberculosis: cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi, and Colombia

Social, Economic and Behavioural Research. Report Series No.3 (TDR)


Ethics and IRB

- 3 different IRBs involved
- Different policies and practices
- Written consent and confidentiality
- Adverse events and repercussions
- Research reinforces stereotypes