Culturally-tailoring a Communication Intervention for Advance Care Planning with Alaska Native and American Indian People in Primary Care

Jennifer Shaw¹, Lisa Dirks¹, Emily Haozous², J. Randall Curtis³, Carey Candrian⁴, Jean Kutner⁴

¹Southcentral Foundation, ²University of New Mexico, ³University of Washington, ⁴University of Colorado-Denver

Funder: National Institutes of Nursing Research (R21NR016611)

65,000 Voices
Overview

- Background of a multiphase, multisite study to improve Advanced Care Planning (ACP) with Alaska Native and American Indian people with serious, life-limiting illness
- Approach, aims, activities
- Phase 1 findings
Vision
A Native Community that enjoys physical, mental, emotional and spiritual wellness

Mission
Working together with the Native Community to achieve wellness through health and related services

Alaska Native People Shaping Health Care
© 2014. Southcentral Foundation. All Rights Reserved.
Advance Care Planning (ACP)

- Lays a path for the direction of future care
- Includes—not limited to—naming a health care agent and making known one’s wishes for care (i.e. advance directive)
- Ongoing communication process, not a “one-off” conversation
ACP in AI/AN communities

- High need, low utilization
- Cultural “barriers”—reality or racist myth?
- ACP in ANAI—and all distinct communities—must be timely, appropriate, acceptable, accessible and understandable
Approach

- Community-based Participatory Research
- Mixed-methods
- 2 sites
  - >250 AI/AN tribes represented by participating tribal health organizations
First Nations Community HealthSource
- Albuquerque, New Mexico
- Federally Qualified Health Center serving 11,000 AI/AN people from >25 tribes across the Southwest

Southcentral Foundation
- Anchorage, Alaska
- Alaska Native-owned and operated health system serving 65,000 people >229 tribes across 107,000 sq. miles
# Study Aims & Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus groups</td>
<td>Tailor a communication intervention for use with AI/AN people with serious, life-limiting illness</td>
</tr>
<tr>
<td>Cognitive interviews</td>
<td>Evaluate the usability, acceptability, and relevance of the tailored intervention</td>
</tr>
<tr>
<td>Group-randomized Trial</td>
<td>Compare the tailored intervention with usual care for increasing the frequency and quality of ACP, as well as satisfaction, with ACP communication among AI/AN people with serious, life-limiting illness.</td>
</tr>
</tbody>
</table>
Group-randomized Trial

60 patients / 12 providers consent to participate in RCT; randomized to intervention or control group

Intervention Group
30 patients / 6 providers

Usual Care Group
30 patients / 6 providers

Participants in both groups complete baseline ICSI Questionnaire

Patients and providers receive individualized summaries to prompt ACP communication

Participants in both groups complete follow-up ICSI Questionnaire
What is the intervention?

Identify patient preferences for ACP communication

- Patient completes Improving Communication About Serious Illness questionnaire

Summarize individual preferences

- Responses collated into 1-page summary of individualized patient preferences

Prompt ACP communication

- Jumpstart form provided to patient and clinician
Focus Group Participants

- Collected feedback on the ACP Intervention
- 35 participants
  - 3 groups with healthcare providers/administrators
  - 3 groups with patients/caregivers
    - AIAN adults (18+yrs) with serious illness (e.g., COPD, cancer, liver disease) and/or adult caregivers of same

Gender

- Female: 46%
- Male: 54%

Age

- 40+ Years: 37%
- Under 40: 63%

Location

- Alaska: 43%
- New Mexico: 57%
Feedback on General Content

• Simplify, simplify, simplify
• Get more info from the patient
• Reframe ‘pain’ as ‘suffering’ to be more inclusive of all types of the illness experience
Feedback on Cultural Content

• Normalize the expectation for culturally relevant and appropriate information
  – “I have received culturally relevant and appropriate information about the care I could receive if I were to become very sick.”

• Provide opportunities for patient to acknowledge and share the influence of cultural influences on health behavior and decision making
  – “People in my culture do not talk about these things.”
Feedback on Cultural Content

• Reframe context of the questions from confrontational to contributory
  
  – Original questionnaire asked patients to be critical of their providers in rating quality of communication
  
  – Tailored questionnaire asks patients to be as honest as possible in rating provider communication to help improve health system and delivery of care to the community.
Cognitive Interview Findings

- 8 interviews with focus group patient participants

- Each participant completed entire questionnaire and gave feedback on 2-3 sections

- Overall, feedback very positive
  - Clear, straightforward, understandable, easy to follow

- Suggested improvements:
  - Streamline response categories
  - Revise to use fewer words
  - Include open-ended responses so feedback can be individualized

MORE
ICSI Questionnaire

Original

CHOOSING CARE

We are also interested in the kind of care you might choose at this time. The next questions are about those choices.

1. If you had to make a choice at this time, would you prefer a plan of medical care that focuses on extending your life as much as possible, even if it means having more pain and discomfort, or would you want a plan of medical care that focuses on relieving your pain and discomfort as much as possible, even if that means not living as long? (Please check one box)

☐ Extending life, even if it means having more pain and discomfort
☐ Relieving pain and discomfort as much as possible, even if that means not living as long
☐ I’m not sure which I would choose

Tailored

CHOOSING CARE

We are also interested in knowing what kind of care you might choose if you had to make a choice today. These next few questions may be difficult to answer. Please remember that these questions are only about your thoughts and feelings today about your care. These choices are not permanent. You can make different choices in the future. (Flesch-Kincaid=5.4)

1. If I had to make a choice today, I would prefer medical care that focuses on: (Please check one box)

☐ Extending my life as much as possible, even if it means having discomfort and suffering
☐ Relieving my discomfort and suffering as much as possible, even if that means not living as long
☐ I am not sure
ICSI Questionnaire

• Culture items
  – Quality of communication
    How good is your provider at talking with you about your cultural values and beliefs?

  – Barriers/facilitators to talking about ACP
    My provider respects my cultural beliefs and values.
    My provider does not understand my culture or language.

  – Role of culture in health care decisions
    Cultural beliefs and values influence my choices about health care.
Getting a Jumpstart on Talking with Your Primary Care Provider

Thank you for participating in this study. You recently filled out a questionnaire. This is a friendly reminder that you will have an appointment with your provider soon. Please take this with you to make the most of your appointment.

Here is some information from your questionnaire. These are just reminders for you. You can change your mind at any time.

We asked: Have you talked to your provider about medical care you want if you got too sick to speak for yourself?
You answered: [Yes/No]
We asked: Would you like to talk about what is important in your medical care if you got too sick to speak for yourself?
You answered: [Yes/No]
We asked: Do you prefer that your medical care is more focused on extending life, or on quality of life?
You answered: [Yes/No]
We asked: Seems focused on [Extending life/Quality of Life (relieving pain and discomfort)].
You answered: [Yes/No]
We asked: Have you thought about whether you would want CPR?
You answered: [Definitely Yes/Probably yes/Probably Not/Definitely Not want CPR]
You answered: If I was confined to bed and dependent on others, I would [Definitely Yes/Probably yes/Probably Not/Definitely Not want CPR]

We asked about your preferences for your medical care. This is what you told us.

1. You [have/have not] talked to your provider about medical care you want if you got too sick to speak for yourself.
2. You [would/would not] like to talk about what is important in your medical care if you got too sick to speak for yourself?
3. Your preference right now is for your medical care to focus more on [extending life/quality of life (reducing discomfort and suffering)].
4. You feel your medical care right now is more focused on [extending life/quality of life (reducing discomfort and suffering)].
5. In your current state of health, you [definitely would / probably would / probably would not / definitely would not / do not know if you would not].
6. If you were confined to bed and dependent on others for your care, you [definitely would / probably would / probably would not / definitely would not / do not know if you would not].
<table>
<thead>
<tr>
<th>Language</th>
<th>Translation</th>
<th>Region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qạgaasakung</td>
<td>Thank You</td>
<td>Unangan</td>
</tr>
<tr>
<td>Quyanaq</td>
<td>Quyana</td>
<td>Inupiaq</td>
</tr>
<tr>
<td>‘Awa'ahdah</td>
<td>Awa'ahdah</td>
<td>Eyak</td>
</tr>
<tr>
<td>Mahsi'</td>
<td>Gwich’in Athabascan</td>
<td></td>
</tr>
<tr>
<td>Igamsiqanaghkhalek</td>
<td>Igamsiqanaghkhalek</td>
<td>Siberian Yupik</td>
</tr>
<tr>
<td>Háw'aa</td>
<td>Háw’aa</td>
<td>Haida</td>
</tr>
<tr>
<td>Quyana</td>
<td>Quyana</td>
<td>Yup’ik</td>
</tr>
<tr>
<td>Way Dankoo</td>
<td>Way Dankoo</td>
<td>Tsimshian</td>
</tr>
<tr>
<td>Gunalchééesh</td>
<td>Gunalchééesh</td>
<td>Tlingit</td>
</tr>
<tr>
<td>Tsin'aen</td>
<td>Tsin’aen</td>
<td>Ahtna Athabascan</td>
</tr>
<tr>
<td>Quyanaaa</td>
<td>Quyanaaa</td>
<td>Alutiiq</td>
</tr>
<tr>
<td>Chin’an</td>
<td>Chin’an</td>
<td>Dena’ina Athabascan</td>
</tr>
</tbody>
</table>