Community Based Participatory Research: What is it and how has it contributed to grantee suicide prevention work

Mary Cwik, PhD
Novalene Goklish
Lauren Tingey, MPH, MSW

Introduction

**TOPIC:** Use of Community-Based Participatory Research (CBPR) methods to prevent youth suicide on the White Mountain Apache Reservation

**TALK:**
- Background on CBPR
- Background on White Mountain Apache Tribe
- Tribal-university partnership to address youth suicide
- Lessons learned
- Tips, advice, how to address barriers
What is CBPR?

• Group Discussion:
  – Definition
  – Aims
  – Functions
  – Principles
  – Values

CBPR

• DEFINITION: CBPR is a broad term for a wide range of approaches to empower community members to engage in research that increases citizen power and voice
• AIMS: CBPR aims to involve community groups and/or community members in an egalitarian partnership with researchers
• FUNCTIONS: Formal boundaries between traditional roles are reduced/eliminated and anyone involved in the research can take on different roles and responsibilities
  – These factors lie along a continuum
CBPR

• PRINCIPLES:
• CBPR recognizes the benefits of partnership between those with the scientific knowledge and those with the cultural knowledge
• Community is involved at all levels of decision making

• VALUES:
— Reciprocity
— Interdependency
— Mutuality
— Respectfulness
— Honesty
— Engagement
— Specificity AND generalizability of data

Process of Community-Based Research Development

• Formative research to understand problem, generate ideas, and draft proposal:
  • Met with various medical and MH staff, Health Board, Tribal Council, Elder’s Council, newspaper staff, local radio station, and Elder’s Council to discuss problem
  • Based on this feedback, Hopkins designed various proposals
  • Brought proposals back to these groups for further feedback and to determine if proposals were addressing their needs and concerns
  • Iterative, collaborative process of drafting proposals
  • Received support from all groups to proceed for various IRB approvals

• Scientific review of proposal by Hopkins staff

• Review and approval of funded research plan by:
  - Tribal Health Board
  - Tribal Council
  - Local and Phoenix Area IHS
  - Johns Hopkins University
Process of Community-Based Research Implementation

- Hiring and training of local Apache staff
  - Challenges: Finding qualified people with experience working with youth and with the community
    - Example: home-visiting
- Ongoing collaboration in implementing research and interpreting data
- Development of local advisory boards
  - Successes: Identified individuals from organizations with which we were collaborating: ABHS, IHS, Tribal Council, Health Board, Tribal Social Services, Law Enforcement
- Tribal review and approval (by Health Board and Tribal Council) of all data distribution or results for publications and conferences

White Mountain Apache Tribe

- ~15,500 enrolled tribal members
- Fort Apache Res. (1.6 million acres)
- Geographically isolated
- Spectrum of traditional and mainstream cultures
- Governed by White Mountain Apache Tribal Council
- 28-year relationship with JHU Center for American Indian Health (CAIH)
Apache Youth

- Strong traditions for families and youth
- History and culture of resiliency
- 54% of tribal members are <25 years old
- Youth have many strengths and challenges

Apache Youth Suicide

- Prior to 1950 very low suicide rates
- Spikes in youth suicide rates:
  - 1990-1993
  - 2001-present
Tribal Response to Crisis

- Tribal resolution created in 2001 mandating the report of all suicidal behavior to Tribal Suicide Prevention Task Force
- Tribal Registry created
  - Paper and pencil reporting system
  - Limited follow-up & financial resources
- Formalized partnership with JHCAIH to create public health approaches to problem
Tribal/JHU Response to Crisis

“Celebrating Life:”
• Phase I
  – Update, computerize and analyze suicide registry system
  – Case management and referral for suicidal youth

• Phase II
  – Study youth suicide attempters aged 10-19 years old
    » Short-term (N=75)
    » Long-term (N=25)

“Empowering Our Spirits:”
• Phase III
  – Design and piloting of prevention interventions
    » Universal, targeted, selected
  – Selected intervention development and evaluation
    » ED Intervention
    » Life-skills Intervention
    » Enhanced Evaluation

“Celebrating Life”
Phase I: Outcomes
• Apache youth suicide rate: 13x U.S. All Races, ~6x AI/AN rates

• Highest completion rates: 15-24 yr olds; highest attempt rates: 15-19 yr olds

• Male: Female ratios: 6:1 completions; ~1:1 attempts

• Methods - 80% Hanging despite availability of fire arms

• Known triggers for attempters: conflict with partner or close relative; loss of loved one; substance use
How do Apache Rates Compare?
Average suicide incidence rates per 100,000/year

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population, Age Adjusted</td>
<td>10.7</td>
<td>10.3</td>
<td>40.1 (~4x US)</td>
</tr>
<tr>
<td>Ages 15-24</td>
<td>9.8</td>
<td>17.25 (~2x US)</td>
<td>129.9 (~13x US)</td>
</tr>
</tbody>
</table>

“Celebrating Life”
Phase I: Community Insights into Data

Proposed Risk factors
- Depression or other mental illness
- Confusion about spiritual/cultural identity among youth
- Spike in METH use
- Role of abuse/domestic violence
- Emotional state uncertainty (I FEEL “SOMEHOW”)
- Outside media incongruous to Apache culture
- Family and community history
- Lack of school connectedness/literacy
- Loss of community taboos against suicide
- Access barriers to mental health care
- Lack of coordination among community service providers
- Youth and family treatment preferences unknown
- No ability to place intoxicated and suicidal teens in secure setting

Protective factors
- How culture/family strengths serve as protective factors?
- Community commitment to address the problem
- Apache paraprofessionals track record for addressing priority health problems
“Celebrating Life”
Phase II Methods

- Recruit consecutive series of youth (10-19 years) suicide attempters (N=75) for one-time assessment:
  - Suicide method and severity
  - Risk factors
  - Protective factors
  - Treatment/intervention preferences

- Recruit subsample for longitudinal assessment (n=25/75)
  - 5 follow up interviews over 12 months
    - Qualitative assessment
    - Life events
    - Treatment/service utilization
    - Re-attempt rates

“Empowering Our Spirits”
Phase III Methods

- Garrett Lee Smith Memorial Act/State-Tribal Youth Suicide Prevention Grant Program
- Design and piloting of prevention interventions
  - Universal, targeted, & selected
  - Selected intervention development and evaluation
    - Enhanced Evaluation: ED and Life-skills interventions
“Empowering Our Spirits”
Phase III Methods

• **Universal** Intervention
  • Goal: to raise awareness and educate the community
    – Consultation to Tribal Council and community leaders
    – Elders Advisory Council
    – Youth/Elder-Directed Media Campaigns promoting protective factors
    – Community education at district meetings, schools, churches, traditional meetings, health fairs, and community meetings
    – Implementation of AFSP Media Guidelines

• **Targeted** Intervention
  • Goal: identify and refer youth at risk
    – ASIST Care Taker Training (aka “Gatekeeper Training”)
      ▪ Teachers/counselors/school personnel
      ▪ Ministers
      ▪ Coaches
      ▪ Police
      ▪ Social service professionals
      ▪ Youth group leaders
      ▪ EMS
      ▪ Political leaders
“Empowering Our Spirits”
Phase III Methods

• **Selected** Intervention
• Goal: increase the capacity of Apache paraprofessionals to enhance adherence to and supplement mental health services for youth suicide attempters and families
  – Emergency Department Crisis Intervention (J. Asarnow)
  – Home-Based American Indian Life Skills Training (T. LaFromboise)

“Empowering Our Spirits”
Phase III Methods

• **Selected** Intervention Development
• Goal: adapt, expand, and evaluate programs to reduce suicide attempts and suicide in Apache youth
  – Adaptation of Emergency Department-Based Intervention (EDI) and Life Skills Intervention (LSI)
  – Pilot testing of interventions with 30 Apache youth
  – Randomized controlled trial of EDI versus EDI + LSI
Lessons Learned
Research Protocol Specific

Assessments
• Registry length
• Assessment battery burden

Recruitment challenges
• Parent participation: need to emphasize the importance and value of their involvement
• Literacy levels
• Youth involvement

Staff considerations
• Psychological burden; staff are seen by families as a resource and are asked to go above and beyond their roles as defined by the research
• Local staff could overcome cultural barriers
• Importance of confidentiality

Participant risk management
• Tiered response to risks for study participants
• Ability of community providers to absorb referrals

Lessons Learned
General
– First community-based surveillance system for suicidal behavior
– Model of CBPR methods that respond to:
  • Unique population-based risk and protective factors
– Treatment/service preferences
– Evidence-based plus culturally accepted/adapted
– Use of paraprofessionals
– Rigorous evaluation that will inform future intervention development
Tips, Advice, Addressing Barriers

• Do not skip formative research stage
  – Understand problem from community’s perspective
    • How is it conceptualized?
    • How did it start?
    • What will solve/alleviate the problem?
  – What are communities strengths and weaknesses to address the problem
  – Formulate study design incorporating community involvement at each point

Tips, Advice, Addressing Barriers

• Be present in research communities
• Be flexible and respond to the priorities and needs of different communities
• Create advisory boards
  – Invite tribal health directors, state people, IHS and members of population of interest (youth, etc.)
  – Board can then help overcome barriers you encounter
Tips, Advice, Addressing Barriers

• Importance of previous relationships or connections with leaders, tribal councils, & government agencies
• Face-to-face communication is essential
• Important for all partners to keep a shared focus and common understanding
• Offer opportunities to celebrate accomplishments together

Conclusions

• Tribally mandated registry system allows for more accurate reporting of suicidal events
• Paraprofessionals successful at addressing community mental health concerns
• Community’s interpretation of data informs study design
• CBPR methods have the potential to reduce mental health disparities in AI and other culturally distinct communities
Resources

- Agency for Healthcare Quality Research. The role of Community Based Participatory Research. [http://www.ahrq.gov/research/cbprrole.htm]

Thank you