Community engagement and Research with Alaska Native communities

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This project is supported through grants from the National Institutes of Health (NIAAA R01AA11446, NIAAA R211AA016098, NIAAA R21AA01554, NIMHD R24MD001626, NIAAA R01AA023754) and the State of Alaska (DL-12-CD-580)
Presentation Overview

• Qungasvik (Toolbox) Projects: A Case Example for Engaging Alaska Native Communities in Research to Reduce Disparities in Youth Suicide and Alcohol Use Disorder

• Ethics in the Translation and Measurement of Culture in Health Interventions to Reduce Suicide/Alcohol Risk with Yup’ik Alaska Native Communities

• Ethical Considerations in Tribal Community Engagement and Health Intervention Research with Alaska Native Communities
The Unacceptable Burden of Youth Suicide in Alaska

Suicide Rate per 100,000 population 2004-2010

Rates are age-adjusted per 100,000 population
*The Alaska rate for 2005 is preliminary.
**US rate for 2004 is preliminary and the US rate for 2005 is unavailable at the time of publication.
Suicide Clusters in Alaska Native Communities

In a 16-month period there were eight suicides involving residents of the small Yukon Delta community of Alakanuk. This chart projects what the death toll would mean to a city the size of Anchorage if the same proportion of its youth killed itself. (The figures are estimates and necessarily assume the percentage of young people in both communities is the same.)

- ALBERT MARBY
  Age 25
  Died 6/25/86
  Gunshot

- TIMOTHY STANISLAUS
  Age 25
  Died 7/25/86
  Hung

- BENJAMIN EDMUND
  Age 31
  Died 5/2/86
  Gunshot

- KAREN GEORGE
  Age 17
  Died 8/25/86
  Gunshot

- JERRY AUGLIN
  Age 21
  Died 2/21/86
  Gunshot

- STEVEN KAMEROFF
  Age 22
  Died 1/22/86
  Hanged (St. Marys)

- MELVIN TONY
  Age 23
  Died 10/23/86
  Gunshot

- LOUIE EDMUND
  Age 22
  Died 3/22/85
  Gunshot

Compared to Anchorage
(Population 229,117)

The first suicide. For a city the size of Anchorage the impact would be same as 41.5 deaths.

Graphic by Benny Boyut
Alaska Native Protective Factors Project
(R01AA11446 NIAAA/NIMHD)

Intervention Development and Pilot Projects
Cuqyun (Measurement) (2004-2006)
(R21AA016098 NIAAA)
Ellangneq (Awareness) (2005-2008)
(R24MD001626-1 NIMHD)
People Awakening Resilience Project (2005-2008)
(R21AA015541 NIAAA)

Prevention Trial I and Dissemination Projects
Elluam Tungiinun (Towards Wellness) (2008-2013)
(R24MD001626-4 NIMHD)
State of Alaska (2011-2014)
(Designated Legislative Grant, DS-11)
Qasgiq (Communal House) (2013-2016)
(R24MD001626-8 NIMHD)

Prevention Trial II
Qungasvik (Toolbox) (2015-2020)
(R01AA023754 NIAAA/NIMH)
A Community-Driven, Protective Factors Approach to Health Intervention Research

• What are our community and cultural strengths?
• What are our historical strengths?
• What kinds of protective experiences did our Elders have when they were growing up?
• How can we increase exposure to protection and Yup’ik cultural strengths today for our youth?

“I know what this prevention is,” he said. “It is what my parents gave me when I was growing up. They gave me yuuyaraq, which is everything I needed to live a good life.”
Alakanuk: A people Awakening

Alakanuk Digital Story: Outcomes of an Indigenous Intervention

Alaska Native Youth Legacies of Strength and Resilience
Ethics in the Translation and Measurement of Culture in Health Interventions to Reduce Suicide/Alcohol Risk with Yup’ik Alaska Native Communities

- Focus on protection rather than risk reduction
  - Community identified outcomes of *reasons for life* and *reasons for sobriety*

- Culturally-developed versus adapted interventions
  - Qasgiq (Communal House) Model describes the indigenous theory of change and local intervention implementation process

- Measuring outcomes of culturally-developed interventions using rigorous research designs
  - How to adapt the science of health intervention research to assess cultural strengths and protections in Alaska Native youth and their impacts on ultimate outcomes of reasons for life and reasons for sobriety
Protective Factors
Qanruuyutet: Teachings, words to live by
... Click on words to hear audio. ...

**AWARENESS**
Ellangneq: Awareness
Being aware of the consequences of one’s own actions and how they affect family and community. Being conscious and developing a relationship with Ellam Yua/God.

**SELF-EFFICACY**
Piyungnaunga: I can
A person’s belief and confidence that he/she can solve their own problems.

**COMMUNAL-MASTERY**
Kauuukut: We are strong
Confidence that personal problems can be solved by working together with other people, such as family and community members.

**WANTING TO BE A ROLE MODEL**
Ciuliqagnangut: I want to lead
Setting an example for others by choosing to live life in a good way. A person’s actions can influence others’ behavior.

**GIVING**
Naklegtalria: Someone who is giving, loving
Sharing with others and contributing to family and community. This cultivates a sense of purpose and responsibility.

**AFFECTION/RECOGNITION**
Quyavikluku: To be thankful to him
Recognize a child/youth’s accomplishments in specific ways. Give praise for good behavior and efforts toward helping the family such as catching birds or picking berries.

**CLEAR LIMITS AND EXPECTATIONS**
Alerquutet: Teachings, instructions
Define acceptable behavior for the child/youth. Expectations are clearly and consistently repeated and enforced.

**FAMILY MODELS OF SOBRIETY, WELLNESS**
Takarnargellirkit: Someone who is respected
Family members lead by example and encourage others to be sober.

**SAFE PLACES**
Qiniulinguit uittavit: Safe places
Places which are free from substance abuse and violence. Abusive behavior is not tolerated.

**OPPORTUNITIES**
Ciunertkaat illirdluq: Opportunities
Positive things for youth to do to prevent boredom and increase a sense of belonging and purpose.

**ROLE MODEL**
Nukalpiat: Good provider
Non-family members such as elders, community leaders, and others who work hard, live a good, clean and sober life, and share what they know with others.

**VILLAGE RULES**
Nunam Inerquutai: Village rules
Enforcement of local alcohol laws and youth curfew laws.

**BEING TREATED AS SPECIAL**
Pirpakumaliria: One who is cherished
Children and youth are valuable, worthwhile members of the family and community. Encourage them to find and fulfill their path by guiding them in a specific direction or cultural role.
Murilkelluku Cikuq = Watch the Ice
Yup’ik Values and Traditions Promoted in this Cultural Activity

- Respect for land
- Respect for nature
- Always be prepared and don’t panic
- Always be aware of danger and your surroundings
- Always have a partner with you when traveling or hunting

Testing the Ice: Reasons for Life
Maliqnianeq = Seal Hunt
Protective Factors Promoted in this Cultural Activity

- Ellangneq (becoming aware)
- Self-Efficacy
- Communal Mastery

Giving the seal a drink of water:
- Reasons for Sobriety
An Indigenous Theory-Driven Intervention Implementation Model to Build strengths and protections against suicide and alcohol misuse
Adapting Our Science to assess outcomes of a Yup'ik theory-driven intervention

We looked for growth in how well youth felt protected by:
• Their own belief in their abilities
• Their families
• Their community

We also looked for growth in protection against suicide/alcohol risk by measuring reasons for life and reasons for sobriety
Using Rigorous Methods to Evaluate Impacts of Strengths-Based & Indigenously-Developed Interventions

- Assess youth at four time points during intervention with two baselines

Protected Factors Pathways Model for Alaska Native Youth (n=431)

Cuqyun Measurement Model
- Individual Protective Factors
- Family Protective Factors
- Community Protective Factors
- Peer Influences
- Reflective Processes about Alcohol Use
- Consequences/Reasons for Sobriety
- Reasons for Life
Ethical Considerations in Tribal Community Engagement and Health Intervention Research with Alaska Native Communities

- How the research addresses Tribal health priorities

- How deeply is community/culture engaged within a research process
  - Not all research will need/allow for intensive community engagement

- How Tribal governance structures are engaged in the research
  - Tribal Council resolutions

- Who owns the data
  - Data and Material Sharing and Ownership Agreements (DMSOA) and NIH requirements regarding public access to data and results

- Cultural and ethical considerations of rigorous research designs (e.g. RCTs) in culturally-diverse and small populations

- How results from the research is shared with the communities

- How community-driven and cultural health interventions are sustained beyond the period of research funding