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Found in translation: decoding local understandings of genetics and heredity in a Yup'ik Eskimo community

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Abstract

The Center for Alaska Native Health Research is a community-based participatory research center that conducts studies involving genetic research with Yup'ik Eskimo community members in Southwest Alaska, where Yup'ik remains the first language for most residents. Cultural equivalents are needed to communicate results of these studies among all partners and members of the participating communities, since many scientific terms have no direct translation in Yup'ik. To inform that effort, we examined local understandings of genetics and heredity in one community. Here, we report results from back-translated Yup'ik interviews, and identify working genetic concepts shared by participants from interviews and focus groups. We suggest issues involved in, and some potential steps toward, developing a concise, scientifically accurate and culturally relevant term for “genetics” and other health concepts.

Keywords

back-translation; Center for Alaska Native Health Research; community-based participatory research; genetic concepts; public understanding of science; science communication; Yup'ik Eskimo

1. Introduction

The Center for Alaska Native Health Research (CANHR) was initiated with a focus on identifying protective and risk factors for obesity and related diseases in rural Yup'ik Eskimo communities (Boyer et al., 2005). The program includes a multi-disciplinary, longitudinal community-based participatory research (CBPR) partnershipⁱ with the Yukon-Kuskokwim Health Corporation (YKHC) and rural communities in the Yukon-Kuskokwim (YK) Delta of Alaska. In addition to assessments of body composition and dietary intake, investigators have begun to identify genetic factors associated with obesity phenotypes. Investigators and community partners have developed culturally meaningful strategies for disseminating clinically actionable research results (e.g., blood pressure, glucose levels), but have not reported back genetic findings (Boyer et al., 2007). Disseminating such data is problematic, given its technical nature, and lack of clinical utility. However, as a partnership, we must consider how such research might be meaningfully communicated. To do this, university investigators must understand the cultural context regarding genetics in the communities. Moreover, partners should discuss ethics surrounding dissemination of genetic information so as to make informed decisions about the types of information that should be returned, in what format, and to whom. Effective communication lies at the heart of this collaboration.

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ⁱFor an explanation of CBPR, see Minkler and Wallerstein (2003).

As is true for the reverse, no directly equivalent terms exist for many English scientific words, such as “genetics” and “health” in the Central Yup'ik language (Jacobson, 1984). However, culturally equivalent descriptions, which can vary by generation and local dialect, are available. Twinn (1997) examined how qualitative data can be impacted by the translation process when no direct equivalents are available; she recommends an ethnographic approach to minimize such distortions. Shaw and Ahmed (2004) discuss challenges and options available to explain specific genetic concepts to others whose first language is not English. They recommend using English for critical scientific terms (“genes,” “chromosomes”), but including a lay language description when initially used. Back-translation, pilot testing, one-on-one communication, and use of written materials provide additional means for enhancing accuracy and minimizing misunderstanding.

In the present study, we address the challenge of devising scientifically accurate, culturally appropriate explanations of technical terms by exploring local knowledge of genetics and heredity. During this brief ethnographic effort, we discovered that investigators can learn much from examining the transfer of information that occurs during translation between Yup'ik and English speakers. In this manuscript, we make innovative use of back-translations to explore equivalents of genetic concepts used by Yup'ik community members.

2. Methods

Study

This study was conducted in one small, rural Yup'ik Eskimo community, not identified as per our confidentiality agreement. After securing approvals from the University of Alaska Institutional Review Board, YKHC Human Studies Committee, and the local community's governing council, we conducted interviews, focus groups and participant observation. Participants were recruited during a community-wide presentation, enrolling a sample that nearly represented the age range of participants in the CANHR study, using convenience and purposive sampling methods. We concluded the study with a visit to conduct member checks (Emerson and Pollner, 1988) and report back to the community leaders.ⁱⁱ

The sample included seven Yup'ik-only speakers, with whom interviews were conducted through two local interpreter/translators (research assistants who, while not professionally trained, had prior experience interpreting for CANHR studies), and eight bilingual residents, with whom interviews were conducted in English. The two focus groups included eleven participants, and all but one spoke English. One local interpreter/translator was employed to concurrently interpret for the Yup'ik speaker, although other participants also offered interpretations of the Yup'ik speaker's stories.

Prior research (Mohatt et al., 2004), distinguished three age groups differentiated by linguistic usage and community status: elders (over 55), middle adults (30–55), and younger adults (18–29). Elders generally speak only Yup'ik; an older, richer version of the language as compared with the language spoken by younger generations. Middle adults speak both Yup'ik and English, recognize many linguistic differences among age groups, and are thus the community's most competent interpreter/translators. Younger adults are also bilingual, having learned a leaner version of Yup'ik at home, then English at school and through media. Informants in all age groups agree that linguistic differences contribute to impaired communication across the generations.

ⁱⁱSeveral authors on this paper had spent significant time building relationships in this community. The student, KW, was introduced after many years of prior collaboration within the partnership.

Procedures

Interviews lasted an average of 45 minutes and were recorded and later transcribed into English by a third CANHR interpreter/translator. The Yup'ik interviews with elders were conducted in their homes, surrounded by family members, television and other distractions. Six of seven elders preferred to be interviewed in pairs. All English interviews were conducted individually, in a school office. Focus groups were conducted in a public meeting room, audio recorded, and lasted 1.5 and 2 hours, while a cofacilitator took concurrent notes on a laptop. Demographic information was collected from participants, and rapport was established before turning to health and genetic topics.

Differences in interview settings can confound both collection and interpretation of qualitative data (Briggs, 1986). While interviewing participants in their homes could present concerns regarding confidentiality, elder participants preferred to share their knowledge in the familiar setting, surrounded by their families. Moreover, familiarity could be established prior to conducting the interview by visiting with them informally, learning through participating in daily activities and sharing meals. This contrasts with the younger participants' scheduled interviews, which ensured privacy, but might have hindered the flow of conversation. These differences should be considered in evaluating responses.

Analysis

Atlas.ti software was used to conduct a modified grounded theory analysis of all transcripts (Charmaz, 2007). These data were further contextualized both through direct participant observation and by consulting relevant ethnographies and literature (Fienup-Riordan, 1994, 2005; Kawagley, 2006; Morrow, 1987; Napoleon, 1996); together, this revealed ways of discussing genetics in Yup'ik and in local dialects of English, and of embedding genetics/heredity within the local knowledge system. Four formal member-check interviews were conducted with one elected leader, and past CANHR research assistants. All were bilingual, between 30 and 55 years old, and filled roles as interpreter/translators for the community. These interviews addressed the investigators' interpretations of the findings, and invited collaborative refinement of the ethnographic account.

Reporting back to the community

During the return visit, available participants reviewed a copy of their interview transcripts and summary page with key findings. Focus group participants were invited to review the transcript from the group in which they participated. The findings were then presented to the leadership council representing the local community for comment and approval.

Limitations to data collection include the short time available (as a Master's thesis) and restriction to a single community that may not represent the entire region. Given time and budgetary constraints, embedding the study in one community seemed appropriate and helped lay the groundwork for future research.

3. Findings

Back-translation as data

In our study, belated attention to unrehearsed back-translations enabled us to document the process of cultural transcription in action. It was the routine back-translation of the Yup'ik interview recordings into English transcripts for analysis that alerted us to traditional understandings of “health,” “disease” and “genetics” (see Table 1). Methodologically, back-translation is the preferred technique for validating the semantic/cultural equivalence of items, instruments and measures used in cross-cultural research (Brislin, 1970; Flaherty et al., 1988; Maneesriwongul and Dixon, 2004). Critical discussions of back-translation have

addressed the use of this method for validating translation of qualitative research tools such as interview guides, and described particular issues that differ from those of quantitative questionnaires (Lopez et al., 2008; Twinn, 1997). Other studies recommend accounting for the translator's perspective and influence on the data, which is inherent in the process of translation, to enhance the validity of transcripts (Freed, 1988; Temple, 1997; Hsin-Chun Tsai et al., 2004). We suggest that if carefully monitored and treated as unobtrusive data collection techniques in their own right, back-translations can alert researchers to how scientific concepts are conceptualized within a Yup'ik cultural context, avoiding potential "working misunderstandings" (Bohannon, 1995) of shared terms, and increasing mutual understanding of technical concepts.

To illustrate, "genetics" was explained by one interpreter as: "Some diseases are passed down through our blood from generation to generation." Another explained the concept as: "You know how people who are related get diseases (like cancer) that are similar," (Table 1). Both interpretations link heredity explicitly and narrowly to disease risk. The first identifies blood as the mechanism of transmission, though whether this is meant literally or figuratively is unclear; both usages are common in Yup'ik contexts. The second uses shared disease vulnerability to illustrate what is passed on within families.

The challenge of translating scientific concepts was illustrated during the thesis approval process, in which KW presented her work to the YKHC Human Studies Committee (HSC).ⁱⁱⁱ Concerns were raised regarding investigator use of the scientifically inaccurate (but Yup'ik adviser approved) phrase, "things that are passed down in families through the blood." Community members typically expect scientists and physicians to provide scientifically accurate information in precise terms (HSC member, 2009, personal communication). However, our participants expressed concern that they do not generally have the background needed to understand scientific terms. In order to provide accurate explanations that also translate into Yup'ik, the concerned HSC member suggested discussing the ideas using locally understood, traditional concepts (perhaps drawing from back-translations), then integrating scientific terms into these conversations.

Perceptions of Genetics

Responding to questions regarding *how* diseases are passed through families, elders cited relevant knowledge from their ancestors' teachings in the form of memorable adages designed to provide a basis for evaluating a situation (compare Fienup-Riordan, 2005). Some indicated that children often have their parents' diseases because diseases are passed "through the blood." Other teachings, found both in conversation with residents and in ethnographic literature, regulate marriage in ways that indicate indigenous understandings of genetics. Marrying one's parallel first cousin is prohibited, because unions of close relatives would produce "children that do not function normally" (Fienup-Riordan, 2005: page 160). Elders expressed confidence in their traditional knowledge of heredity.

In striking contrast to the elders' responses, younger study participants protested that they *didn't* know about genetics, (perhaps interpreting the interview question as a test), or that they understood only that some diseases and personal traits can be passed from parents to children. One middle generation man explained that his genetics education in school didn't resonate: "I took that. Even if I learned it, it didn't really sink in." He explained that as an adult, his elders' teachings made more sense, as he integrated what he had learned from his elders into his intuitive understanding of the world. Heredity information was reported to

ⁱⁱⁱThe HSC is comprised of YKHC staff as well as representatives from communities in the region. They all received a full text copy of the thesis to review prior to the meeting.

circulate in the community through school, media, and healthcare providers/researchers, but no one expressed confidence that they could explain what is meant by “genetics” beyond stating terms such as “DNA” and “molecules.” (These observed differences in confidence are further described in the Discussion section.)

Familial connections—Many participants gave examples of familial connections in response to interview questions regarding genetics. One elder man explained that if a parent has a disease, then the child will have it too, because the child “ate from the mother's body and shares her blood.” One elder interviewed with her sister reported: “She always mentions what I've been thinking [without my saying it], because we're blood;” a non-disease example of familial connection. Both sisters expressed belief that while diseases are passed through families, the blood changes and thus diseases weaken from generation to generation. The fact that families share diseases was asserted by participants of all ages; however, specific mechanisms for this were unclear.^{iv}

Ethnographic literature reveals additional complexities of kinship in Yup'ik society that could confound understandings of heredity. For example, adoption is commonplace and thus recognized kinship does not always imply biological relationship (Fienup-Riordan, 2005). Additionally, some personal traits are said to be “inherited” from the deceased person after whom one is named, a cultural concept at odds with conventional biomedical notions of heredity (Napoleon, 1996; Morrow, 1987).

Warning against prediction of diseases—The belief that “people get what they anticipate” is widespread; elders and young people alike cautioned against using family history to predict future disease risk. For some, it generates needless worry. Several elders said it was better to maintain a positive attitude and ignore illness, instead of increasing one's chance of actually becoming sick by fretting. Traditionally, there is no clean division between the spiritual and physical, and the mind is a powerful force requiring close attention to consequences that may derive from one's thoughts and feelings (Kawagley, 2006; Napoleon, 1996; Fienup-Riordan, 1994). Attitude can both hasten progress of an illness to which one “submits” or “invites” and otherwise, ward off ailments through force of will (Fienup-Riordan, 2005: page 52). As conveyed through our interview transcripts, health is seen as the holistic concept of “living a good life,” adhering to ancestral teachings, and maintaining a balance between mind, body and soul, and in the world at large (Wolsko et al., 2006; Napoleon, 1996; Kawagley, 2006). Thus, heredity captures only a minor, mechanical part of disease determination.

Many younger participants also affirmed that observations of disease are appropriately used in an explanatory, not predictive manner for reasons articulated by elders: to speak of future risk is, essentially, to tempt fate. But several younger participants did express interest in learning whether a disease in their family was genetic, and, further, whether anything could be done to reduce their risk, a concept rooted in medical science.

Outside, not inside of the body—Younger participants explained that it is more acceptable to discuss hereditary traits for body parts that are visible from the outside than those not in view. People freely discuss appearance (e.g., facial features or height), gait, manner of laughing, or male pattern baldness, in families. Differences in visible traits among

^{iv}The formulation of “things that are passed through the blood from parents to children” can house real misunderstandings of the genetic basis of disease. One young man offered an example: “Parents who have HIV or AIDS will pass it on to their daughters or sons.” An elder male also offered tuberculosis as such an example, as indeed it might appear to be, if the sick person has contact only with his or her family members. Such confusions highlight the need to clarify the differences between infectious and genetic mechanisms in discussions of hereditary traits, especially if using the “through the blood” descriptor.

siblings might be explained by noting how one child was raised differently than the others. For example, a woman whose son was much taller than his siblings said, “it was probably because of feeding him evaporated milk instead of breast milk.” But talking and joking about diseases or what is on the “inside of the body” are considered inappropriate.

Parentage—As shown above, environmental factors might be invoked as a normative alternative to confronting other reasons for differences among siblings, namely adoption or undisclosed paternity. Indeed, discussions of heredity are inherently intrusive, and great care must be taken in broaching such questions. Younger participants offered that genetic questions might be seen as sensitive, especially to their elders. As one middle generation female pointed out, referencing the example of siblings with disparate heights, “it might be that they have different fathers...it's a disrespectful question.” Sometimes, another woman explained, “our elders get offended by the questions that you want to know, because that wouldn't be a proper question for me to ask them.” Complex proscriptions regarding tabooed practices and speech meant to maintain social balance and community peace have been described in ethnographic literature (Fienup-Riordan, 2005), but descriptions have not previously been extended to the hidden world of genetics.

A leader's perspective—A prominent leader has said, “If we integrate the teachings of the [Yup'ik people] and the [non-natives], our knowledge will be greater” (Fienup-Riordan, 2005: page 236). An instance of such melding may be seen as a prominent elder in our study related an idea he had learned from the *kass'at* (non-natives):^v “We don't all have the same blood. Since a couple's children have the same blood, they can inherit their parents' disease, through the blood.” His statement neatly blends knowledge sources, traditional and Western concepts; this, in turn, might be a result of his more extensive experience working with researchers and receiving related training. If the hybrid form is passed on, it may become part of the knowledge that is transmitted through the generations as commonly held beliefs. It is to that process that the CANHR research has, wittingly or not, become an active party.

Science is not at odds with religion—Religion (locally, Catholicism) represents an important health influence to many participants. Traditional beliefs endorse a spiritual cause to all physical effects including health (Napoleon, 1996). Thus, it was not unexpected to hear discussions of God, spirit and religion in our interviews. One elder woman explained in reference to disease, “God has given us our life that is already preplanned.” Yup'ik consultants for the project, however, denied that scientific research would be an affront to the idea of God's role in planning lives; local people, they assured us, recognize differences between the influences of science and religion. In this community, fears that discussing genetics might pose a threat to religious beliefs, previously expressed in nearby communities holding different religious orientations, proved unsubstantiated.

4. Discussion

In addition to interview setting (discussed in the Methods section), language and age contributed to differences in types of responses elicited. Younger participants who spoke English with an investigator were more familiar with research, but appeared somewhat uncomfortable with the locally uncommon question-answer format, and their role as interviewee. Their responses tended to be short, direct, often including a statement of uncertainty, as they expressed, they do not have the knowledge and experience to claim expertise. This contrasts with the elders' certainty of their answers, which were given in

^vThis participant had attended the Genetics Education for Native Americans workshop, provided for community leaders by Dr. Linda Burhansstipanov in 2002.

longer, story-format responses. Also, a Yup'ik speaker asked the elders questions, whereas the non-Yup'ik investigator interviewed the younger participants. Different participants may have had different interpretations of what information was sought, based on the interviewer's background.

Contemporary anthropological admonitions about divisions within indigenous cultures are worth considering. Different age-groups embody the same culture differently (O'Neil, 1984); this was clear in our attempts to discuss genetics with Yup'ik Eskimo participants. Younger generations access genetic information through school, media, and healthcare providers/researchers, but also learn teachings from their elders. The ways in which they discussed genetics reflect both Western and traditional understandings, expressed in contemporary terms. Elders generally do not have formal genetic education, and have limited exposure to the scientific terminology (with few exceptions), and thus speak from – while improvising upon – a traditional point of view. The leader elder who received genetic research education demonstrated a hybrid understanding as well. His responses alert researchers to the undoubted existence of other diversity within the community in terms of their exposure to and interpretations of heredity and genetics.

In addition to these indigenous divisions, visiting researchers constitute a fourth language-use group. Not only do they use terms unfamiliar to many local residents, for which no Yup'ik equivalent exists, but they also speak a different dialect of English. Dialect differences can be subtle, easily missed, and lead to 'working misunderstandings' (that is, the mistaken impression on the part of all involved that a common understanding prevails). Thus, opportunities for miscommunication in community-based participatory research abound. In our study, we aimed to extract themes from the interviews to help us understand potential pitfalls and directions for moving forward toward improved genetic research communication within our partnership.

Lessons Derived

Our findings suggest that concepts of genetics and heredity are, indeed, discussed within the community, even if strictly comparable terms do not exist in the Yup'ik language. The scientific questions that genetics researchers frame and investigate have counterparts in the daily life of Yup'ik culture, upon which common understanding might be built. Most elders still hold largely traditional understandings, while leaders and younger participants shared a more hybridized knowledge of Western terms. Initial insight into Yup'ik understandings of genetics can be gleaned by examining the ways in which bilingual residents translate genetic concepts into Yup'ik. Back-translation has been used in cross-cultural research for decades, but little has been written about its practical utility in cuing researchers to ongoing processes of syncretism and assimilation.

The present-day nuanced ways in which Yup'ik Eskimos discuss hereditary traits as explanatory and not predictive could have important implications for how researchers share genetic information with communities. Researchers often couch the benefits of genetic research in predictive terms (i.e. managing individuals' risk). Discussions of genetics should be carefully crafted to ensure that they are not construed as inviting misfortune. Likewise, taboo or sensitive subjects raise additional concerns, such as the potential for discussions around genetics to be interpreted as disrespectful (talking about the inside of the body and inadvertently suggesting alternative parentage).

Limitations

In addition to typical biases involved in inter-personal communications, speaking through an interpreter dramatically increases the potential for miscommunication. In addition to the two

field interpreter/translators conducting interviews, a third translator, a CANHR team member no longer living in the region, translated and transcribed the interviews directly to English. While the latter interpreter/translator has formal Yup'ik training and is a professional interpreter/translator for CANHR, the two who interpreted the live interviews were not formally trained. Employing more than one interpreter/translator might be considered problematic as doing so decreases uniformity of interview questions (Temple and Edwards, 2002; Twinn, 1997). In our case, multiple interpreter/translators resulted in a wider variety of interpretations for health terms that don't have direct equivalents, and thus provided us with a deeper understanding of local concepts upon back-translation. In addition, employing interpreter/translators who are highly familiar with all of the participants might have limited the freedom of responses, due to diminished confidentiality. Conversely, we believe that this familiarity, enabled by working with non-professionals, helped elders to speak confidently, as their knowledge is valued locally.

Future Directions

One of our key (although unsurprising) findings is that dissemination of genetic information likely requires not only transliteration of terms, but also relocation of concepts in a proper cultural context (compare Twinn, 1997). In the late 1980s, a team of representatives from YK Delta communities developed Yup'ik equivalents of medical and legal English terms, and compiled a translator's handbook, *Mumigcistet Kalikait*, of Yup'ik descriptions, approximating English terms (Alexie et al., 1990). Linguist Steven Jacobson suggests that many of these Yup'ik terms would probably not elicit the English terms they are meant to represent if back-translated. For example, the created word for "hereditary" is *kinguvatuluni*, but the term back-translates roughly as "continue after you" (Steven Jacobson, 2009, personal communication). Additionally, Jacobson explained, terms that even local people derive often don't attain common use, so the average person might not recognize the scientific meaning of the word. Therefore, additional methods for enhancing communication of scientific terms are needed.

We have only begun to approach the establishment of scientifically accurate, culturally acceptable means for discussing "genetics" and other health concepts. We suggest drawing on the collective translation experiences of local interpreter/translators and community representatives in back-translating individual scripts used in the research process. For example, community research assistants, local health care providers, and educators might provide valuable insight as to how they discuss genetics with Yup'ik community members. Collectively, we might work together and advance previous approaches to develop this language, supplemented by anthropological methods. The goal is an appropriate blend of scientific accuracy and traditional accuracy, particularly for the generation(s) for whom Western science is a foreign encounter. As suggested by the HSC member, starting conversations with locally understood, traditional concepts, (that we might gather through the back-translations,) then integrating the English scientific concepts, may improve community understanding of scientific terms.

Continuing to develop an understanding of how community members converse with each other across age/linguistic groups, and how hybridized understandings take shape, might also provide the partnership with better quality data and an increased ability to conduct relevant, community-beneficial research and dissemination activities. The community's capacity to participate more actively in the research partnership would be strengthened as their hybridized understandings of scientific concepts develop, the researchers' comprehension of the community's perspectives improves, and they are better able to situate genetic information within the community's cultural context. This "co-learning process" exemplifies key principles of CBPR (Israel, 2003: page 56). We hope our findings can be used to develop a culturally relevant, scientifically appropriate and concise explanation of

genetics that will provide a basis for mutually understanding dissemination efforts within the communities. This process of community consultation on translation of scientific terms may have broader application to include research findings from this and other health studies in culturally distinct populations.

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References

- Alexie, O.; Barnes, S.; Domnick, G. Mumigcistet Kalikait. Yup'ik Language Center, University of Alaska Fairbanks; Bethel, Alaska: 1990.
- Bohannon, P. *How Culture Works*. The Free Press; New York: 1995.
- Boyer BB, Mohatt GV, Lardon C, Plaetke R, Luick BR, Hutchinson SH, de Mayolo GA, Ruppert E, Bersamin A. Building a Community-Based Participatory Research Center to Investigate Obesity and Diabetes in Alaska Natives. *International Journal of Circumpolar Health*. 2005; 64(3):281–90. [PubMed: 16050322]
- Boyer BB, Mohatt GV, Pasker RL, Drew EM, McGlone KK. Sharing Results from Complex Disease Genetics Studies: A community-Based Participatory Research Approach. *International Journal of Circumpolar Health*. 2007; 66(1):19–30. [PubMed: 17451131]
- Briggs, CL. *Learning How to Ask: a Sociolinguistic Appraisal of the Role of the Interview in Social Science Research*. Cambridge University Press; Cambridge: 1986. Interview Techniques Vis-à-Vis Native Metacommunicative Repertoires; or, On the Analysis of Communicative Blunders; p. 39-60.
- Brislin RW. Back-Translation for Cross-Cultural Research. *Journal of Cross-Cultural Psychology*. 1970; 1(3):185–216.
- Charmaz, K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Sage Publications; Thousand Oaks, CA: 2007.
- Emerson RM, Pollner M. On the Use of Members' Responses to Researchers' Accounts. *Human Organization*. 1988; 47(3):189–98.
- Fienup-Riordan, A. *Boundaries and Passages: Rule and Ritual in Yup'ik Eskimo Oral Tradition (The Civilization of the American Indian, Vol. 212)*. University of Oklahoma Press; Norman, OK: 1994.
- Fienup-Riordan, A. *Wise Words of the Yup'ik People: We Talk to You Because We Love You*. University of Nebraska Press; Lincoln, NE: 2005.
- Flaherty JA, Gavilia M, Pathak D, Mitchell T, Wintrob R, Richman JA, Birz S. Developing Instruments for Cross-cultural Psychiatric Research. *Journal of Nervous and Mental Disease*. 1988; 176(5):257–63. [PubMed: 3367140]
- Freed AO. Interviewing Through an Interpreter. *Social Work*. 1988; 33(4):315–19.
- Hsin-Chun Tsai J, Choe JH, Mu Chen Lim J, Acorda E, Chan NL, Taylor V, Tu Shin-Ping. Developing Culturally Competent Health Knowledge: Issues of Data Analysis of Cross-Cultural, Cross-Language Qualitative Research. *International Journal of Qualitative Methods*. 2004; 3(4): 16–27.
- Israel, BA.; Schulz, J.; Parker, EA.; Becker, AB.; Allen, AJ.; Guzman, JR. Critical Issues in Developing and Following Community Based Participatory Research Principles. In: Minkler, M.; Wallerstein, N., editors. *Community Based Participatory Research for Health*. Jossey-Bass; San Francisco: 2003. p. 53-76.

- Jacobson, SA. Yup'ik Eskimo Dictionary. Alaska Native Language Center, University of Alaska; Fairbanks: 1984.
- Kawagley, AO. A Yupiaq Worldview. 2nd ed.. Waveland Press, Inc.; Long Grove, IL: 2006.
- Lopez GI, Figueroa M, Connor SE, Malinski SL. Translation Barriers in Conducting Qualitative Research With Spanish Speakers. *Qualitative Health Research*. 2008; 18(12):1729–37. [PubMed: 19008363]
- Maneesriwongul W, Dixon JK. Instrument Translation Process: A Methods Review. *Journal of Advanced Nursing*. 2004; 48(2):175–186. [PubMed: 15369498]
- Minkler, M.; Wallerstein, N., editors. *Community-Based Participatory Research for Health*. Jossey-Bass; San Francisco: 2003.
- Mohatt GV, Rasmus SM, Thomas L, Allen J, Hazel K, Hensel C. Tied Together Like a Woven Hat: Protective Pathways to Alaska Native Sobriety. *Harm Reduction Journal*. 2004; 1(10) doi: 10.1186/1477-7517-1-10.
- Morrow, P. Making the Best of Two Worlds: An Anthropological Approach to the Development of Bilingual Education Materials in Southwestern Alaska, Doctoral Dissertation. Cornell University; 1987.
- O'Neil, JD. Is it Cool to be an Eskimo?: A Study of Stress, Identity, Coping, and Health Among Canadian Inuit Young Adult Men, Doctoral Dissertation. University of California; San Francisco: 1984.
- Napoleon, H. Yuuyaraq: The Way of the Human Being. Madsen, E., editor. Alaska Native Knowledge Network; Fairbanks: 1996.
- Shaw A, Ahmed M. Translating Genetics Leaflets Into Languages Other Than English: Lessons From an Assessment of Urdu Materials. *Journal of Genetic Counseling*. 2004; 13(4):321–42. [PubMed: 19736697]
- Temple B. Watch Your Tongue: Issues in Translation and Cross-Cultural Research. *Sociology*. 1997; 31(3):607–18.
- Temple B, Edwards R. Interpreters/Translators and Cross-Language Research: Reflexivity and Border Crossings. *International Journal of Qualitative Methods*. 2002; 1(2):1–12.
- Twinn S. An Exploratory Study Examining the Influence of Translation on the Validity and Reliability of Qualitative Data in Nursing Research. *Journal of Advanced Nursing*. 1997; 26(2):418–23. [PubMed: 9292378]
- Wolsko C, Lardon C, Hopkins S, Ruppert E. Conceptions of Wellness Among the Yup'ik of the Yukon-Kuskokwim Delta: The Vitality of Social and Natural Connection. *Ethnicity and Health*. 2006; 11(4):345–63. [PubMed: 17060033]

Table 1

Yup'ik phrases to describe English terms.

English Term	Yup'ik Translations
To be healthy	To have a strong mind, strong body, blood, no illness ["toward our body"];
	To have a good life, follow the right path, live righteously, stay out of trouble
	Something that would ruin our bodies;
Diseases	Something that gets into their system
Genetics	Some diseases that are passed down through our blood from generation to generation;
	You know how people who are related get diseases (like cancer) that are similar