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Culturally Adapting an Advance Care Planning Communication Intervention With American Indian and Alaska Native People in Primary Care

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Abstract

Introduction: Advance care planning (ACP) is a process in which patients, families, and providers discuss and plan for desired treatment goals. American Indian and Alaska Native people (AI/AN) have higher prevalence of many serious, life-limiting illnesses compared with the general population; yet AI/ANs use ACP considerably less than the overall population.

Method: We conducted a qualitative study to culturally adapt an existing ACP intervention for AI/ANs in two primary care settings.

Results: We found that it is important to incorporate patients' cultural values and priorities into ACP, determine who the patient wants involved in ACP conversations, and consider the culturally and locally relevant barriers and facilitators when developing an ACP intervention with AI/AN communities.

Discussion: At the core, ACP interventions should be clear and understandable across populations and tailored to facilitate culturally appropriate and meaningful patient–provider communication. Our results and methodology of culturally adapting an intervention may be applicable to other underrepresented populations.

Keywords

advance care planning; Alaska Native; American Indian; culturally acceptable; culturally adapt; Native American; palliative care; palliative medicine

Introduction

Advance care planning (ACP) is an important process of communication and planning for desired outcomes during a serious illness. This process involves identifying and discussing

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decisions that might need to be made during the course of a serious illness (e.g., how to address progressive respiratory failure), identifying a patient's preferences for those decisions (e.g., to receive invasive mechanical ventilation), determining how to meet these identified patient-specific needs, and communicating about those preferences, needs, and plans with family members, treatment providers, and others involved in the person's care (National Institute on Aging, 2018). Engaging in ACP is empirically associated with decreased psychological distress (e.g., anxiety, depression) for patients, increased quality of life, reductions in the use of costly end-of-life care, and decreased acuity and duration of grief for family members (Luckett et al., 2014; Meghani & Hinds, 2015; Silvester & Detering, 2011a, 2011b; Sobanski, Jaarsma, & Krajnik, 2014; Walczak, Butow, Bu, & Clayton, 2016; Walczak et al., 2015; Wright et al., 2008).

ACP could especially benefit patient populations with higher burden of serious illness and limited access to health care resources. American Indian and Alaska Native people (AI/AN), for example, generally have poorer access to care, consistently worse health outcomes, and higher prevalence of many serious illnesses compared with the general U.S. population (Indian Health Service, 2018). Yet ACP and palliative care services are used considerably less by AI/AN patients than the general population (Bush et al., 2014; Connor, Elwert, Spence, & Christakis, 2008; Cort, 2004; Karim, Bailey, & Tunna, 2000; Schim, Doorenbos, & Borse, 2006; Sharma et al., 2015). However, Marr, Neale, Wolfe, and Kitzes (2012) found that AI/ANs were just as likely as non-AI/ANs to utilize palliative care services when they were presented with the opportunity in a clear, understandable, and relevant manner.

Efforts to improve ACP must go well beyond specialty care settings, as providers in primary care commonly treat and diagnose patients with serious illnesses, and represents a setting in which patients and providers routinely develop long-term relationships (Detering et al., 2014; Hebert, Moore, & Rooney, 2011; McCormick, Chai, & Meier, 2012). Increasingly, nurses are among those providers being trained to provide ACP to patients (Christensen, Winters, Colclough, Oley, & Luparell, 2019; Epstein et al., 2019). One promising intervention for improving ACP in both specialty and primary care settings is a patient-provider communication tool developed by Curtis and colleagues at the University of Washington (Au et al., 2012). The tool uses a questionnaire, Improving Communication about Serious Illness (ICSI), to assess individual patient preferences, as well as barriers and facilitators, for communicating about life-sustaining therapy and experiences at end of life. This information is then collated into a one-page "Jumpstart" form that is provided to the patient and the provider with a summary of the patient's personal preferences for ACP, as well as suggestions tailored to these preferences about how to initiate a conversation about ACP at the next clinical appointment.

Earlier efforts to improve ACP focused on training nurses and other providers to have the knowledge, tools, and skills to initiate conversations about ACP (Lesperance et al., 2014). Curtis et al.'s (2018) intervention expanded previous efforts by providing an individualized, patient-centered tool that prepares patients and their families (or other caregivers) to initiate conversations about ACP, thereby enabling patients to participate more actively and equally in communication and decisions about their health care. A recent trial of the intervention with outpatients with diverse underlying illnesses resulted in a borderline significant

increase in the frequency of ACP conversations and significant improvement in patient-reported quality of ACP conversations (Curtis et al., 2018).

Previous studies demonstrate the importance and effectiveness of adapting interventions for cultural acceptability (Allen et al., 2006; Barrera, Castro, Strycker, & Toobert, 2013; Boyd-Ball, 2003; Hirschak et al., 2018; Lau, 2006). Cultural acceptance is defined as the extent to which a treatment is relevant and engaging among a cultural group in which the intervention has not been previously implemented (Barrera et al., 2013; Lau, 2006). Adaptations related to cultural acceptability typically involve modifying “nonactive” treatment components of the intervention: style or language or the intervention, the person delivering the intervention, or the treatment setting. Few studies have focused on AI/AN perceptions and cultural acceptability of ACP. One study found that AI/AN patients perceived health care providers as making advanced care decisions for them, while health care providers reported that patients made autonomous decisions for themselves, highlighting highly divergent cultural views of communication and decision making (Colclough & Brown, 2014). ACP ideally begins when patients are well enough to participate in ongoing discussions about anticipated prognosis and potential care trajectories (Houben, Spruit, Groenen, Wouters, & Janssen, 2014; Jones, Moss, & Harris-Kojetin, 2011; Luckett et al., 2014). Health care providers and systems, however, may not be prepared to engage AI/AN patients and families in discussions about ACP that recognize, respect, and consider important factors that affect patient preferences and priorities, including spiritual beliefs, social norms, and cultural values about autonomy, decision making, and hope (Colclough & Brown, 2014; Hampton, 2005; Kissane et al., 2012; McConnell, O’Halloran, Donnelly, & Porter, 2015; Walczak et al., 2014). Thus, development of culturally acceptable and appropriate tools that promote patient-centered ACP with AI/AN patients is important to ensure that all seriously ill patients receive optimal palliative and end-of-life care (Kissane et al., 2012; McConnell et al., 2015; Walczak et al., 2014).

In this study, we developed a culturally acceptable, patient-centered ACP intervention, referred to herein as ACP-AIAN, for use with AI/AN populations in primary care settings. This article reports on the cultural adaptation process resulting in the ACP-AIAN. The findings of our study are applicable to all health care professionals, including nurses and providers, who interact with patients with serious illness.

Method

Design

We used a mixed-method design and community-based participatory research (CBPR) approach to culturally adapt and test the ACP-AIAN in two primary care settings in two states with AI/AN adults living with serious illness. CBPR is a community-engaged approach that requires the long-term commitment and equitable involvement of researchers and community partners to address a topic of mutual interest to improve community health. CBPR has been called a “transformative research paradigm that bridges the gap between science and practice through community engagement and social action to increase health equity” (Wallerstein & Duran, 2010, p. S40) and is particularly relevant to research involving health disparities, such as palliative care research and practice in AI/AN

communities. This CBPR study originated within Southcentral Foundation (SCF), a large tribally owned health care organization in Alaska, which established an internal research department to promote self-determined research by AI/AN people and for AI/AN people. The SCF Research Department is staffed by a largely AI/AN work-force. More than 75% of the SCF Research Department staff are AI/AN. In 2016, an investigator within the SCF Research Department approached tribal health leaders to propose this study to improve primary palliative care, which they endorsed. In addition to consenting to participate in the study, AI/AN people were employed on this study from design to dissemination as principal investigators, clinical research coordinators, data analysts, research assistants, and authors. A Community and Scientific Advisory Board (CSAB) was also engaged to provide oversight of all study activities, as described below. The university and study site institutional review boards approved the study.

Community and Scientific Advisory Board

A CSAB was formed to provide input on the protocol and study procedures and guide the development of the ACP-AIAN. Members included AI/AN community members with personal or professional expertise related to palliative care and scientific experts in palliative care communication and tribal health research. Scientific advisors were consulted regularly through email or phone conference for feedback on scientific implications of proposed adaptations to the intervention based on focus group data. The community advisors, including three members from each site, met in July 2017 in Anchorage to provide input on interpretation of focus group data and feedback on proposed changes to the intervention. The community advisors met again with the study team in September 2017 to provide feedback on the next version of the revised intervention, and this feedback was used to finalize the ACP-AIAN. Community advisors represented diverse AI/AN communities from Alaska and the Southwestern United States.

Sample

Purposive sampling was used to recruit patients with serious illnesses, caregivers, primary and palliative care providers, and health care administrators to participate in focus groups. Patients and caregivers were recruited through flyers, word-of-mouth, and Facebook; we used emails to recruit providers and administrators.

- *Patient eligibility criteria:* (1) AI/AN, (2) age ≥ 18 years, (3) in the care of a primary care provider at a participating clinic, (4) seen in primary care at least twice in the previous 12 months, and (5) having a diagnosis of at least one serious, life-limiting illness as defined by International Statistical Classification of Diseases and Related Health Problems
- *Caregiver eligibility criteria:* (1) age ≥ 18 years and (2) the primary caregiver of a family member who was eligible for participation
- *Provider and administrator eligibility:* (1) a provider (MD, DO, NP, PA) or administrator or other member of an integrated primary care or palliative care team (e.g., RN, CMA, LPC) and (2) having been employed at SCF or First

Nations Community HealthSource (FNCH) for at least 1 year prior to the focus groups

Setting

This study was conducted in two AI/AN health care systems: SCF and FNCH. SCF is a tribally owned and operated nonprofit health care organization serving 65,000 AI/AN people living in Anchorage, Alaska; the Matanuska-Susitna Valley; and 55 rural villages. FNCH, the only Title V Urban Indian Health program in New Mexico, is a federally qualified health center in Albuquerque serving an urban AI population of about 12,000 from rural and urban communities across the Southwestern United States. Combined, these organizations serve people representing more than 250 federally recognized tribes, nearly half of all such tribes in the United States. In October 2015, the Alaska Native Tribal Health Consortium, of which SCF is a member and with which it shares a health campus in Anchorage, established the first palliative care program specifically designed to serve AI/AN people. The Alaska Native Tribal Health Consortium subsequently partnered with SCF to develop and pilot, in one SCF primary care clinic, a culturally adapted ACP conversation guide and advance directive form. These partners also developed online modules to train SCF primary care providers to engage patients in conversations about ACP. Our study was developed to complement these efforts by developing a culturally adapted tool designed to “jumpstart” these conversations by providing both patients *and* providers individualized information about patient preferences for ACP communication.

Focus Groups and Cognitive Interviews

There were six focus groups conducted between March and July 2017. Each focus group lasted 1 to 2 hours. Information was presented about palliative care and specifically ACP and an overview of study procedures and instruments, including the original ICSI and Jumpstart form (see Au et al., 2012, for details on original ICSI and Jumpstart). Participants were asked to provide feedback throughout the presentation and make suggestions for improving the intervention and study procedures. Specifically, participants were asked for feedback on the ICSI and Jumpstart form that would improve the tools’ capacity to collect patient preferences and priorities for ACP communication and communicate this information in writing back to patients and providers in a clear, easily understandable, and effective manner.

Following analysis of focus group data and initial cultural adaptation of the ACP intervention (ICSI questionnaire and Jumpstart form), 10 patients and caregivers who had previously participated in a focus group participated in individual cognitive interviews to assess the revised, culturally adapted ACP-AIAN. Each participant completed one section of the ACP-AIAN. Participants were then asked to provide feedback on how to improve the materials for maximal usability and acceptability. While participants each completed and gave feedback on different sections of the intervention, they were also asked to share general feedback on the instruments overall. Focus group and cognitive interview participants each received a \$50 gift card.

Analytic Approach

Audio recordings of focus groups were transcribed verbatim. Researchers uploaded transcripts into ATLAS.ti 8 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Two researchers initially independently reviewed two transcripts and then met to compare observations and identify a set of codes and code definitions. The data were then coded by the same two researchers, who regularly discussed and compared coded data manually to assess inter-rater reliability. Discrepancies in code applications were discussed until consensus was reached. Codes and code definitions were revised accordingly, and data were recoded. This iterative process was repeated until consistency between the coders in code application was achieved.

Coded data were analyzed using thematic analysis (Braun & Clarke, 2006) to identify key themes about culturally acceptable and appropriate palliative care, generally, and ACP, specifically. We decided to align themes with the domains of the ICSI questionnaire (e.g., Talking about Health care, Barriers/Facilitators, etc.). We used an iterative process for finalizing the adaptations to the ACP-AIAN. First, we shared results and suggested adaptations with the CSAB for direction and feedback. We then used the focus group data and CSAB feedback to further refine the ACP-AIAN for use in the cognitive interviews. We then reviewed interview data to generate a second, refined version of the ACP-AIAN, with consultation from the scientific advisors. Last, the ACP-AIAN was again presented to the CSAB for a final revision.

Results

Thirty-five people enrolled in the study, including 19 patients/caregivers and 16 health professionals. The sample was nearly evenly split between men and women. Two thirds of the sample were AI/AN, and about one half had a college or graduate-level degree. About half the sample was between the ages of 40 and 60 years. Table 1 provides detailed demographic information on the sample.

General feedback from focus group participants indicated that the original ICSI questionnaire and Jumpstart form should be made more understandable and easier to use by reducing reading level, removing jargon, and simplifying language (e.g., “barrier to ACP” became “what makes talking about ACP harder”). Other suggestions included adding “I don’t know” as an option on the ICSI questionnaire, using the term *provider* instead of *doctor* to be more inclusive of all types of health professionals providing primary or palliative care, and replacing the word “pain” with “suffering” to more broadly include psychological, spiritual, and physical aspects of illness experience. Few suggestions were made for adapting the Jumpstart form, and these focused on making the language clearer, removing unnecessary words, and simplifying the layout to be less visually distracting and “busy”. Table 2 summarizes overarching themes, discussed below.

Culture

The original ICSI questionnaire assessed the influence of spirituality and religion on the patient and his or her health care wishes. Focus group participants strongly endorsed adding

questions about the importance and role of culture in the patient's life and health care choices in addition to the spirituality and religion questions. Thus, we added content specifically focused on cultural beliefs and values on the questionnaire portion of the ACP-AIAN (Figure 1).

Talking About Health Care

The original ICSI questionnaire focused on ACP conversations solely between the patient and his or her doctor. Focus group participants suggested asking patients who they want involved in ACP communication in addition to their primary care provider, reflecting awareness that health care decisions are, in some contexts, considered a collective action and responsibility. Therefore, we added a question on the questionnaire portion of the ACP-AIAN to determine if the patient wanted anyone else involved in the ACP conversation with his or her primary care provider (e.g., spouse, children, behavioral health clinician).

What Makes Talking About Care Harder/Easier

The original ICSI questionnaire asked patients about "barriers" and "facilitators" to talking with providers about advance care. Focus group participants suggested removing the jargon and simply asking patients what makes talking about their care harder or easier. Focus group participants provided numerous suggestions regarding what would potentially make talking about care harder or easier for AI/AN patients, including the availability of culturally relevant and appropriate information about ACP and wanting to reduce or prevent conflict in the family regarding their care. Thus, we added several options on the questionnaire portion of the ACP-AIAN regarding what makes talking about care harder (Table 3) or easier (Table 4).

Cognitive Interviews

Participants in cognitive interviews provided overall positive feedback on the ACP-AIAN, indicating that it was clear, straightforward, understandable, and easy to follow. Participants did suggest a few improvements to the ACP-AIAN, such as to streamline response categories, revise the documents to include fewer overall words, and include open-ended responses in order to further individualize the questionnaire and allow patients to add information pertaining their ACP communication preferences not already asked on the questionnaire. We revised the ACP-AIAN in accordance with these suggestions.

Discussion

Our study provides insight into increasing the cultural acceptability and usability of a patient-centered, individualized ACP intervention for AI/AN people. We believe that the findings of our study are potentially applicable to other AI/AN communities as our study sites represented a large, diverse range of AI/AN geographic and cultural groups. Our results indicated that asking about the role of cultural beliefs and values in a person's life is a critical component of understanding individual preferences and priorities for ACP communication. In response to this finding overall, and specific data collected on the relevance of culture to ACP communication, we added a section in the ACP-AIAN on the importance of AI/AN cultural beliefs and values to the patient and how the patient perceives

these factors to influence the specific health care choices (Figure 1). Our findings also suggested the importance of asking who the patient *does* and *does not* want to be involved in their ACP conversations (e.g., spouse, children, other health care providers). We also found that a multitude of barriers (Table 3) and facilitators (Table 4) may exist for AI/AN patients when talking about health care (e.g., cultural values, spiritual and religious beliefs, past experiences with a provider) that were not captured in the original intervention developed for a general U.S. population. Last, our results indicate that ACP communication needs to be clear and understandable *to the population and individual with whom it occurs*. For AI/AN communities in this study and, we would argue most, or all communities, this means using language that is straightforward and descriptive, without jargon, and not unnecessarily “wordy”, as well as acknowledging that ACP communication is not a quick, one-time conversation, and inviting patients time to contemplate, ask questions, consult with family members, and discuss ACP at subsequent visits. We advise that our results be considered when planning and implementing palliative care interventions more generally, and specifically ACP with AI/AN communities to maximize the benefits of these interventions for patients and the likelihood that patients will initiate and engage in ACP conversations. In the next phase of this research, we will evaluate the effectiveness of the ACP-AIAN for increasing the occurrence and quality of ACP communication with AI/AN patients as well as their satisfaction with the intervention.

The methodology we employed to increase the cultural acceptability of the intervention is not limited to ACP interventions and AI/AN communities but may also be applicable to other health-related interventions and populations. We gathered feedback and suggestions from stake-holders on the intervention via qualitative focus groups and cognitive interviews, and we used these data to culturally adapt the intervention in an iterative manner, based on our findings. We included patients, caregivers (all family members), providers, and administrators as the stakeholders, since all had a common interest in high-quality, patient-centered palliative care communication. Moreover, we engaged—through a CSAB—diverse people with experience and expertise with AI/AN cultures, research with Tribal communities, health communication, and palliative care to ensure the successful development of a culturally adapted intervention for ACP. Our study reinforces the importance of culturally adapting an intervention to a target population, undertaking a CBPR approach, and involving stakeholders in every aspect of the research, as the adaptation yielded differences that our data suggest will improve the understandability, relevance, and effectiveness of intervention with AI/AN people and their providers (Barrera et al., 2013; Hirschak et al., 2018).

This study has some important limitations. Our data were collected at primary care facilities in two urban locations: Anchorage, Alaska, and Albuquerque, New Mexico. Thus, our findings may primarily be representative of urban AI/ANs. Although rural AI/ANs travel to these facilities to seek care and likely were included in our sample, we did not look at how perceptions of ACP and palliative care interventions may have differed between rural and urban AI/ANs. Rural and urban AI/ANs appear to differ in health disparities (Baldwin et al., 2002; Grossman, Krieger, Sugarman, & Forquera, 1994) and access to health care (Kulinna et al., 2017), which likely also influence ACP communication. One study found that urban AIs reported inadequate access to care and public transportation, while rural AIs reported

communication, culture, structural, physical, and supportive barriers (Itty, Hodge, & Martinez, 2014). Thus, it is plausible that a culturally acceptable ACP intervention might differ between rural and urban AI/ANs, and future research should explore this further. Another limitation to our study was that our findings were derived from a relatively small sample of patients and providers ($N = 35$) at only two institutions serving AI/AN populations, which suggests that our findings may have limited generalizability, although we mitigated this limitation by selecting sites with a broad range of tribes represented by the patient population.

In conclusion, this study demonstrates the feasibility and acceptability of culturally adapting an ACP intervention for use in and with AI/AN populations. Our findings suggest that such adaptations are critical for the success of health service interventions in diverse populations, particularly those that rely on a shared understanding of patient, family, and/or community-based values, priorities, and goals. In addition, our results may inform policymakers and public health officials who are interested in ACP with AI/AN populations across the United States. Nurses often spend the most time with patients compared with other health care providers, and increasingly, nurses are being trained to provide ACP to patients and their families (Christensen et al., 2019; Epstein et al., 2019). Therefore, there is increasing evidence that it is beneficial for health care systems to educate and empower nurses in discussing end-of-life care with AI/AN people and other underrepresented groups, so that they can initiate such discussions and advocate for these growing patient populations. The next phase of our research will examine the effectiveness of this culturally adapted ACP intervention with AI/AN communities. We encourage researchers to use similar, stakeholder-engaged, community-based and participatory, qualitative methodology to culturally adapt interventions with specific patient populations, especially those that are underrepresented in research, for the purpose of increasing access to acceptable, inclusive, and effective palliative care services.

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CULTURE

These questions ask about cultural beliefs and values. Cultural beliefs and values have also been found to affect the choices people make about their health care. We have included these questions to understand how culture may affect your health care choices. If any of these do not apply to you, please check the “Does not apply to me” box. (Flesch Kincaid=7.7)

1. Cultural beliefs and values play an important role in my life. (Please check one box)

- 0 ☐ Definitely *not* true
- 1 ☐ Mostly *not* to be true
- 2 ☐ Unsure
- 3 ☐ Mostly true
- 4 ☐ Definitely true

2. Cultural beliefs and values influence my choices about health care. (Please check one box)

- 0 ☐ Definitely *not* true
- 1 ☐ Mostly *not* to be true
- 2 ☐ Unsure
- 3 ☐ Mostly true
- 4 ☐ Definitely true

3. My provider respects my cultural beliefs and values. (Please check one box)

- 0 ☐ Definitely *not* true
- 1 ☐ Mostly *not* to be true
- 2 ☐ Unsure
- 3 ☐ Mostly true
- 4 ☐ Definitely true

Figure 1.

The “Culture” section that was added on the questionnaire portion of the revised, culturally adapted ACP-AIAN (advance care planning intervention for American Indian and Alaska Native people), based on findings from focus groups and cognitive interviews at Southcentral Foundation (SCF) in Anchorage, Alaska, and First Nations Community HealthSource (FNCH) in Albuquerque, New Mexico.

Table 1. Demographic and Site Information for Focus Group Participants Conducted From March 2017 to August 2017 at Southcentral Foundation (SCF) in Anchorage, Alaska, and First Nations Community HealthSource (FNCH) in Albuquerque, New Mexico.

Characteristic	SCF (N = 20), n (%)	FNCH (N = 15), n (%)	Total (N = 35), n (%)
Role			
Provider/administrator	10 (29)	6 (17)	16 (46)
Patient	10 (29)	9 (26)	19 (54)
Gender			
Male	11 (31)	5 (14)	16 (46)
Female	9 (26)	10 (29)	19 (54)
Race			
AI/AN	14 (40)	9 (26)	23 (66)
Non-AI/AN	4 (11)	6 (17)	10 (29)
Unknown	2 (6)	0 (0)	2 (6)
Education			
Less than high school	0 (0)	1 (3)	1 (3)
High school graduate	2 (6)	2 (6)	4 (11)
Some college	5 (14)	7 (20)	12 (34)
Bachelor's	7 (20)	0 (0)	7 (20)
Master's	2 (6)	2 (6)	4 (11)
PhD	4 (11)	3 (9)	7 (20)
Age (years)			
18–39	9 (26)	2 (6)	11 (31)
40–59	8 (23)	10 (29)	18 (51)
60–79	3 (9)	3 (9)	6 (17)

Note. AI/AN = American Indian and Alaska Native.

Table 2.

Key Themes and Subthemes From Focus Groups to Adapt an Advance Care Planning (ACP) Communication Intervention for Use with American Indian and Alaska Native People.

Theme/subtheme	Example quote
Culture/role in ACP communication	"Can you add maybe like a suggestion, of adding the word culture, I know you have the religious and spirituality but maybe putting cultural beliefs, I think some people might register that more."
Talking about health care/identifying key people	"Sometimes it's the CMA that's taking your blood pressure that has a better rapport with the patient, than the care provider ... it doesn't necessarily have to be the person that had the "MD" behind their name, or their BSN. It's really [about] who's the person that best can speak with the patient, because they're part of the team, too."
What makes talking about care harder or easier/providerinitiated communication	"... when you're scared about something and you don't really want to talk about it, you're going to avoid if ... And if your provider doesn't bring it up, then you're gonna get out of that appointment and think, "Whew, I didn't have to touch that, this time."

Table 3.

The “What Makes Talking About Care Harder” Section of the Revised, Culturally Adapted ACP-AIAN.

What makes talking about care harder?	
1	I don't know what kind of care I would want if I got very sick.
2	I'm not ready to talk about the care I would want if I got very sick.
3	I don't like to talk about getting very sick.
4	My provider never has time to talk about what would happen if I got very sick.
5	I would rather concentrate on staying alive than talk about this.
6	Talking about things like death or dying can bring them closer.
7	I have a living will, and that means I don't need to talk with my provider about the care I would want if I were too sick to speak for myself.
8	My ideas about the kind of medical care I want change at different times.
9	I have not been sick enough to talk with my provider about the care I would want if I got very sick.
10	I'm not sure which provider would be taking care of me if I got very sick.
11	<i>There is not a trustworthy person who could make health decisions for me.</i>
12	<i>I cannot talk about this due to my spiritual or religious beliefs.</i>
13	<i>I do not think that my wishes would be followed at home.</i>
14	<i>I have other priorities in my life that I need to focus on right now.</i>
15	<i>I never have an opportunity to speak with my primary care provider alone.</i>
16	<i>It is difficult to talk with my provider about this.</i>
17	<i>I would rather talk with someone other than my primary care provider.</i>
18	<i>My provider does not understand my culture or language.</i>
19	<i>My primary care provider does not talk with my other health care providers.</i>

Note. ACP-AIAN = advance care planning intervention for American Indian and Alaska Native people. The added responses on the ACP-AIAN are in italics.

Table 4.
The “What Makes Talking About Care Easier” Section of the Revised, Culturally Adapted ACP-AIAN.

What makes talking about care easier?	
1	I have had the experience of being very sick so it is easier to talk about.
2	I have had family or friends who were unable to participate in decisions about their care, and that makes it easier for me to talk about.
3	I want to have the best quality of life I can in the future if I become very sick.
4	I do not want to be a burden on my friends and family if I become very sick.
5	<i>A health care provider other than my primary care provider has discussed this with me, and that makes it easier to talk about.</i>
6	<i>I know what I want if I were to become very sick and I want my wishes to be followed.</i>
7	<i>I want my friends and family to know what I want if I got too sick and cannot speak for myself.</i>
8	<i>I do not want my family to be in conflict about my care if I become very sick and cannot speak for myself.</i>
9	<i>I have received culturally relevant and appropriate information about the care I could receive if I were to become very sick.</i>

Note. ACP-AIAN = advance care planning intervention for American Indian and Alaska Native people. The added responses on the ACP-AIAN are in italics.