The Importance of the Trauma Consumer Community Driving Research

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The importance of researching male trauma survivors

What is Community-Based Participatory Research?

How to apply CBPR for male trauma survivors

The ethics and challenges of conducting CBPR
At least 1 in 6 boys is sexually abused by their 18th birthday (ACES, 1997)

At least 1 in 4 men will experience sexual abuse in their lifetime (NISS, 2014)

Majority of research on sexual trauma focuses on girls and women

There are gender differences in the experience, response, and impact of trauma
Greater risk for:
- Depression
- PTSD
- Substance abuse problems
- Suicidal thoughts and behavior

Lower quality of life and rated happiness for males
Gender role socialization teaches us that boys:
- Are powerful
- Are invulnerable
- Should never cry/experience sadness
- Should welcome sexual activity
- Less likely to identify experiences as abuse
- Myths about male sexual abuse:
  - Men cannot be raped
  - Men should feel “lucky” if the perpetrator was female
  - Survivors go on to become abusers
EBPs for PTSD indicate that women make more rapid gains (Galovski et al., 2013)

Preference for gender-targeted information about sexual trauma (Turchik, Rafie, Rosen, & Kimerling, 2014)

Participating in health care seems different and more limited as compared to female survivors

Health care providers may perpetuate commonly misheld beliefs about male sexual trauma
What is Community-Based Participatory Research (CBPR)?

- Orientation
- Collaborative
- Equitable amongst all partners
- “Co-learning process” (McTaggart, 1997)
- Embodies cultural humility
- Aims to create social change
- Aims to reduce health disparities
CBPR: Forming Equitable Partnerships

- Survivors/mental health users are full partners who contribute expertise
- And share in decision-making and ownership of research

Spectrum for community engagement in research

<table>
<thead>
<tr>
<th>INFORM</th>
<th>CONSULT</th>
<th>COLLABORATE</th>
<th>EMPOWER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate the community</td>
<td>Get feedback from the community</td>
<td>Community gets involved/helps decide</td>
<td>Community takes lead role/makes final decision</td>
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CBPR vs. Traditional Orientations

**CBPR**
- Co-researchers
- Processes
- Inductive

**Traditional**
- Outside researchers
- Outcomes
- Deductive

Lyke (2007)
What Can CBPR Do?

- Improve cultural sensitivity
- Address community-level, not just individual-level, issues
- Facilitate true informed consent
- Support the development of questions that reflect community members’ concerns
- Foster trust in the community thereby facilitating recruitment and retention
- Increase validity of interpretations
Step 1: Identify the Community & Team

- Select your community
- Specify members of the team and their unique roles
- Allow topic to be loosely defined, as this will change with input from community members
Step 2: Build Trust and Engagement

- Partners, not subjects or participants
- Joint ownership
- Attention to histories of discrimination and marginalization
- Transparent discussions of power
- Document community strengths and local knowledge
- Identify co-learning opportunities
- Build capacity, focus on systems development and sustainability

Step 3: Topic & Question Development

- Topic and objectives should come from the community
  - Can be initiated by an outside researcher
- Expert vs. citizen knowledge
- Make it clear as to who helped to develop the topic and proposal, and how it was developed
Step 4: Design & Conduct Study

- Use community feedback to determine best methods

- Methods:
  - Mixed methods
  - Surveys
  - Focus groups
  - In-depth Interviews
  - Workshops
  - Observations
  - Stakeholder dialogues
  - Community feedback
  - Ethnographic interviews

- Assessments and instruments

- Data collection
Step 5: Disseminate

Steps to not only conduct the research, but carry it forward in terms of action, policy, change and ways to benefit the community

Ensuring equitable benefit

Ways to benefit the community:
- Document and/or sustain effective programs, services, and interventions
- Extend interventions to real-world settings
- Promote policy and advocate
- Create products
- Promote empowerment at micro and meso-levels
Ethical Principles with CBPR

- Research should do no harm
- Relationships should be based on trust and mutual respect
- Community partners should have real influence
- Should benefit the community
- Respect for diversity

Yolanda Suarez-Balcazar (2004, in Jason et al., 2004)
Challenges in CBPR

- Scientific integrity/rigor
- Distrust of academia
- Insider-outside tensions
- Commitment issues
- IRB barriers

Table 4
Salient themes from the interpretation of scientific integrity.

<table>
<thead>
<tr>
<th>Professional investigators</th>
<th>Community investigators</th>
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<tbody>
<tr>
<td>Conceptual flexibility</td>
<td>Trust</td>
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<tr>
<td>Logistical flexibility</td>
<td>Benefit to the community</td>
</tr>
<tr>
<td>Balancing scientific integrity with community needs</td>
<td>Accountability to the community</td>
</tr>
<tr>
<td>CBPR is traditional inquiry</td>
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Kraemer Diaz et al. (2013).
Working with MaleSurvivor

- Step 1: Identify the community and team
- Step 2: Build trust and engagement
- Step 3: Topic & Question Development
- Step 4: Design Research Study
- Step 5: Disseminate
Working with Male Survivor: Challenges & Lessons Learned

- Recruitment difficulties
- Scientific integrity challenges
- Attention to ethical issues and appropriate boundaries
- Address issues of safety and trust
- Minimize risk of harm when addressing trauma material
- Be mindful of own biases/assumptions

Refer to Guidelines on Trauma Competencies for Education & Training for additional information:

Tips for Developing a CBPR Framework

- Establish significance and relevance beyond national data
- Describe needs *and* strengths
- Describe barriers to community members’ participation
- Describe ways in which the community will be built upon
- Be clear about funding; do not leave majority of funding to be retained by the academic organization
- Leave room for flexibility, the cornerstone of a participatory framework

References & Suggested Readings


