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

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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

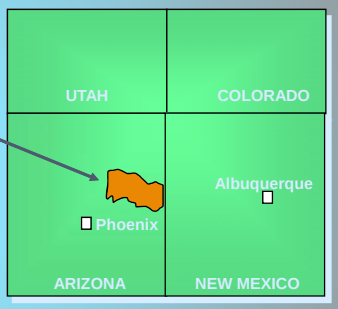
- Formative research to understand problem, generate ideas, and draft proposal:
  - Met with various medical and MH staff, Health Board, Tribal Council, Elder's Council, newspaper staff, local radio station, and Elder's Council to discuss problem
  - Based on this feedback, Hopkins designed various proposals
  - 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)

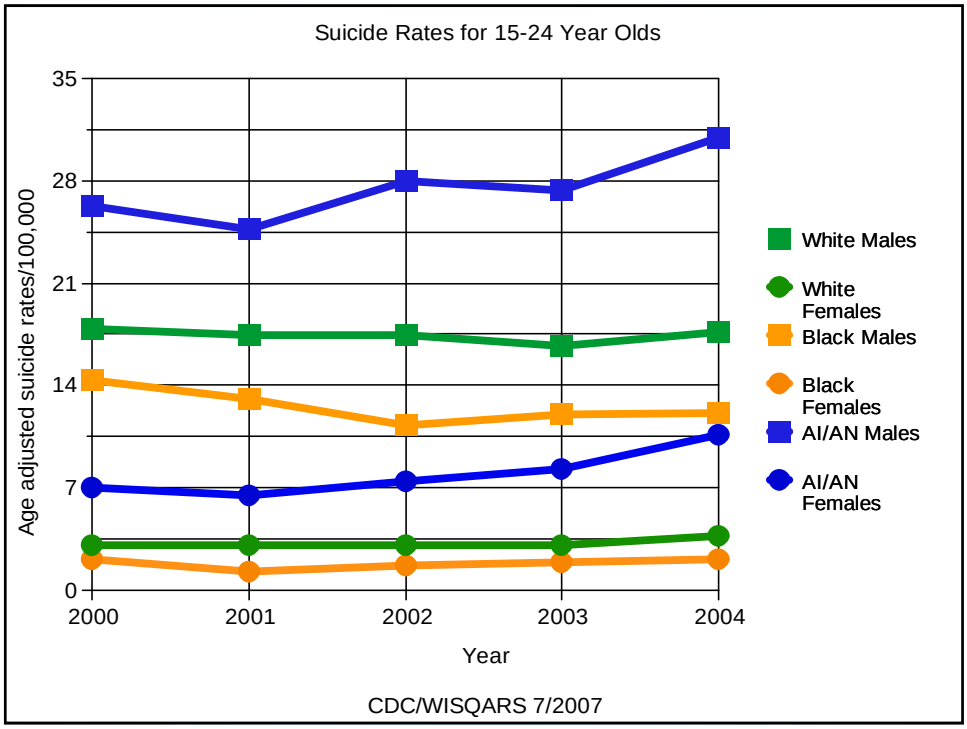


Apache Youth

- 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 Sprits:"

- 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

	U.S. All Races (2003)	AI/AN (2003)	White Mountain Apache (2001-2006)
Total Population, Age Adjusted	10.7	10.3	40.1 (~4x US)
Ages 15-24	9.8	17.25 (~2x US)	129.9 (~13x US)

"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

"Empowering Our Spirits" Phase III Methods

- **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

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Thank you