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Value of Community Partnership for Understanding Stress and Coping in Rural Yup’ik Communities: The CANHR Study

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ABSTRACT

Stress and trauma can compromise physical and mental health. Rural Alaska Native communities have voiced concern about stressful and traumatic events and their effects on health. The goal of the Yup’ik Experiences of Stress and Coping Project is to develop an in-depth understanding of experiences of stress and ways of coping in Yup’ik communities. The long-range goal is to use project findings to develop and implement a community-informed and culturally grounded intervention to reduce stress and promote physical and mental health in rural Alaska Native communities. This paper introduces a long-standing partnership between the Yukon-Kuskokwim Regional Health Corporation, rural communities it serves, and the Center for Alaska Native Health Research at the University of Alaska Fairbanks. Within the context of the Stress and Coping project, we then discuss the value and challenges of taking a CBPR approach to advance science and address a priority community concern, and share strategies to respond to challenges. Focus groups were conducted to culturally adapt an existing structured interview and daily diary protocol to better fit Yup’ik ways of knowing. As modified, these interviews increased understanding of stress and coping particular to two Yup’ik communities. Challenges included the geographical nature of Yup’ik communities, communication barriers, competing priorities, and confidentiality issues. Community participation was central in the development of the study protocol, helped ensure that the research was culturally appropriate and relevant to the community, and facilitated access to participant knowledge and rich data to inform intervention development.

Key Words: stress, coping, Alaska Native, rural, CBPR
The negative effects of chronic stressors on physical, mental, and behavioral health are well established (Juster, McEwen, & Lupien, 2009; McEwen, 1998). American Indian and Alaska Native communities shoulder a disproportionately high burden of stress and trauma. This has been attributed, in part, to historical trauma, such as a vast history of colonization, loss of culture and epidemics, and to rapid changes in culture and lifestyle patterns (Dinges & Joos, 1988; Duran & Duran, 1995; Walters & Simoni, 2002; Wolsko, Lardon, Hopkins, & Ruppert, 2006). Such changes include the partial reliance on a cash economy, adaptations in traditional subsistence activities and migration, as well as a relatively new dependence on snowmachines, cell phones, and processed store bought foods (Bersamin et al., 2008; Lardon, Drew, Kernak, Lupie, & Soule, 2007). Trauma and stress experienced by Indians and Natives has been inextricably linked with unacceptably high rates of depression, anxiety, post-traumatic stress disorder, substance abuse, and suicide (Manson, 1996; Manson, Beals, Klein, & Croy, 2005; Robin, Chester, & Goldman, 1996). These mental and behavioral health disparities pose detrimental effects to the health of individuals, families, and entire communities (Hawkins, Cummins, & Marlatt, 2004; Manson, Bechtold, Novins, & Beals, 1997). For example, intentional injury, specifically suicide, is one of the leading causes of death for Alaska Natives (Lanier, Kelly, Maxwell, McEvoy, & Homan, 2006), and a particularly critical issue among young Alaska Native men (Alaska Injury Prevention Center, Critical Illness and Trauma Foundation Inc., & American Society for Suicideology, 2007; Goldsmith et al., 2004). In turn, suicide has been associated with depression, severe stress, substance use, conflict, isolation from family and community, maladaptive coping, historical trauma, and loss of culture (LaFromboise, Medoff, Lee, & Harris, 2007; Manson et al., 1997; Wexler, 2006; Wilson et al., 1995). Suicide affects not only individuals and families, but the health and well-being of an entire community (Wexler, 2006). Alcohol abuse also devastates community health as a primary factor in suicide, and through its association with homicide, fetal alcohol spectrum disorder, domestic violence, and sexual assault (Goldsmith et al., 2004). However, individual, family and community strengths are protective against alcohol abuse among Alaska Natives, and facilitate reflection and decisions to maintain sobriety (Mohatt, Rasmus, et al., 2004).

Rural Alaska Native communities have voiced great concern about stressful and traumatic events and their impact on health (Wolsko et al., 2006). Research conducted by University of Alaska Fairbanks’ Center for Alaska Native Health Research (CANHR) in partnership with Yup’ik communities in Southwest Alaska highlights the importance of enculturation (e.g., immersion in traditional Yup’ik values and practices and cultural identity) as a buffer to certain experiences of stress (Wolsko et al., 2006; Wolsko, Lardon, Mohatt, & Orr, 2007). Specifically, enculturation is associated with greater happiness and spiritual coping, and less drug and alcohol coping in the face of cultural change (Wolsko et al., 2007).

Findings from preliminary research in tandem with the identification of stress and its impact on health as a priority concern of partner Yup’ik communities gave rise to the Yup’ik Experiences of Stress and Coping Project [Stress and Coping Project]. The goal of this project is to develop an in-depth understanding of experiences of stress and ways of coping in Yup’ik communities. The long-range goal is to use project findings to develop and implement a community-informed and culturally grounded stress management intervention for Yup’ik communities.

The Stress and Coping Project is guided by a framework that conceptually illustrates the direct and indirect pathways through which psychosocial stress can impact health. The framework integrates McEwen’s model of stress physiology (Juster et al., 2009; Mcewen, 1998; McEwen & Seeman, 1999; McEwen & Stellar, 1993), ecological models of stress and coping (Dohrenwend, 1978; Hobfoll, 1988; Lazarus & Folkman, 1984), and frameworks for understanding stress and coping among American Indians and Alaska Natives (Dinges & Joos, 1988; Walters, Simoni, & Evans-Campbell, 1999).
2002). As shown in Figure 1, individual, family, and community stressors (e.g., job loss, family suicide, acculturation pressures) and coping resources (e.g., social support, spiritual guidance, community integration) interact to influence perceptions of stress. These perceptions influence physical and mental health directly by affecting psychological and physiological states (e.g., depression, blood pressure, stress hormones) and indirectly by affecting health behaviors (e.g., smoking, alcohol use) (Juster et al., 2009; Pickering, 1999; Taylor, Repetti, & Seeman, 1997; Tice, Bratslavsky, & Baumeister, 2001). Critical to the framework are the social and cultural context and their effects on the experience of stressors, the availability and use of coping resources, and the pathways through which stress and coping impact health. Yup’ik community leaders and other stakeholders were most interested in information that would be useful for development of a stress management program. In response, the Stress and Coping Project focuses on aspects of the model with the greatest practical utility for planning a stress management program.

**Call for CBPR Research with Alaska Native Communities**

Research plays a necessary role in informing appropriate strategies for identifying and addressing priority individual and community needs (Noe et al., 2007; Trickett & Birman, 1989; Trickett & Espino, 2004; Trimble, 2009a, 2009b). The dearth of research with ethnic minority populations in North America, particularly Alaska Native, precludes the ability to develop beneficial evidence-based practices. Significant concerns expressed by American Indian and Alaska Native populations about research conducted on, in, and with their own communities can perpetuate mistrust and pose barriers to participation (American Indian Law Center, 1999; Burhansstipanov, Christopher, & Schumacher, 2005; Cochran et al., 2008; Trimble, 2009a, 2009b). In part, this mistrust is historically rooted within a tradition of research that employs methods and practices that fail to honor and incorporate local cultural traditions, Native language, and the importance of identity and self-determination (Burhansstipanov et al., 2005). Particularly damaging are repercussions from a history of unfulfilled promises made by researchers at the outset of a study that guarantee significant benefit to the participating individuals and communities in terms of new knowledge, data, and services. When these promises are broken, Native communities can actually be harmed, particularly when findings are reported in ways that reinforce negative stereotypes, fail to identify community strengths while emphasizing negative behaviors, and perpetuate the misconception that indigenous people, as a whole, represent a problem that needs to be solved by outsiders (Casillas, 2006; Cochran et al., 2008). Such misperceptions can result when projects exclude indigenous participants from the research decision-making process (Burhansstipanov et al., 2005) and fail to incorporate indigenous ways of knowing (Chino & DeBruyn, 2006).

In response to these and other concerns, research principles have been set forth to guide ethical research conducted with American Indian and Native Alaska populations. These guiding principles
expand on normative professional research ethical standards to accentuate the importance of establishing firm collaborative relationships with participating communities (C. B. Fisher et al., 2002; Jason, Keys, Suarez-Balcazar, Taylor, & Davis, 2004; Mohatt, Thomas, & Team, 2005; Trickett & Espino, 2004). Noteworthy are the eight parallel principles developed by the National Science Foundation's Interagency Arctic Research Policy Committee (IARPC) and the Alaska Federation of Natives which emphasize the importance of: 1) informing community leaders of planned research activities; 2) involving community members throughout the research process; 3) affording respect to cultural traditions, languages, and values; 4) providing a clear and transparent informed consent process; 5) protecting sacred lands and intellectual property; 6) guaranteeing confidentiality and anonymity; 7) providing all research materials to the community; and 8) communicating results in a manner that is appropriate and responsive to local concerns (National Science Foundation Office of Polar Programs [OPP], 2006).

These guiding principles are also reflected in elements defining a community based participatory research (CBPR) approach. CBPR is a collaborative approach to research that focuses on establishing the participation and influence of “community” in the process of creating knowledge (Mohatt et al., 2005; Trickett & Birman, 1989; Trickett & Espino, 2004). An important distinction of this approach is conducting research with a community as a social and cultural entity with active engagement and influence of community members in all aspects of the research process (Israel, Schulz, Parker, & Becker, 1998). The principles of CBPR are congruent with those created for research with American Indian and Alaska Native populations. As such, CBPR (Cochran et al., 2008; P. A. Fisher & Ball, 2005; Noe et al., 2007) is well suited for use with Alaska Native communities because it facilitates inclusion of community values, cultural heritage, and historical perspectives (P. A. Fisher & Ball, 2005).

Indigenous communities strongly value personal relationships and face-to-face communication. Consequently a CBPR approach to research is vital to better understanding and addressing the complex health disparities experienced by Alaska Native populations. However, this perspective and orientation also adds new challenges to conducting research with ethnocultural populations (Trimble, 2009a, 2009b; Trimble & Fisher, 2005; Trimble, Scharron-del Rio, & Bernal, 2010). The purpose of this paper is to describe how the Center for Alaska Native Health Research (CANHR) conducts CBPR in rural Alaska Native communities, the value of CBPR for advancing science and addressing community needs, and the challenges and facilitators to conducting a CBPR process within the context of identifying stressors and coping strategies in Yup’ik communities.

Yukon-Kuskokwim Health Corporation and CANHR Partnership

The Stress and Coping Project is one of several projects conducted within a long-standing partnership developed between the Yukon-Kuskokwim Health Corporation (YKHC), the tribal communities the corporation represents, and the Center for Alaska Native Health Research (CANHR). The YKHC is a tribal owned, non-profit organization that manages a comprehensive health care system on behalf of 58 federally recognized Tribes in 50 rural communities located in southwest Alaska. With a mission of “Working together to achieve excellent health,” the YKHC is governed by a Board of Directors that comprises leaders from the tribal communities it serves (Yukon-Kuskokwim Health Corporation). Important contributions of YKHC include the human subjects’ protection committee that helps to provide oversight over CANHR projects, and their membership on the CANHR external advisory council.

The 50 communities represented within the YKHC service area are each self-governed by a Tribal Council whose officials are elected by community tribal members. Each Tribal Council decides with which research projects they collaborate. Two Tribal Councils identifying stress as a priority community issue are the partners on the Stress and Coping Project. To ensure optimum support, the Tribal Council also formed a community steering committee (CSC) composed of elected officials and other community members. The CSCs work closely with the academic team in providing feedback
and developing a culturally appropriate research process.

CANHR, a Center for Biomedical Research Excellence (COBRE) funded by the National Institutes of Health (NIH) National Center for Research Resources, is located within the University of Alaska Fairbanks Institute of Arctic Biology, and was established to develop unique biomedical knowledge for translation into culturally appropriate research and intervention for the prevention and reduction of health disparities among Alaska Natives. CANHR has established long-term and trusting relationships with Yup’ik communities and provides an effective model for culturally appropriate and long-term research (Boyer et al., 2005). Adhering to the principles of CBPR, CANHR works in partnership with regional health corporations and the communities they serve in conceptualizing, developing, and implementing research and interventions that are appropriate and relevant (CANHR, 2009). The Stress and Coping Project adopted CANHR’s methods of community engagement, and builds on its formation of trust and collaboration with the YKHC and two of its associated tribal communities. CANHR-based researchers and external mentors represent the academic partner of the Stress and Coping Project. Included are faculty, staff, and students from both the University of Alaska Fairbanks and Anchorage who contribute diverse research, substantive, and experience-based expertise within fields of psychology, public health, nursing, and Yup’ik culture.

**METHOD**

The stress and coping project grant application was developed to address a priority concern identified by the community, with critical input, guidance, and ultimately, approval from the YKHC prior to submission for funding. With intent to use findings to apply for additional funding to develop and implement a culturally grounded stress management program for Yup’ik communities, the overarching goal of the Stress and Coping project is to develop an in-depth understanding of the stressors experienced specifically by Yup’ik individuals and families from two partnering communities and the strategies they use to cope with stress. To achieve this goal the Stress and Coping project undertook a two phase research protocol. Phase One involved developing culturally appropriate data collection materials and protocols to gain in-depth understanding. Phase Two involves implementing data collection activities using the materials and protocol developed during Phase One, along with data analysis, interpretation, and dissemination.

**Phase 1: Project Materials and Protocol Development**

To gain insight about the particular stressors experienced by Yup’ik communities, three data collection protocols were developed, including those for a Community Stress and Coping Interview, a Lifetime Events and Trauma Interview, and a Digital Audio Diary.

The Community Stress and Coping Interview is a short interview guide that focuses specifically on individuals’ perceptions of stress and coping experienced at the community level. In addition it invites participants to share suggestions for developing a successful community-based stress management program.

The Lifetime Events and Trauma Interview guide invites participants to share information about their personal experiences with an array of different types of stressors and how they were able to cope. As a foundation, the interview drew upon questions from an existing Lifetime Events and Trauma survey used in the continental US to assess stress and trauma in American Indian communities (American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project – AI SUPERPFP; Manson et al., 2005).

Lifetime Events interview participants are also invited to complete Audio Diaries. For these diaries, participants are provided digital audio recorders, and are asked to take a few minutes each
day (for one week) to record their thoughts and feelings about the stressors they experienced or were reminded of during that day. Specifically, participants are asked to talk about how their stress affected them and describe their coping strategies for the stressors experienced. In addition, participants are also invited to talk about the positive aspects of their day. This type of interval-contingent Experience Sampling method (Wheeler & Reis, 1991), assessing experiences at daily intervals, can be an important adjunct to understanding stress and coping. Retrospective recollections of stress and coping are prone to recall errors which can be minimized by assessing responses to stressful experiences closer to the time frame when stress occurs (Ptacek, Smith, Espe, & Raffety, 1994; Stone et al., 1998). Furthermore, audio recording is consistent with the oral tradition in Yup’ik culture. Research also suggests that narrative processing of stressful experiences by writing or talking about them results in better health and psychological well-being (Frattaroli, 2006; Pennebaker, 1993; Ullrich & Lutgendorf, 2002). Thus, recording thoughts and feelings could provide benefit to participants.

**Community participation in protocol development.** To ensure that the interview guides accurately reflected experiences unique to Yup’ik culture, we gained insightful feedback about the interview questions and protocol from the community tribal councils and community members during three extended visits to the participating communities. During these visits, we met with both tribal councils and the community steering committee, and conducted a series of 11 focus groups. The community steering committee provided feedback on focus group procedures (including the content and structure of PowerPoint slides), interview questions, and study protocol. Individuals from the committee helped pilot test the audio diary protocol to provide their feedback on how it worked for them. The committee also helped recruit participants for the focus groups. In addition, two men from the community steering committee helped co-facilitate men’s focus groups, and an elder from the steering committee served as a translator both for the steering committee meeting and for some of the focus groups.

The focus groups averaged 9 participants and lasted approximately two hours. During the focus groups, PowerPoint slides that listed each interview question were presented for discussion. Participants were asked to assess the fit of each question with the Yup’ik life experience, and to provide suggestions for rewording, omitting, and developing new questions. To protect confidentiality while discussing the questions, participants were asked to refrain from actually answering the questions in terms of their own or other’s experiences with stress. However, many participants still answered in terms of their experiences and told stories in response to the questions, consistent with the oral tradition in Yup’ik culture. The research team’s emphasis on confidentiality, and the commitment of focus group participants to keep what was shared in the group confidential, helped participants feel comfortable sharing their experiences even when not directly prompted to share. Both the responses providing direct feedback on the interview, and the stories participants shared, were useful in guiding and validating the interview.

To accommodate both English and Yup’ik language speakers, most focus groups were co-facilitated by a Native Yup’ik speaker and a CANHR researcher. Further, to foster open sharing, and diverse representation across age and gender groups, we conducted focus groups specifically for younger men, younger women, older men, and older women, based on previous experiences of working with these communities. This was especially important for younger Yup’ik participants who out of respect will often defer to community elders and men (Wolsko et al., 2006). Conducting separate men’s and women’s focus groups is consistent with traditional Yup’ik cultural practices. In the past, boys were instructed by men in the Qasgiq – “the men’s house”, while the mother or female relative instructed the girls. However, we also conducted three mixed (age and gender) focus groups.
to accommodate strong community values for inclusion and desires to hear others’ views as well as share their own in a group that included diverse segments of the community.

The community feedback was integrated into a new version of the *Lifetime Events and Trauma Interview*. Examples of topics for which new questions were added include those pertaining to: individual understanding of stress, feeling accepted in the community, social support, loved ones in the military being deployed overseas, conflicts between the “Kass’aq” (non-Native) and Yup’ik, and youth and elder ways of living, parenting issues, gossip, bullying, access to healthcare, isolation, geographical barriers, climate change, migration, expense of food and fuel, lack of law enforcement, community involvement, and adult educational programs. Feedback from the community also emphasized individual and community differences in stressors and effective coping strategies, and the importance of the stress management program being sensitive to those differences.

A separate and shorter *Community Stress and Coping Interview* was also developed. Rationale for developing this instrument was based on the community value of inclusiveness, and the need for a screening tool that could help identify participants who might be vulnerable (experiencing acute crisis or other mental health issues) or at risk for adverse reactions if they were to answer the extremely sensitive and personal questions included in the *Lifetime Events and Trauma Interview*. The shorter community perspective interview could be completed with many individuals who wished to share their perspectives, and then researchers could decide, case-by-case, who would be invited to complete the longer *Lifetime Events and Trauma Interview*. Not only would this minimize risk of harm, but it would also ensure the correct number of participants were included per the purposive sampling plan (see sampling).

With regard to the *Audio Diaries*, focus group participants were generally enthusiastic, and even interested in pilot testing the protocol. They recorded their thoughts and feelings about stress they experienced and let us know what it was like to use the audio diaries. Nevertheless, it became clear that several community members, particularly elders, were uncomfortable with using a digital recorder. This was attributed to the technology itself, and to the concern that other individuals might find and listen to the recording. In response, it was decided that the *Audio Diary* protocol would be an optional component of the study. We also offered that the diaries could be completed in writing, via in-person reporting, or over the phone with a research team member.

**Member checking.** To ensure that newly revised interview accurately reflected community feedback, another round of focus groups was conducted after the first series of revisions. The focus groups resulted in additional suggestions for improvement along with new opportunities for researchers and community members to interact and discuss important issues related to stress and coping. Final revisions to the data collection materials and protocol were submitted for approval by both the YKHC and the University of Alaska Institutional Review Board for Human Subjects (IRB). The traditional council in the community also provided feedback on and approved changes in the assessment, sampling, recruitment, and other study procedures, including the ones described above.

**Phase 2: Implementation of Interviews**

**Sampling.** Our goal was to complete the shorter *Community Stress and Coping Interview* with up to 60 participants in each of the two partnering communities, and the longer *Lifetime Events and Trauma Interview* with up to 30 participants in each of the two communities (who would also be invited to complete *Daily Diaries*). Data collection was to be completed in two waves, where researchers would visit each of the two communities two times at different times of the year to
gain perspectives on Stress and Coping that might be seasonally based. A major consideration was to develop a sampling strategy that would ensure a diverse representation of perspectives while respecting the community desire for inclusiveness. The project employed a purposive stratified sampling strategy that would be feasible, useful and respectful in small rural communities while allowing a diverse representation of perspectives by age and sex. Random sampling would not be accepted in these communities. However, the community supports the value of including diverse perspectives from multiple segments of the community.

With guidance from the tribal council, we created a matrix to guide our sampling plan that involved recruiting participants by gender and age range, until we completed the 30 shorter community interviews with the goal of including five women and five men within each of the designated age ranges: younger (18-30 years), middle (31-50 years), and older (51 years and older) age ranges. Of these participants a subset of two to three women and two to three men within each age range (for a total of 15) would be invited to complete the *Lifetime Events and Trauma Interview* and *Audio Diaries*.

**Interviews.** The second phase of the project involved actually conducting data collection activities using the revised interview and *Audio Diary* protocols developed during Phase One. Prior to conducting interviews, we met with the community tribal council to provide an update on the project, and review the data collection protocol, including the sampling and recruitment plan. With support and championing from the tribal council, we successfully recruited men and women from varying age groups and from different areas of the community.

The tribal council was invaluable to our ability to recruit participants. Specifically, the tribal council administrator, an individual who is well known and respected in the community, was particularly instrumental in recruitment. He projected great respect for the partnership, project and its goals, and used his personal and professional connections to ensure that community members were aware of the project, its purpose and the interview opportunities. Whenever participants from a certain sex or age group were needed, he was able to recruit individuals throughout the community to achieve our sampling goals. In this community of approximately 700 persons, those who participated were known by each other but they did not represent any clique.

The short community interviews helped inform purposive stratified sampling, and identify individuals who might have been too vulnerable to participate in the more intense *Lifetime Events and Trauma Interview*. Based on discussions with the tribal council and the experiences participants shared during focus groups and interviews, it was clear that individuals and the community as a whole had historically encountered extremely traumatic situations and were also currently experiencing a great deal of stress. To try to minimize the risk of causing additional stress during the interviews, we provided referrals to available services, “checked in” with participants during and after the interview, offered breaks as needed, and reminded participants that they were free to skip questions or stop the interview at any time. The research team also consulted with the local behavioral health provider and supervising clinician about the research protocol to minimize risks, and referred participants to them.

**RESULTS**

Community participation was vital in the Stress and Coping project. However, the Stress and Coping Project partnership encountered challenges and facilitators that are both common to the CBPR process, and unique to Alaska and the sociocultural context of Yup'ik communities, that are underserved, marked by low-income with high costs of living, and are rural and extremely remote. Essentially, the day-to-day operations of the project experienced challenges related to: 1)
Geographical nature of Yup’ik communities; 2) Communication challenges; 3) Competing priorities; and 4) Confidentiality issues, each of which will be explicated in turn:

Geographical Nature of Yup’ik Communities

Geography and weather conditions made travel to and from partnering communities extremely difficult. Due to the lack of a road system, at least one full travel day was required and involved a commercial flight to the regional hub, followed by small-craft “bush” plane to the community’s airstrip, then snowmachine or 4-wheeler from the airstrip to the school or community center. Once in the community, people typically walk and use snowmachines, 4-wheelers, and boats. Recent increases in fuel costs have made travel for research far more expensive than what was allotted in the original grant’s budget. Unpredictable and extreme weather conditions led to travel delays, postponed project-related activities, and often extended stays in the community. Flexible schedules for all partners and adequate travel funds were paramount.

Communication Challenges

Face-to-face interaction is the preferred method of communication in the communities. Yet, in-person meetings were not as frequent as would be ideal. This was, in part, attributed to the remoteness of Yup’ik communities. Supplementing in-person interactions with long-distance communication was vital to the Stress and Coping Project’s CBPR process. Nevertheless, there have been challenges to such communication. For example, calls between communities within Alaska were long-distance. Although CANHR offered a toll-free number, it was not specific to the project and was used infrequently. Furthermore, many people in the community used VHF radios to communicate within their community and some did not have a telephone in their home. Cell phone service has recently been introduced, but they can be cost prohibitive and result in disconnected numbers. Regular communication with community partners has also been challenged by limited internet access capacity, as internet is only available in certain homes and public buildings (e.g., the school) and is often disrupted due to weather. Finally, language differences have proven difficult. Specifically, because many elders’ and community partners’ first language was Yup’ik, communication required an interpreter. Furthermore, some words or concepts do not have a direct equivalent in English, so interpreters often used several examples to get the point across. Likewise, some Yup’ik words do not have a direct translation in English. It is difficult to “find the right word” when there is no “right word”.

Competing Priorities

Competing priorities often presented challenges for community and academic partners. An important community priority is the need for a timely intervention that addresses the stress in the community. However, it is important to first understand stress and coping in the community, in order to inform the intervention and provide preliminary data to be used in grant applications for funding development and testing of the intervention. The time it takes for the research trajectory, from development of culturally appropriate measures, to assessment for understanding causes of stress and coping strategies and resources, to results interpretation and dissemination, to use of results in grant applications to develop the program, created a tension with community needs for a timely intervention addressing the issues currently affecting the community. Ongoing conversations and education among all partners about research and community life were necessary to increase awareness of the need to better understand stress and coping before an appropriate intervention could be developed.

Competing priorities in the lives of community and academic partners also presented challenges.
Daily life in rural Yup’ik communities extensively revolves around subsistence activities, including hunting, fishing, gathering, processing, and sharing food. These activities have been a way of life for many years. However, with limited opportunities for full time employment, subsistence activities continue to have cultural, social and economic importance. In response, all project-related activities were scheduled around subsistence schedules such as those taking place during summer and early fall, when many families left for fish camp and hunting. For example, a data collection trip was rescheduled when a five-year moratorium on moose hunting was lifted and many men in the community left to hunt moose to feed their families. Scheduling was a challenge, because most research-related travel and activities needed to occur during the winter or early spring, when travel is increasingly arduous. At the same time, CANHR researchers also needed to juggle their professional and personal schedules, responsibilities, and priorities. Also important was that all travel activities be respectful and sensitive to events such as holidays or celebrations, or times when the community was coping with a crisis such as a flood, or a death in the community.

Confidentiality Issues

Yup’ik communities are essentially rural and small, with populations ranging from less than 100 to 1000 residents. As such, everyone is interconnected and knows the happenings in the community. This posed both strengths and challenges. On one hand, it facilitated community awareness of the project and recruitment through word of mouth. However, it also posed challenges to maintaining confidentiality. Community members were aware of research activities taking place in their community. They saw participants arriving for data collection activities and therefore knew who was taking part in the research. People often lived with many others in the same home, and when a researcher made calls to schedule or remind a participant of an appointment, some knew that person was a participant in the study. As a result, maintaining confidentiality of research participants’ identities was a challenge in the community.

IRB principles emphasize both the confidentiality of participants’ identities as well as their responses. However, we have learned that participants’ main confidentiality concern is the confidentiality of specific responses to the sensitive interview questions about stress and coping, not the confidentiality of their status as a research participant. In response, we used interviewers who did not live in the community. This decision was supported by community partners who preferred that interviews be conducted by academic partners. This may contrast with ideas that local interviewers should be involved in data collection (P. A. Fisher & Ball, 2005). However, this decision was important to addressing community preferences and needs, reducing participants’ concerns about others in the community learning about their responses, and allowing participants to open up and share sensitive personal experiences. Although involvement of community partners in the research is important, we cannot make the assumption that the community desires extensive involvement in all tasks. Community partners helped guide research activities and recruit participants. However, they did not conduct individual interviews, due to these confidentiality concerns.

DISCUSSION

A key question raised with regard to CBPR is, does it add value to the science of research and, if so, how. There are a number of key areas which it is clear what the value added nature of CBPR was for our project.

1. Gaining access to participant knowledge. Stress is difficult to discuss and demands that a rapport has been established between the research team and the participants. Community members showed a willingness to share sensitive personal information with the outside interviewers, trusting the confidentiality of the information shared. We believe this trusting relationship was based on
previous positive experiences with CANHR researchers. These experiences included time spent with researchers during visits to the community, the willingness of the research team to respond to community concerns, and the commitment to a long-term partnership. In addition, the community and tribal council support for the project facilitated participants’ commitment to share personal information that could provide vital insight when developing a relevant and targeted stress management program.

2. Richness of data. Qualitative data aims to gather rich, fully described ideas about a phenomenon. Without this richness the data collection can yield trivial sets of data that are characterized by a paucity of detail. Although we are just beginning to examine the results of the interviews, we are finding that our partnering communities have shared experiences of significant trauma as well as considerable day to day stress, including the stress of cultural and economic change. Trauma and stress affects not only the individual and family, but the entire community. For example, a participant noted, “It’s kind of a close-knit community, like most of them are related and like when there is a suicide or someone’s, like a traumatic injury, it affects not just one person, but a lot of people in the community.” Participants’ stories about stress and coping also highlighted internal and external forces acting on their community, as well as the traditions and values that help the community heal. For example, a participant said “When we continue to use what our elders have told us, things start to emerge that would be helpful for us”.

A key factor in participants’ sharing their perspectives was that the questions resonated with their experiences. Many of the stressors participants reported were assessed with questions that were added in response to community steering committee and focus group feedback. Thus, community participation was critical for developing an interview tool that assessed the types of stressful experiences commonly experienced in these communities. Further data collection, analysis and community participation in interpretation of results will facilitate an understanding of the stressful experiences affecting these communities, how people find healthy ways of coping with stress, and how traditional values and practices, as well as contemporary practices for dealing with change, can be integrated into stress management programs.

3. Reducing attrition. Tracking participants after they had taken part in the Community Stress and Coping Interview to schedule them for the longer interview proved difficult. Some did not have phones, others had cell phones that were no longer in service, and many had competing priorities that took precedence over completing the interviews. In response, the team scheduled appointments for Lifetime Events and Trauma Interview immediately after the Community Stress and Coping Interview, and worked with the tribal council and local research assistants to facilitate recruitment and tracking. Local community members, who are familiar with the community, culture, and language, play a crucial role in all phases of the project (e.g., providing feedback on the study protocols, recruiting participants, contextualizing results, helping to plan the intervention, and problem solving implementation issues as they arise). Nevertheless, they do not conduct interviews and will see only compiled data which does not identify particular participants’ responses. As noted in the results, the communities chose to have outside interviewers to assure confidentiality and trust, opening a space for participants to share sensitive information with interviewers who do not see them in the community on a daily basis. The role of local staff will increase as the project moves to results dissemination and intervention planning and implementation stages. The current project includes part-time community research positions, but a subsequent grant will include more positions for community members who will be involved in planning, coordinating, and implementing the intervention.
Lessons Learned

Community guidance and participation was critical throughout the phases of the stress and coping project. The community determined priorities for research, guided the research questions, provided valuable input for developing the interview and diary protocol, guided sampling and recruitment procedures, and planned the timing of subsequent data collection visits. Community participation will continue to be critical for guiding data analysis and interpretation, and planning the intervention. The isolation of these rural communities, combined with researchers’ academic responsibilities, pose challenges to CBPR, yet opportunities for face-to-face interaction and community guidance are critical.

Project experiences illustrate strategies for addressing CBPR principles in health disparities research in rural Alaska Native communities, even with geographical and communication barriers. The tribal councils and the research team developed a respectful relationship, and met together to guide the project and nurture the partnership when the researchers were in the community. Researchers were also welcomed at community activities, were present and approachable to community members out in the community, and forged relationships with local teachers and community members employed at the school and community center. This allowed the researchers to acquire a deeper understanding of the community's strengths and barriers, and also allowed the community members to learn more about the researchers, facilitating relationship-building. Developing and maintaining long-term, trusting relationships in community research and intervention is a critical part of the ‘real’ work itself” (Israel et al., 1998, p. 62).

Our experiences also illustrate the need to balance methodological rigor with flexibility and responsiveness. This issue is faced in many CBPR projects (Mohatt, Hazel, et al., 2004; Stiffman, Freedenthal, Brown, Ostmann, & Hibbeler, 2005). It requires responsive adjustments in the methodology to address community needs, priorities, and cultural issues. For example, random sampling to recruit interview participants would not be feasible nor accepted in the communities, violating community values of inclusion. Purposive sampling combined with multiple opportunities for participation helped address the need for inclusion and the need for diverse community perspectives on stress and coping. Gathering focus group feedback only through direct input on the questions would miss the less direct but very valuable input in stories participants chose to share about life in the community and the stressors and changes that affected them.

Community participation helps ensure that the knowledge gained from this project is accurate and relevant to the community. Conducting this research with community participation provides unique information about adaptation to significant trauma and change that is difficult to learn elsewhere. Yet it also provides information applicable to other rural indigenous communities undergoing stress and change. Therefore, this culturally specific knowledge, and the intervention it helps to inform, will be useful both in the local communities it is developed in, as well as more broadly. It can help inform the process of future community collaborations to develop culturally appropriate interventions, and strategies for addressing stress in indigenous communities undergoing rapid cultural change. It is clear that each of these contributions of CBPR adds value to our science making it more accurate, relevant and allowing us access to the internal worldview and perspectives of a minority group experiencing significant health disparities.

Conclusion

This process paper illustrates the challenges to conducting CBPR in rural Alaska Native communities, how these challenges were addressed in the current project, the value of community partnerships, and lessons learned to nurture community partnership throughout the research process. Community participation was critical in the development and implementation of measures
for the Stress and Coping project, and will continue to be critical in interpretation and use of findings, helping to ensure that the resulting stress management program draws on community strengths and resources, that barriers to intervention implementation are addressed with sensitivity, that the intervention is targeted at appropriate social-ecological levels, and that it aptly manages the complicated factors that impact stress, coping, and community health.

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Responding to American Indian Communities: Southwest American Indian Collaborative Network (SAICN) Cancer Educational Activities

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ABSTRACT
Developing educational materials and providing trainings in American Indian communities is a highly rewarding activity. However, to do so successfully a number of complex issues must be faced and cultural-tailored strategies to promote awareness must be developed based on the unique traditions of each tribe. In this paper we describe the educational activities conducted over a four year period by the Southwest American Indian Collaborative Network, a project funded by the National Cancer Institute's Center to Reduce Cancer Health Disparities. Activities fell into two broad areas: dissemination of cancer information through trainings and workshops and development of culturally-tailored educational materials.

Key Words: Health education, American Indians, cancer disparities

INTRODUCTION
In 2004, the Southwest American Indian Collaborative Network (SAICN) was awarded a five-year community network program grant from the National Cancer Institute, Center to Reduce Cancer Health Disparities (NCI-CRCHD) to eliminate cancer health disparities among American Indians in Arizona, Utah, and Nevada. SAICN, a multi-agency partnership between the Inter Tribal Council of Arizona, Inc. (ITCA), the Phoenix Indian Medical Center (PIMC) and the Mel and Enid Zuckerman College of Public Health (MEZCOH) and Arizona Cancer Center (ACC) at the University of Arizona works to close the gap between the health-needs of the American Indian communities within the
three states and the promise of cancer prevention and control through participatory education, training and research.

The fundamental goal of the SAICN is to significantly improve access to and utilization of beneficial cancer interventions in American Indian communities to reduce cancer health disparities. To achieve our goal, SAICN developed a core organizational infrastructure to support community-based participatory activities and effective partnerships between tribal communities, cancer prevention/care delivery systems, and research discovery/development systems at many levels to increase and sustain delivery of beneficial interventions. Five separate but interrelated core work groups were developed to achieve our goal: (1) Data and Evaluation, (2) Outreach and Services, (3) Policy, (4) Research, and (5) Training and Education.

The Training and Education Core was established to promote cancer-related education, training and outreach activities among tribal communities, tribal health departments, clinicians, case managers, and American Indian graduate students and university faculty. Our primary hypothesis is that if we are to improve access to and utilization of beneficial cancer interventions in American Indian communities, education and training must respond to community interests. Working with the SAICN Cores and the SAICN Community Advisory Board and Steering Committee, we identified gaps and opportunities for potential partnerships in cancer education and training activities. These include: cancer training and conferences, cancer outreach, information and dissemination, and the development of educational materials.

In this paper we describe the culturally-tailored educational activities developed and conducted by the Southwest American Indian Collaborative Network (SAICN). These activities consisted of training workshops for health providers and community members, participation in health fairs, and development of conference workshops on spirituality and cancer, and on resilience and historical trauma. The development and dissemination of unique educational materials including an interactive genomics glossary, innovative cancer education materials, and a spiritual care toolkit are essential measures in building on the cultural strengths of delivering cancer education and reducing cancer health disparities among American Indians in the Southwest.

**Background and Significance**

Cancer data on American Indian populations are limited, inconsistent and often do not reflect the increasing impact of the disease in tribal communities. While numbers are small, making it difficult to calculate incidence rates, it is well established that American Indians suffer disproportionate cancer mortality (Trends in Indian Health, 1997; Espey et al., 2007) and indicate increased cancer incidence (Trends in Indian Health, 1997; Espey et al., 2007; Wiggins et al., 2008). While these findings suggest the need for more cancer awareness and education, this can be a challenge in many American Indian communities. Efforts are hindered from the start as there are only a few established cancer programs in tribal reservation communities that conduct outreach, education, and offer early detection services. While there is a lack of cancer programs and resources for American Indians, the SAICN Training and Education Core worked diligently to provide cancer resources for American Indian communities in Arizona, Utah and Nevada.

Since cancer is primarily a disease that occurs later in life, it becomes more challenging to convince American Indian elders to participate in cancer screenings (ICC website http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf. Accessed 01/29/10), especially since there may not be a term for cancer in many Native languages (Burhansstipanov & Hollow, 2001). If a term for cancer exists, it is commonly described as either a “disease that will not go away” or “sore that cannot be seen” which often
reinforces cancer myths and misconceptions. While many American Indians remain connected to their cultural ways, some cultural traditions and practices may present barriers to cancer education. For example, some tribes believe that it is inappropriate to carry ill-health messages. Some believe that cancer is an obscene, unspeakable, and shameful condition that is related to sin or guilt (Coulehan, 2003). For many of the traditional American Indian elders it may be deemed immodest and thus not culturally acceptable to speak of and/or illustrate screening methods for the breast, colon, and genital cancers. Despite the proven effectiveness or availability of cancer screenings, some American Indians may be less likely than others to seek medical care for conditions that are treatable and curable (ICC website http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf. Accessed 01/29/10); and they may opt to see a traditional healer or medicine man for a traditional healing ceremony (Coulehan, 2003). Nonetheless, the Western medical treatment is becoming more acceptable (Coulehan, 2003) especially as more American Indians are beginning to reside in urban areas for employment and education opportunities (ICC website http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf. Accessed 01/29/10).

METHODS

The Training and Education Core was established to promote cancer-related education, training and outreach activities among tribal communities, tribal health departments, clinicians, case managers, and American Indian graduate students and university faculty. The SAICN Training and Education Core was comprised of individuals who are experienced trainers and educators in American Indian communities and the leadership is composed of two co-chairs who convened quarterly meetings. Membership of the Training and Education Core included the Health Educator from ITCA, the Oncology Specialist from PIMC, a representative of the Chaplains Association at PIMC, ITCA Staff, Health Promotion faculty from the Zuckerman College of Public Health, the American Cancer Society and members of the Arizona Comprehensive Cancer Coalition. The members were identified by the Training and Education Core group, the SAICN Community Advisory Board, the SAICN Steering Committee or recommended by tribal representatives and/or programs. The Training and Education Core convened meetings quarterly to address concerns in developing and supporting community-based participatory educational activities; in addition to developing effective partnerships between communities, cancer prevention/care delivery systems in order to increase and sustain delivery of beneficial cancer educational interventions.

The Training and Education Core integrated tribal community feedback into the cancer-related education and training activities, in addition to working with the other SAICN Cores and SAICN Community Advisory Board and Steering Committee in order to identify gaps and opportunities for potential partnerships in our cancer education and training activities. The co-chairs presented information on cancer and gathered input from community leaders and members at SAICN Community Advisory Board meetings, at Steering Committee Meetings, Primary Partner meetings and at Core meetings. A list of potential cancer education projects were listed and then prioritized and voted by the Training and Education Core. The Cancer Education and Training work plan focused on 1) providing Cancer 101 training workshops for health providers and community members, 2) increasing cancer outreach through participation in health and wellness events 3) developing two conferences on (a) spirituality and cancer, and (b) resilience and historical trauma 4) creating skilled-based learning opportunities for students and tribal communities; and 5) developing and disseminating educational materials including an interactive genomics glossary and a spiritual care toolkit.

As the teachings and beliefs vary among American Indians, it is becoming more apparent to adapt the [cancer] health education messages and outreach efforts that engage a wider audience
that includes new and innovative methods that still integrate cultural elements. The activities and programs described in this paper demonstrate the increased role of community members in community-driven cancer education efforts for their respective communities. The projects allow for development in cultural awareness and sensitivity that have addressed the specific health needs of American Indian communities in addition to providing field experience for American Indian graduate students and employment for local community members.

RESULTS

Training and Educational Activities

Activities conducted by the Training and Education core included both the development of culturally tailored educational materials and the dissemination of cancer information. The design of culturally tailored products was essential to the education and training process. Training and education activities included “Cancer 101,” a cancer curriculum for community health providers, cancer prevention awareness and activities at community health fairs, conferences on spiritual care and on historical trauma, and opportunities for American Indian graduate students, health professionals and para-professionals, and tribal communities.

Cancer 101

The Cancer 101 curriculum was developed through a collaborative effort between the Northwest Portland Area Indian Health Board’s Northwest Tribal Cancer Control Project, the Mayo Clinic’s Spirit of the E.A.G.L.E.S. program, the National Cancer Institute Cancer Information Service (NCI CIS), and the Fred Hutchinson Cancer Research Center. The curriculum was designed as a cancer education and training program to help community-based health professionals gain a better understanding of basic cancer information. The Cancer 101 curriculum includes the following seven modules: 1) Cancer among American Indians; 2) What is Cancer? 3) Cancer Screening and Early Detection; 4) Cancer Diagnosis and Staging; 5) Cancer Risk Factors and Risk Reduction; 6) Basics of Cancer Treatment; and 7) Support for Patients and Caregivers.

The SAICN Training and Education core team tailored the existing Cancer 101 for American Indian tribes in the Southwest by including southwest regional cancer incidence and mortality data, by listing the top five cancers for American Indians in the southwest, by collaborating with regional health programs, and by modifying the length of the training into 30- to 90-minutes sessions to fit the schedules of tribal members. The Cancer 101 training was made available at no cost to community health representatives (CHRs), health educators, cancer support group members, and others interested in advocating for and delivering the cancer information with family, community members or coworkers. From 2005-2009 SAICN has conducted 12 Cancer 101 training workshops in tribal communities with over 200 participants.

The information covered during the Cancer 101 trainings can be used in multiple ways. The curriculum materials can be condensed and presented as health topic presentations during health fairs and expositions, and/or as conference breakout sessions. During the Cancer 101 trainings, the SAICN often invited other programs and organizations to set up exhibits for participants to receive additional resources from cancer-related programs. In addition, local individuals and members of organizations were encouraged to serve as presenters for sections of the Cancer 101 curriculum. Individuals from the local Indian Health Services (IHS), tribal senior centers, women’s health, community health representatives, community tobacco education and prevention programs, and the Radiation Exposure Screening and Education Program (RESEP) contributed to these cancer trainings by serving as presenters, exhibitors, and/or training hosts.

In addition to increasing cancer education, the Cancer 101 provides a networking opportunity for
individuals to become acquainted with one another and with the services that each entity provides. This networking allows often isolated communities and health professionals to share resources and combine efforts once they learn who is interested in partnerships and what information is available. Further, the program demonstrated that, when local IHS doctors or nurses introduced and presented the cancer modules, participants may begin to feel more comfortable discussing their health concerns with them in a doctor’s office.

The SAICN has also created new modules when the Cancer 101 trainings linked the tribes to the Radiation Exposure Screening and Education Program (RESEP). RESEP is a federally funded program that helps document claims under the Radiation Exposure Compensation Act (RECA). In addition, RESEP provides educational services to those who resided in the affected areas and were exposed to radioactive fallout due to U.S. atmospheric nuclear testing during 1942 and 1971 (i.e., “down winders” and on-site participants). The program provides public education and information on cancer screenings for uranium miners, millers, and ore transporters and down-winders. Uranium mining occurred on tribal lands located in the southwestern United States and many American Indians spent years working in the mines and mills (Brugge & Goble, 2002).

The Cancer 101 trainings received positive evaluations indicating an overall increase in knowledge across all modules and an appreciation for providing cancer-related resources to the community. Many participants indicated that they were anxious to learn more about specific cancers and eager to share their knowledge with others. One participant stated, “I plan to educate my community by giving a lot of information with the handouts and places they can go for further information.” Another stated, “I plan to read the material on Cancer 101 and educate through our Native tongue.” Other comments include: “I understand cancer a lot better… I’d like to see you all come back and speak to the elders… I know they’d love to hear speakers like you here.” “This training was very helpful to me and the staff… It was very helpful and encouraging having Native Americans doing the teaching and the doctor was very good!”

Cancer 101 trainings have been shown to be essential for emphasizing the importance of practicing early detection methods, in combination with delivering preventive messages regarding health behaviors associated with reducing cancer risks.

**Health and Wellness Events**

SAICN Training & Education core members also delivered cancer education during health fairs, expositions and rodeos that targeted American Indians. The well-attended health fairs were sponsored by tribes or local hospitals, including the Phoenix Indian Medical Center. Participants were encouraged to interact with vendors and visit a specified number of information booths in order to qualify for prizes.

The information provided included verbal interaction, anatomical models, charts, and distribution of printed educational materials such as handouts and brochures. The educational materials included an assortment of published resources from numerous local and national health and cancer related organizations as well as American Indian specific print materials that were either free or available for purchase. The education materials were selected for their utility for the lay public and their ability to convey easy-to-understand messages.

The **Hoops for Awareness** events were a series of basketball clinics and health wellness fairs presented by Right Touch Basketball (RTB) Training and Development. The SAICN collaborated with RTB with the goal of promoting physical activity and cancer awareness among American Indian communities through basketball. Most American Indian sports enthusiasts agree that basketball is highly valued among Native communities. It allows for individual play and success, yet relies on a sense of camaraderie among players, just as traditional games were a way for warriors to physically prove themselves through competitions involving running, hunting and endurance (Pember, 2007).
The Fort Mojave Indian Tribe (FMIT) hosted the first Hoops for Awareness event on June 27, 2009. This project was guided by a SAICN intern who was confident that the event would spark the interest of the FMIT community. The basketball clinic and motivational speeches were presented by Kwame’ Hymes (RTB Founder) and Sam Stith (RTB Director & Former New York Knicks). Both are cancer survivors who are committed to raising cancer awareness through basketball.

The basketball clinics were conducted by addressing game fundamentals and sportsmanship, while family and community members were encouraged to visit the health exhibit booths. The Fort Mojave Health Department was responsible for coordinating and advertising the health fair, while the Fort Mojave Recreational Department was responsible for recruiting 50 youth aged 8 through 12 and another group of 50 youth aged 13 through 16. The SAICN produced the materials for advertisement of the Hoops for Awareness event in addition to contributing towards food and drinks. Various health programs within the FMIT set up booths to distribute information and discuss specific health issues such as diabetes, dental, substance abuse, mental health, and cancer prevention.

The majority (80%) of the participants evaluated the Hoops for Awareness event as excellent while the remaining rated the event as good. Most (76%) participants rated the Boys & Girls Club as an excellent location for the Hoops for Awareness event, while 20% of the participants rated it as good and the remaining rated the location as fair. The health fair exhibits were rated as excellent (73%), good (24%), and fair (2%). The majority of participants (76%) rated the motivational speaking as excellent, while the remaining rated it as good. Over half of the participants (65%) rated the length of time spent on the motivational speaking as excellent and the remaining rated it as good. Both Sam Stith and Kwame’ Hymes received excellent ratings.

One participant stated that they learned that “good decisions make for better living, no matter what hits us. Cancer is not the end of life - just different dreams - maybe even better.”

Participants stated that the part they enjoyed the most was the motivational speaking and watching the kids play basketball. One participant stated that the message of the motivational speaking “was to never give up on our dreams.” Another stated that “it was very comical watching the kids enjoy themselves.” Others stated that they enjoyed the interaction with the community and that next time the parents/grandparents should participate too since it’s good to show families learning and playing together - not just the kids. When participants were asked how they will benefit from the information provided, most stated that they will try to “take better care of my health for my family by getting regular health check ups, eat healthier, learn about available screenings, exercise, and encourage young people to accomplish their goals.”

Since this event, Right Touch Basketball (RTB) has launched the “Athletes 4 Awareness” program in which they provide athletic training clinics with former basketball, baseball, and football professional athletes. The organization raises awareness in the areas of cancer, heart disease, diabetes and healthy lifestyles. The FMIT has also started the second round of planning and coordination of the basketball program known as “Night Side.” The basketball project addresses many issues, including healthy lifestyles and good citizenship. Working in partnership with various FMIT departments (e.g., Health, Police, Fire), Night Side uses positive role-models to engage and inspire young people and promote positive behaviors.

Conferences and Workshops

**Spiritual Care Conference:** Addressing spiritual needs has long been an integral part of health care for American Indians and their families when seeking wellness and healing from illnesses. Long before the practice of Western or modern medicine, traditional Indian practitioners approached their patients as whole persons and the goal of restoring health included the restoration of spiritual well being. The reliance upon spirituality and interpersonal relationships between provider, patient, and
families was and is today, an important part of the provision of cancer care with American Indians. To address this important but often neglected part of health and healing, a two-day workshop entitled “Celebration and Ceremonies for Life’s Transitions: Implications for Cancer Care with American Indians” was sponsored by the SAICN in March 2007.

Over 200 people attended the workshop held at the Heard Museum in Phoenix, Arizona. The conference was overwhelmingly well received as personal stories were shared and collective spiritual strength was experienced by those affected by cancer and working in cancer care. The majority of conference attendees were either American Indians, cancer care providers (e.g., spiritual care provider or health care provider), and/or individuals had been affected by cancer. That is they were living with cancer, were a cancer survivor, were a family member and/or caregiver of a cancer survivor/patient. Presentations such as “Cultural Perspectives on Modern and Traditional Medicine”, “Healing Ceremonies,” and “Keeping the Spirit Strong” provided different perspectives on how persons living with cancer and their families can not only survive a cancer journey but spiritually grow and heal through the experience. As one attendee stated, “The stories really helped put a face, a personal side, to the problem of cancer.”

**Conference on Resilience in the Face of Historical Trauma:** In an effort to provide community members and university graduate students and faculty with knowledge of the models of building resiliency in the face of historical trauma, the SAICN was a sponsor of a full day conference entitled, “Reversing the Trend: Resiliency in the Face of Historical Trauma.” This conference, which was held at the Mel and Enid Zuckerman College of Public Health, University of Arizona on April 18-19, 2008, drew over 70 participants from across the Arizona. The conference was planned, implemented and evaluated by graduate students in the College of Public Health and two SAICN Student Interns/Junior Investigators.

The conference had two primary goals: 1) to focus on cultural aspects that encourage resiliency in the face of historical trauma; and 2) to investigate actual methods to increase resiliency within communities that have and continue to experience historical traumas. Within these goals, participants were provided with awareness, ideas, and methods to implement cultural resiliency that could promote individual and community healing.

The conference planning committee selected presenters from different indigenous groups around the world, as historical trauma is not isolated to one group of people. Presenters were selected based on the body of their work, expertise and the professional and personal experiences using cultural resiliency methods to address historical trauma. Presenters were asked to make the workshops as interactive as possible and to provide some tools or resources for each participant to leave with and use in their community, workplace or personal life.

The conference began at an opening evening reception, with an emotionally moving opening address entitled, “Feet on Country,” by the Samia Goudie, a Bundjalung Mununjali woman from the East coast of Australia and a Fulbright Fellow, Lecturer in Indigenous Health at the University of Queensland, and a recipient of the Torres Strait Islander Award. Her presentation focused on the inter-generational trauma caused by the Australian government policy of stealing or forcefully taking Aboriginal children to missions, reserves and placing them in white homes, often to become servants. These children came to be known as the Stolen Generations.

Ms. Goudie shared her story of being a part of a Stolen Generation and believed that one must forgive to begin healing historic traumas. She accredited her resiliency to being able to forgive and to thrive so that she could tell her story. Interestingly, the audience response was divided as some did believe forgiveness was a key to resilience while others, who were not focused on resilience, did not believe they should forgive those who caused traumas that span generations, particularly because
oppression continues in communities today and is committed by the same dominant culture.

The conference continued with a second powerful keynote address entitled, “500 Years of Indigenous Resistance: Is Social Inclusion Possible in Latin America Today?” This talk was delivered by Dr. Eliane Karp-Toledo, the Former First Lady of the Republic of Peru and a Visiting Lecturer at Stanford University. Dr. Karp-Toledo began by describing the tragic story of the Indigenous struggles in South America against the Spanish conquistadors and the Catholic missionaries. Her presentation contained graphic historic pictorials that depicted scenes of warfare, slavery, and persecution. Her presentation was very effective in conveying the historical trauma experienced by Indigenous groups in South America. Dr. Karp-Toledo explained that the historic brutal and traumatizing experiences of colonization have perpetuated the continual marginalization of the social and political status of Indigenous People in Latin American countries. A panel discussion followed, in which presenters shared their personal experiences with historical trauma that were often compounded by stress, racism and oppression.

Following the panel, two interactive breakout workshops were offered: “We Walk Together,” led by Samia Goudie; and “Healing the Generations: The Multigenerational Trauma Cycle and its Impact on American Indians/Alaskan Natives,” led by Carrie L. Johnson (Dakota), PhD, Licensed Clinical Psychologist. A closing workshop featured the staff and youth from Native Youth Empowerment Project who presented “Building Resilience Through Native Youth Empowerment.” These students showed the artwork they had developed and talked about the effect of the program on their own lives.

The overall conclusion of the participants of these workshops was that 92% (N=37) felt they increased their knowledge on how to use resiliency methods to heal historical traumas. One participant stated, “I have really enjoyed the workshops. They have inspired me to find out more about my culture and traditions.” Another participant stated, “The [workshops] remind me to remember Indigenous peoples from other places. Although we are from different places many of the same issues are universal.” Additionally, 96% (N=37) of the participants indicated that they wanted to learn more about resiliency and historical trauma.

The overall conference evaluations suggest that there is a need for further study and development of resiliency models that can be used to foster healthy outcomes in recovering and healing from historical traumas. In addition, the evaluations imply that conferences like this one are important because they provide a venue for increasing individual and community awareness of models of resiliency that are currently being used to overcome historical trauma. These models include helping to build healthy families by drawing on cultural traditions that strengthen relationships. Further studies need to be conducted on models that focus on resiliency to understand and analyze underlying causes, contributing factors, healthy outcomes and effectiveness in hopes they lead to evidence-based interventions.

Learning Opportunities

Student Internships: A policy of the SAICN was to involve American Indian students from all three of Arizona’s universities (University of Arizona, Arizona State University, and Northern Arizona University) in various aspects of the network’s projects, and through that involvement provide them with support and the development of important skills. This involvement came in the form of paid internships resulting in the development of an interactive genomics glossary (described below, under educational materials) and the development and implementation of the Hoops for Awareness community cancer event described above.
Work on the genomics glossary began when four students, representing all three universities, were hired and began to study genomics terminology, working with the scientific definition to produce a lay definition appropriate for local communities. Once the terms were defined, the interns worked with the Walter Cronkite School of Journalism at Arizona State University to record both scientific and lay terms. Interns also shared their progress at SAICN primary partner and educational core meetings and prepared posters for presentation at the Cancer Health Disparities Summit in Washington DC. Of the four students who contributed to the development of the genomics glossary, one has gone on to pursue a Doctor of Public Health (DrPH) degree in genomics and public health at the University of Washington. Another student is now actively involved in preparing a workbook that will be distributed with the genomics glossary project (described below).

Digital Story Training: Throughout history, stories have been used to teach, express, advocate, and organize groups of people. It is through the sharing of stories that people remember their past, understand their present, and imagine their future. For public health professionals, stories can be an effective tool to create dialogue on a public health issue, to conduct health education outreach activities, and to increase awareness of health issues (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002).

The SAICN introduced media enhanced storytelling training— called “Digital Storytelling” — to tribal communities and health professionals. Digital storytelling is an innovative and visual health education tool for communities to use to increase knowledge about a health topic and to create dialogue on a topic. The process integrates the participants’ own voice and existing images such as photographs and scanned images into brief first-person narratives that can be used to engage others or educate them about a given subject.

The digital storytelling training involves two stages in a two- to four-day workshop. The first stage is an intensive production workshop, where workshop participants go through the process of creating their own digital stories. Participants learn how to craft a script, develop a storyboard, record audio, scan and download images, and edit using digital video software that is available for free on the Internet. Participants are requested to keep their narrative to one page and develop a digital story that will last from two to five minutes. In the second stage, participants receive follow-up support in program implementation and technical assistance as the participants begins to integrate digital storytelling into their work.

After the digital stories are created, participants evaluate the digital stories through a process of informal reflection. To begin, the participants are asked to share their digital story and give informal reflection comments about their making-a-digital-story experience. After their digital story is shared with everyone, comments are invited from other participants. Key questions that are asked included (1) what parts of the story touched you, (2) what images most impressed you, (2) what reaction to the story would you like to share with the storyteller?

Thus far, SAICN staff members have conducted six digital storytelling trainings for six communities and organizations. The stories developed covered organizational programs and activities and highlighted such things as 1) health educators’ activities at the Great Native American Smoke Out, 2) Hopi Cancer Patient Assistance Fund, 3) the Hopi Breast and Cervical Cancer Program, 4) the Inter Tribal of Arizona Inc., 5) Hualapi Health Department and 6) Fort Mojave Health Department. The stories were developed by participants in order to provide information on specific programs, encourage participation into programs, and stimulate discussion about a health topic.

Evaluations of the Digital Storytelling trainings indicate 100% (n=20) satisfaction with the workshop and with the acquisition of technical skills. Comments from participants include the following: “I didn't think I could do this, I thought it was going to be hard...but it turned out to be easier
than I thought.” “I can use this (digital story) in the waiting room…so they can see a video on health instead of just waiting there?” “I can use this so we can get more money for our program.”

**Training in Technical and Science Writing:** A two day class in science and technical writing was developed and taught by university faculty SAICN partners. This class was attended by over 26 students from eight agencies and tribal communities. It focused not only on issues related to formatting, but issues of handling writers block, rules of grammar, and identifying appropriate journals and finding valid sources of information. The classroom experience, included both a lecture and hands-on format, and each student was provided with a laptop computer connected to the internet. The instructors worked with each student individually and discussed topics and themes and, if requested, a critique was given. Students, who all evaluated the class as very successful, were then also given follow-up assignments that were to be returned for review and comments.

**Tribal Small Grants:** A final educational project funded by SAICN included training and technical assistance was the Small Tribal Community Grants Program. Seven tribes/communities were awarded small grant funds based on the communities’ research interest and program development as related to cancer disparities among American Indian communities. The research projects promoted a Community Based Participatory Research approach such that the communities identified and selected the best practices for cancer education services, gaps in services, and effectiveness of existing services and programs. The seven tribes/entities funded included the Gila River Indian Community, Hopi Tribe, Hualapai Tribe, Indian Health Board of Nevada, Kaibab-Paiute Tribe, San Carlos Apache Tribe, and the Tohono O’odham Nation.

The Gila River Indian Community focused on establishing a cancer roster that would identify the boundaries and function of the cancer care system in addition to conceptualize a system for tracking tribal members diagnosed with cancer who did not seek care at the tribal health care corporation or its Contract Health Care Facilities. The project anticipates the establishment of a database for Navigators to track patients both on and off the reservation.

The Hopi Tribe focused on developing a patient navigation system for community members diagnosed with cancer. The data obtained from this study will be used to prioritize the needs to help cancer patients and their families travel the path from cancer diagnosis, treatment, survivorship and/or death.

The Hualapai Tribe focused on developing a “Community-based Model for Cancer Education” in which eight (8) interactive cancer educational modules were offered once a month in community gatherings. The intervention module was adapted to the interests and level of cancer knowledge. The goal was to revitalize the Hualapai traditional beliefs and incorporate the healing songs into cancer awareness and prevention trainings and events.

The Indian Health Board of Nevada focused on developing and implementing culturally-appropriate marketing strategies to raise cancer awareness among American Indians living in Nevada. The Kaibab-Paiute Tribe examined the community’s health beliefs, knowledge and behaviors regarding cancer and their behaviors regarding cancer screening and early detection methods. In order to prevent the incidence and spread of the Human Papillomavirus (HPV) in the San Carlos Apache Tribal community, the study examined the community’s health beliefs and the cultural constructs regarding HPV.

Finally, Tohono O’odham Nation focused on developing and identifying a mapping process of the cancer diagnostic and treatment network project between the Indian Health Service, contract health care and private providers for the community members diagnosed with cancer.
The research projects identified and selected among each entity ranged in methodologies, including focus groups, surveys, and/or assessments of knowledge, attitudes, beliefs, and behaviors related to cancer, cancer risk, and cancer protective factors. Prior to funding, the Inter Tribal Council of Arizona, Inc. established Memorandums of Understandings with the tribal councils and tribal health departments. The projects described above have progressed culturally acceptable programs. The development of a proposal to further develop, implement and evaluate appropriate and culturally sensitive interventions is a planned next step.

Educational and Training Materials

The second category of activities conducted by the SAICN Training and Education Core involved the development of innovative educational materials. These included the development of educational videos using local tribal people, the development of the ‘Gathering Basket’, a CD-Rom compilation of innovative cancer educational materials, and the creation of the interactive Genomics Glossary introduced above.

Education Video Projects: Addressing cancer health disparities that involve American Indians requires providing educational cancer materials that are culturally tailored, culturally sensitive, and appropriate for American Indians going through cancer treatment and for those who provide their care. Currently, few resources are available that specifically address spiritual and cultural aspects for American Indians. The SAICN, in collaboration with Lizard Light Productions, the photographers for the Spiritual Care Conference, saw the potential for reaching a wider, diverse audience by developing videos on lessons learned and stories shared. Two videos on spirituality and cancer, that featured speakers and participants from the Spiritual Care Conference, were developed and have been widely shown and disseminated. These videos are part of a larger toolkit on spiritual care that is being prepared by the SAICN.

The first video, “Cancer Has Crept among Us,” focuses on a family living in a rural reservation in northwestern Arizona and features the story of an American Indian cancer survivor and the many ways that cancer touched her life and the lives of many of her family members. This cancer survivor encouraged viewers to draw upon their spiritual and cultural traditions as a source of hope for the individual, his/her family and for the community. Her story was when she was a participant at the spiritual care conference with her daughter, she asked the question: “Why is cancer killing my family?”

The second video, “American Indian Attitudes and Values: An Integral Part of Cancer Care,” features interviews with American Indian cancer survivors, family members, community leaders and health care providers. The goal of this video is to emphasize the importance of providing spiritually appropriate cancer care services for American Indians.

Both videos, along with a discussion guide booklet, are included as part of an educational toolkit on spirituality and cancer care for health professionals. The aim of this toolkit is to increase awareness and education about the role of cultural and spiritual aspects of cancer care among American Indians.

The Gathering Basket: The Gathering Basket: Journey to Cancer Awareness, is a CD-ROM and web-based (www.gatheringbasket.org) educational tool for Health Educators and Community Health Representatives (CHRs). It provides information and educational materials and resources on breast, cervical, colon, lung, and skin, testicular and prostate cancers which are the leading cancers for American Indians in this region. The Gathering Basket filled an important gap for tribal health educators. While community-focused education on cancer is generally delivered at health fairs, information and resources for tribal health educators and CHRs has been limited and focused
primarily on breast and cervical cancer.

The symbol of a basket was chosen for this project as American Indians have used baskets to fit the varied tasks of farming to gather, store and share food, medicines and give away as gifts. It is a local art, based on materials and dyes originating from the area. Like traditional baskets, this CD-ROM, the Gathering Basket, is a tool to gather information about cancer. A CD-ROM format was chosen due to limited or no internet access in rural American Indian communities. Most community educators only access the internet at work or at Indian Health Service facilities which limit access to downloadable materials.

The Gathering Basket provides downloadable Fact Sheets on each of the seven cancers. The fact sheets include information on signs and symptoms, tips on prevention and early detection and treatment. On the CD-ROM, each cancer module has a different colored ribbon corresponding to an affiliated cancer color. For example, the breast cancer page has a pink ribbon in the gathering basket, while the prostate cancer has a blue ribbon. The goal of each module is to educate men and women about the specific cancer: breast, cervix, colon, lung, skin, prostate and testicular. The objectives are to describe the cancer, when the cancer starts, where it starts, and why it starts. The CD-Rom is currently being field tested in the American Indian community.

**Genomics Glossary:** Through a collaborative process with the Translation Genomics Research Institute (TGen), Indian Health Service, and the three Arizona universities, the SAICN Training and Education Core developed a multimedia glossary of genomic terms, entitled “Talking Glossary of Genomics Terminology.” This talking glossary is modeled after the “Talking Glossary of Genetics” project that was developed by the National Human Genome Research Institute. The glossary initially is available as a user-friendly CD and will eventually be an internet resource on the Inter Tribal Council of Arizona, Inc. website.

The glossary is focused on definitions of genomics terms related to cancer and how the field of genomics research can affect early diagnosis and treatment of cancer. This educational tool was designed to inspire more American Indians to learn more about translational genomics research and about the genetic tie to diseases that affect American Indians. The introduction of the CD includes audio and video commentaries of American Indian tribal leaders and/or elders. These commentaries provide a unique addition to the genomics project with tribal leader viewpoints about often controversial issues such as research, genetics, and the impact of cancer in tribal communities.

The glossary includes approximately 170 genomic and cancer terms along with illustrated diagrams. In addition to the written scientific definition, graduate students from Arizona's three universities recorded lay audio versions of the terms for non-scientific audiences thus allowing opportunity to increase health literacy by explaining genomic terms in lay language. To help conceptualize the terms in application, a written genomics workbook will soon be included to compliment the Glossary. This work book, titled “The Genomics Education Module,” is being developed by a graduate student who participated in the recording of many of the genomic terms. The goal of the Genomics Education Module is to generate a broader understanding of genomics by helping provide an innovative and interactive way to better inform American Indians about genomics research and genetic cancers thus educate and empower American Indian students and community members. The module was based on the premise that the emerging areas of genomics and personalized medicine will have significant impact on the future of medicine and public health. Benefits for American Indian populations may be more widespread if the population has a greater understanding of the basic concepts and terminology.
The SAICN Web link: The Southwest American Indian Collaborative Network web link (www.itcaonline.com/saicn) accessible through the Inter Tribal Council of Arizona, Inc. main website, consists of several pages that provide detailed information about the cancer network, the purpose, the organizational infrastructure, partnerships and collaborations, and the project activities and events. The homepage provides an introduction of the SAICN grant program, the project staff, primary partners, funding sources, as well as the cancer network work plan objectives. A map of Arizona, Utah and Nevada is provided to illustrate the geographical distances between the tribes that are served by the SAICN project. Information on the Spiritual Care Conference and the two videos can be viewed on the SAICN web link. Information on the Talking Glossary and Genomics Terminology project as well as the Cancer 101 Trainings is also provided on the SAICN web link. Contact information for both projects is provided via the web link. Links to a number of national and local cancer organizations also are provided on the SAICN web link. Many of these organizations provide trainings, workshops, and grant opportunities. Partner organizations and collaborators also are able to post upcoming events or training workshops related to cancer.

CONCLUSION AND DISCUSSION

The primary goal of the Training and Education Core was to improve access to culturally-responsive cancer interventions for American Indian communities in Arizona, Utah and Nevada. Through the duration of the SAICN cancer grant, the Training and Education Core established and nurtured its trust through collaborations with the tribes and other entities that facilitate [cancer] health services for American Indians. An important basis of success for the SAICN training and education core was the involvement of tribal leaders, community members as well as the commitment of the primary partners: Inter Tribal Council of Arizona, Inc., Phoenix Indian Medical Center, and the University of Arizona. The inclusion of these elements was crucial in creating a comprehensive voice to reduce cancer disparities among American Indians.

While there continues to be a need for cancer resources for American Indians, the SAICN Training and Education Core facilitated training workshops and conferences for health providers and community members, participated in health fairs and cancer awareness events, hosted conferences that address spirituality and cancer, as well as resiliency and historical trauma. Workshops such as the Cancer 101 train-the-trainer series and Digital Storytelling were instrumental in facilitating opportunities for skilled-based learning related to, but not limited to, increasing participants’ sense of ownership, confidence, and networking as related to cancer education. The development and dissemination of the Gathering Basket: Journey to Cancer Awareness and the spiritual care toolkit (including videos and discussion guide booklet) are fundamental in delivering cancer education and/or support, especially for those [communities] that may have either limited or no internet access.

The activities and programs described in this paper substantiate the value of American Indian community members responsive to the initiation and completion of tribally-driven cancer education and research projects. The SAICN Training and Education projects such as the Tribal Genomics Glossary and the Small Tribal Community Grants are inspirations of the cultural strengths of the tribal communities and they engage American Indian students and local community members. The cancer education activities included in this paper contributed to fulfilling the need for cultural-relevant cancer resources for American Indian communities in the Southwest.

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Results of Universal Prenatal Screening for Hepatitis C Infection in a Remote American Indian Primary Care Population

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ABSTRACT

BACKGROUND: Although chronic liver disease remains a major area of health disparity for American Indian (AI) people, the epidemiology of hepatitis C virus (HCV) infection among AI people is poorly documented. Because of suspected high local prevalence, two remote AI clinics in the Northern Plains implemented universal prenatal HCV screening in 2005. When this screening program reported an unexpectedly high prenatal anti-HCV (anti-HCV antibody) positivity rate, we conducted a case-control study to determine risks for infection and opportunities for community intervention.

MAIN FINDINGS: The clinics screened a total of 205 pregnant women (median age, 22 years). Of these 205 women, a total of 13 (6.3%; 95% confidence interval, 3.4–10.6) had anti-HCV confirmed. Of the anti-HCV-positive women, 10 (76.9%) were aged 15–24 years. We included 10 cases and 40 anti-HCV-negative prenatal controls in a case-control study. On multivariate analysis, only injection-drug use (IDU) remained associated with HCV seropositivity.

CONCLUSIONS: Universal prenatal screening revealed a high prevalence of anti-HCV at these remote AI clinics. This population has not been previously described at being at elevated risk for HCV infection. In order to reduce health disparities, young, rural AI populations seeking prenatal care need to be included in interventions to reduce HCV transmission.

Key Words: American Indians; hepatitis C, infection; prenatal; intravenous drug use; rural
INTRODUCTION

A total of 4.1 million U.S. residents, or 1.6% of the population, has ever been infected with hepatitis C virus (HCV). Of them, 3.2 million, or 80%, are chronically infected (Armstrong et al., 2006). The national prevalence of HCV infection among women of childbearing age is approximately 1%, corresponding to an estimated 40,000 births to HCV-positive women each year (Armstrong et al., 2006). In the United States, HCV is spread chiefly by injection-drug use (IDU), which accounts for 60%–80% of infections (Wang et al., 2007). Prenatal HCV testing is only recommended for women with HCV risk factors (Alter, Kuhnert, & Finelli, 2003), such as a history of injection-drug use or blood/blood product transfusion. Universal prenatal HCV testing is not recommended by the Centers for Disease Control and Prevention (CDC) chiefly because the likelihood of vertical transmission is low (5%–6%) (Centers for Disease Control and Prevention [CDC], 1998).

In July 2005, an Indian Health Service (IHS) prenatal care provider instituted universal prenatal HCV testing (regardless of risk factors) in two IHS clinics in a rural area of the Northern Plains (Montana, Wyoming, and North and South Dakota) where frequent drug use, most notably with methamphetamine and opiates, had been suspected but not documented. Specific population-based data on local injection drug use patterns, and the health-seeking behavior of persons who use them, have not been available for American Indian and Alaska Native (AI/AN) people in this part of the United States. IHS is the federal agency responsible for health care for eligible AI/ANs. In July 2006, the IHS Division of Epidemiology and Disease Prevention was notified by these clinics of a apparently high number of positive prenatal HCV test results among the population seeking prenatal care at these clinics. A field investigation was begun in August 2006 by IHS.

Objectives of the investigation were to confirm the positive prenatal HCV testing results, to estimate the prevalence of antibodies to HCV (anti-HCV), to identify risk factors associated with HCV infection, and to provide recommendations to IHS and the Tribal Health Department to prevent further HCV infections among this population.

METHODS

Human Subjects

The Centers for Disease Control and Prevention and IHS determined that this field investigation was exempt from full Institutional Review Board review. The study was implemented in collaboration with the local Tribal Health Department as a community-based, participatory public health investigation.

Setting

We conducted this investigation at two AI clinical facilities serving remote AI communities in the Northern Plains of the United States. In order to respect local preferences regarding community confidentiality, the specific setting of the investigation will remain confidential.

Prevalence study

For case finding, we used the Resource and Patient Management System (RPMS), an electronic clinical and administrative data software system developed by IHS. At each clinic, we also reviewed medical records and consulted IHS and reference laboratory records. We defined a case of hepatitis C infection, past or current, as the presence of anti-HCV antibodies by enzyme immunoassay (EIA), confirmed by either recombinant immunoblot assay (RIBA® [Chiron Corporation, Emeryville, California]) for anti-HCV (past or current infection) or by nucleic acid testing (NAT) for HCV RNA (current infection) (Alter et al., 2003), in a woman with a first prenatal consultation in either of the two
IHS clinics during July 1, 2005–July 31, 2006. Prenatal anti-HCV prevalence was calculated by dividing the number of pregnant women with confirmed past or current HCV infection by the number of pregnant women who had a first prenatal consultation during the study period and who were screened for HCV infection. Overall and age-specific prevalence estimates were calculated with exact 95% confidence intervals (CI) based on a binomial distribution.

Case-control Study

Subsequently, we conducted an unmatched case-control study to identify risk factors associated with HCV infection. Our case definition for the case-control study was the same as for the prevalence study. First, we randomly selected four control subjects per case-patient from women who attended either of the IHS clinics for their prenatal care and whose prenatal anti-HCV antibody by EIA was negative during the study period. Second, we made up to five attempts to contact each case-patient and selected control subjects by telephone to obtain their oral consent to participate to the study. Third, we asked respondents to complete a standardized questionnaire either at their domicile, or by phone or at the clinics. The questionnaire for HCV infection risk factors included questions on blood/blood product transfusion, solid organ transplant, health-care exposure, occupational exposure, multiple sex partners, sexual intercourse with an infected partner, tattoos, incarceration, drug use, and IDU. We asked respondents about exposures that occurred before the pregnancy during which case-patients and control subjects were screened by using a calendar to help them recall dates.

Data Analysis

Only one and two variable models were considered because of limited sample size. Stata® 10/SE for Windows (College Station, Texas, USA) was used to do exact analyses.

RESULTS

A total of 259 women had a first prenatal consultation at one of the two clinics during the study period. Of them, 205 (79.1%) were screened for HCV infection (median age, 22; range, 13–40). The majority of unscreened women had chosen to seek prenatal care or had been referred to another health-care facility by IHS. Anti-HCV antibodies were detected by EIA in samples from 17 screened women (17/205; 8.3%). A confirmatory RIBA test was requested by treating clinicians for 15 EIA-positive women; no NATs were requested. Two RIBA tests were negative, and 13 confirmed the presence of anti-HCV antibodies. Case patients’ median age was 23 (range, 19–29 years). The overall prevalence, therefore, of confirmed anti-HCV antibody was 6.3%, with the highest age-specific prevalence (7.4%) identified in the 15–24-year age category (Table 1).

<table>
<thead>
<tr>
<th>Age (yrs)</th>
<th>Tested (n)</th>
<th>RIBA®-positive (n)</th>
<th>Prevalence (%)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0–70.8</td>
</tr>
<tr>
<td>15–24</td>
<td>136</td>
<td>10</td>
<td>7.4</td>
<td>3.6–13.1</td>
</tr>
<tr>
<td>25–34</td>
<td>57</td>
<td>3</td>
<td>5.3</td>
<td>1.1–14.6</td>
</tr>
<tr>
<td>35–44</td>
<td>9</td>
<td>0</td>
<td>0</td>
<td>0–33.6</td>
</tr>
<tr>
<td>Overall</td>
<td>205</td>
<td>13</td>
<td>6.3</td>
<td>3.4–10.6</td>
</tr>
</tbody>
</table>

Note. RIBA, recombinant immunoblot assay; CI, confidence interval.
Thirteen (13/15; 87%) case-patients were successfully contacted. Of those patients, three refused to participate; therefore, our case-control study included 10 case-patients and 40 control subjects. Control subjects’ median age was not different from case-patients’ (23 years; range, 16–34 years). In Table 2, we present odds ratios (OR) for risk factors associated with HCV seropositivity. In the univariate analysis HCV seropositivity was strongly associated with IDU before pregnancy (OR, 200.0; 95% CI, 22.7 – infinity; p-value < 0.001), and with illicit drug use, sex with an HCV-positive partner, use of methamphetamine, and having had six or more sexual partners before pregnancy. Therefore, all of the multivariate logistic models we subsequently fit included IDU and one other risk factor associated with HCV seropositivity in the univariate analysis. HCV seropositivity was not associated with blood/blood product transfusion, solid organ transplant, health-care exposure, occupational exposure, tattoos, and incarceration. Ever having used illicit drugs, having sex with HCV-positive partner, methamphetamine use, and having had six or more sex partners did not remain associated with HCV seropositivity after adjusting for IDU, indicating strong confounding.

**DISCUSSION**

This is the first report to describe anti-HCV prevalence and risk factors associated with HCV seropositivity in prenatal patients from a rural AI population. The prenatal confirmed anti-HCV antibody prevalence (6.3%) described in this report was six times higher than the prevalence among women of childbearing age in the U.S. population (Armstrong et al., 2006). The strongest risk factor for HCV seropositivity was IDU before pregnancy. These results represent an important step toward investigating and understanding the nature of HCV risk for AI women.

Because data are generally lacking in regard to HCV infection prevalence among AI/AN people, our work adds significantly to the body of work in this population. The most directly comparable work is a 2004 study among an urban AI population that reported results of universal prenatal anti-HCV testing. The overall prevalence of positive anti-HCV EIA in that study was 3.1% (Wilson, 2004). As opposed to our results, the trend in that study was toward increasing anti-HCV prevalence with increasing age. In a population-based study in Alaska, the minimum HCV infection prevalence estimate among ANs was 0.81% among those aged 20–39 years and 0.88% among females (McMahon et al., 2004). Our investigation reported a higher HCV infection prevalence than either of these studies.

Clearly, the population of rural Americans with a history of IDU is one that is crucial to include in public health interventions designed to reduce HCV-associated health disparities. We identified IDU before pregnancy as the primary risk factor for HCV infection. All other risk factors associated with HCV infection in the univariate analysis, e.g. ≥ 6 sexual partners before pregnancy, were not associated after controlling for IDU. Other studies have reported IDU as the most important risk factor for HCV transmission even among a population with high sexual risks (McMahon, Pouget, & Tortu, 2007). IDU has been reported as the strongest risk factor for HCV infection among the general U.S. population (Armstrong et al., 2006), among U.S. blood donors (Murphy et al., 2000), and in an HCV prospective screening study in an urban AI clinic (Neumeister et al., 2007). In a recent publication, pregnancy hospitalizations with a diagnosis of amphetamine abuse had doubled during 1998–2004 and were most frequent among rural women aged < 24 years living in the western United States (Cox, Posner, Kourtis, & Jamieson, 2008), which is similar to the population in which we conducted our work. We identified lifetime methamphetamine use reported by 67% of case-patients and 13% of control subjects (Table 2).
Table 2. Risk factors for hepatitis C virus seropositivity among pregnant American Indian women — Northern Plains, 2005–2006

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Cases</th>
<th>Control</th>
<th>Unadjusted OR (exact 95% CI)</th>
<th>Risk factors adjusted by IDU* OR (exact 95% CI)</th>
<th>IDU adjusted by risk factors* OR (exact 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDU</td>
<td>8/9 (89)</td>
<td>0/40 (0)</td>
<td>200.0 (22.7–inf)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Ever used any illicit drugs</td>
<td>9/9 (100)</td>
<td>8/40 (20)</td>
<td>42.8 (6.0–inf)</td>
<td>3.6 (0.1–inf)</td>
<td>39.2 (4.1–inf)</td>
</tr>
<tr>
<td>Sex with HCV-positive partner</td>
<td>4/9 (44)</td>
<td>1/39 (3)</td>
<td>6.2 (1.3–46.3)</td>
<td>5.8 (0–38.5)</td>
<td>74.4 (7.5–inf)</td>
</tr>
<tr>
<td>Ever used methamphetamine</td>
<td>6/9 (67)</td>
<td>5/40 (13)</td>
<td>12.9 (2.0–107.3)</td>
<td>7.2 (0–280.8)</td>
<td>83.4 (9.6–inf)</td>
</tr>
<tr>
<td>≥6 sex partners</td>
<td>8/10b (80)</td>
<td>11/38b (29)</td>
<td>9.3 (1.5–103.6)</td>
<td>2.2 (0.1–inf)</td>
<td>84.2 (9.8–inf)</td>
</tr>
</tbody>
</table>

Note. Cases, case-patients; Controls, control subjects; OR, odds ratio; CI, confidence interval; IDU, injection drug use; inf, infinity.

*Four separates models were constructed, each model includes IDU and one risk factor

a One case-patient refused to answer questions related to illicit drug use.

b Two control subjects refused to answer questions related to sexual behavior.

A high prevalence of anti-HCV antibodies was identified in this study because universal prenatal HCV testing was implemented. However, universal HCV testing in pregnancy has been demonstrated not to be cost-effective, and is therefore not a standard of care (Plunkett & Grobman, 2005). In the long-term, a standard HCV infection risk assessment, together with counseling, might be a more effective strategy to identify women at risk for HCV infection in this rural community. This approach might avoid unnecessary anxiety for women without risk factors. Conversely, because of the suspected high rate of IDU among this population and the risk for IDU underreporting (Magura & Kang 1996), a standard HCV infection risk assessment might miss a substantial number of patients at high risk among this prenatal population.

Confirmation of positive anti-HCV EIA by HCV NAT and genotyping of HCV were not performed by the treating clinicians in the patients reviewed in this investigation. Since 20-30% of those testing antibody positive might be expected to clear the virus and only those chronically infected (i.e. NAT positive) can transmit the virus, this information is important to inform women about the risk of vertical transmission. Similarly, HCV genotype results can provide patients and providers with valuable information on the likelihood of responding to antiretroviral therapy (Hoofnagle & Seeff, 2006). Incomplete workup of AI/AN patients diagnosed with HCV infection has been documented in other settings, and is thought to relate to lack of treatment resources (Norton, Redd, & Bryan, 2009).

The major strength of our study is that it was conducted using clinical data, available both in paper charts and in a robust electronic data system (RPMS), from a rural population with universal access to primary health care. Our findings are, however, subject to certain limitations. First, our sample size was limited by the size of the population served by the two prenatal clinics, and the setting of only two clinics in a specific geographical region limits our ability to generalize study results to other AI groups. Second, studies of volunteer blood donors have reported that 30%–50% of those with an HCV-positive screening admitted to a history of IDU after being presented with their result. None of these donors had reported this risk factor at the time of donation (Orton, Stramer, Dodd & Alter, 2004). In our study, all case-patients (who knew about their seropositivity) reported IDU, but none of the control subjects did, raising the question of underreporting of IDU among...
the control subject group. This might have overestimated the association between IDU and HCV infection. Third, during the study period, HCV NATs were not requested as either confirmatory tests (Alter et al., 2003) or as part of the standard hepatitis C workup. Therefore, we cannot report on the proportion of patients who were HCV RNA-positive.

CONCLUSION

Our discovery of a high prevalence of prenatal HCV infection represents a challenge to providers of prenatal and general medical care, particularly in this isolated AI population with existing health disparities and behavioral risk factors (Mahoney & Michalek, 1998). Both IHS clinics involved in this investigation have added an IDU assessment to standard patient intake to help identify patients who should be screened for HCV infection. In addition, the Tribal Health Department, in coordination with the local IHS clinics, has been active in encouraging tribal members with a history of IDU to obtain HCV screening. Prevention activities to reduce HCV transmission through IDU need to include access to testing and counseling services and drug treatment. Special programs have been developed to address the challenge of delivering HCV infection treatment to populations who have limited access to specialty care (Arora, Thornton, Jenusky, Parish & Scaletti, 2007), meaning that although the patients identified in this screening programs face substantial barriers to treatment, such treatment has been successfully delivered to rural Americans, including AI/AN people. These programs may be complicated by the difficulty of providing HCV treatment to intravenous drug users with limited eligibility criteria (Hagan et al, 2006). Continued investigation is needed in rural AI and non-AI populations to evaluate HCV prevalence and the contribution of IDU to HCV infection, and to guide prevention measures that are appropriate for the specific communities affected. Providers of rural health care should, like other providers, perform an accurate and complete assessment of behavioral health risks, and refer patients with behavioral risks for appropriate testing and treatment.

DISCLAIMERS

(1) Use of trade names is for informational purposes only and does not constitute endorsement by the Centers for Disease Control and Prevention or the Indian Health Service.

(2) The findings and conclusions of this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention or the Indian Health Service.

ACKNOWLEDGEMENTS & SUPPORT

We gratefully acknowledge the Indian Health Service public health nurses, laboratory supervisors, the Service Unit Director, and other staff involved in this investigation. We also acknowledge the members of the Tribal Health Department for their support, and for their assistance in working with the involved community.

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REFERENCES


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Many older bone densitometer (DXA) machines are programmed to calculate T-scores for African-American patients using peak African-American bone mass as reference standard.

This presents a problem because most data regarding fracture risk has been derived using Caucasian data (Binkley 2002). If the T-score for an African-American woman is calculated using a race-adjusted reference, the same absolute bone density will yield a lower T-score for an African-American than for a Caucasian woman. For this reason, the International Society for Clinical Densitometry has recommended that T-scores for all women, regardless of ethnicity, be calculated from Caucasian reference standards (ISCD 2007).

An African-American patient was referred to our clinic because of an abnormal bone density study. Her DXA measurements (gm/cm²) and the reported T-scores are shown in Table 1. We suspected these calculations were done using the African-American reference standard and asked that the T-scores be recalculated on the same machine, entering the patient as Caucasian. The results are shown in the 3rd column of Table 1.

### Table 1. Density and T-scores for a 64 year-old African-American Woman

<table>
<thead>
<tr>
<th>Site</th>
<th>Bone mineral density (g/cm²)</th>
<th>Race-adjusted T-score</th>
<th>Non-race-adjusted T-score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spine</td>
<td>0.824</td>
<td>-3.0</td>
<td>-2.0</td>
</tr>
<tr>
<td>R total hip</td>
<td>0.865</td>
<td>-1.1</td>
<td>-0.6</td>
</tr>
<tr>
<td>R femoral neck</td>
<td>0.740</td>
<td>-1.5</td>
<td>-1.0</td>
</tr>
<tr>
<td>L total hip</td>
<td>0.932</td>
<td>-0.6</td>
<td>-0.1</td>
</tr>
<tr>
<td>L femoral neck</td>
<td>0.728</td>
<td>-1.6</td>
<td>-1.1</td>
</tr>
</tbody>
</table>
Using the initial calculations, the patient has a diagnosis of osteoporosis and is therefore a candidate for bisphosphonate therapy. Using the recalculated values and the World Health Organization fracture risk assessment tool FRAX® pharmacologic therapy is not recommended.

Clinicians who treat African-American women should ascertain whether bone density T-scores for these patients are being calculated with African-American or with Caucasian peak bone density as the reference standard. Older machines that report T-scores based on an African-American reference standard can be replaced or updated with software available from the manufacturer.

REFERENCES
Binkley, N.C., Schmeer, P., Wasnich, R.D., & Lenchik, L. (2002). What are the criteria by which a densitometric diagnosis of osteoporosis can be made in males and non-Caucasians? *J Clin Densitom, 5* (supplement), S19-27.


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Poverty and Mortality Disparities in Central Appalachia: Mountaintop Mining and Environmental Justice

Michael Hendryx, PhD, West Virginia University

ABSTRACT

Objectives. This study investigated the associations between poverty rates, Appalachian mountaintop coal mining, and age-adjusted total mortality rates to determine if persons exposed to this form of mining experience greater poverty and higher death rates compared to other types of mining or other areas of Appalachia.

Methods. Mortality rates, poverty rates, Appalachian designation and mining activity were examined for counties in Kentucky, Tennessee, Virginia and West Virginia (N=403). Linear least squares models tested for annual group differences from 2000-2007 in total and child poverty, and total mortality, based on mining type and Appalachian location. Nested linear models accounting for state-level effects were used to determine whether mountaintop mining and poverty were associated with mortality rates controlling for other risks.

Results. Mountaintop mining areas had significantly higher mortality rates, total poverty rates and child poverty rates every year compared to other referent counties of these states. Both poverty and mountaintop mining were independently associated with age-adjusted mortality rates in nested models.

Conclusions. Persons living in MTM areas experience persistently elevated poverty and mortality rates. Higher mortality is independently associated with both poverty and MTM, the latter effect suggestive of a possible environmental contribution from mining activities. Efforts to reduce longstanding health disparities in Appalachia must focus on those areas where disparities are concentrated: the Appalachian coalfields.

Key Words: environmental justice; Appalachia; coal mining; mortality; poverty
BACKGROUND

The relationship between poverty and population health disparities including premature mortality is well established (Shaw & Smith, 2006). For example, a recent study found that poverty had a larger impact on reducing quality-adjusted life years than more traditional public health and health services variables including smoking, obesity, binge drinking, and health insurance (Muennig, Fiscella, Tancredi, & Franks, 2009). There is increasing recognition in the United States and internationally for the critical need to focus public health efforts on the fundamental determinates of population health including socioeconomic disadvantage (Aday, 2005).

The Appalachian region of the United States contains all of West Virginia and parts of 12 other states extending from southern New York to northern Mississippi, and has a population of almost 25 million people (ARC, 2007). Persons living in Appalachia are known to experience adverse health outcomes at greater rates compared to national averages (Barnett, Halverson, Elmes, & Brahman, 2000; Wingo, et al., 2008) and this disparity is due in part to socioeconomic disadvantage (Hendryx & Ahern, 2009). The National Institutes of Health recognizes Appalachia as a priority area in efforts to reduce and eliminate health disparities (Zerhouni & Ruffin, 2002).

Coal has been mined in Appalachia since the 1700s. Within the last approximately 30 years, a form of surface coal mining called mountaintop mining (MTM) has become widespread in parts of central Appalachia including areas of Kentucky, West Virginia, Virginia and Tennessee, with most of this activity occurring since 1995 (Skytruth, 2009). Surface mining as a percent of total mining has correspondingly increased over this time (Freme, 2008). The MTM process involves stripping vegetation and topsoil from ridges and peaks, using explosives to remove up to hundreds of feet of rock above and between the coal seams, and disposing of excess rock into adjacent valleys. MTM has deforested approximately 2,000 square miles, and permanently buried 2,000 miles of Appalachian headwater streams (EPA, 2010; McQuaid, 2009). The evidence is strong that MTM is highly polluting to the air and water of local environments during and after mining activity (EPA, 2010; Hitt & Hendryx, 2010; McAuley & Kozar, 2006; Palmer, et al., 2010; Pond, Passmore, Borsuk, Reynolds, & Rose, 2008).

One motivating factor in the attractiveness of this form of mining for coal companies is the reduced labor costs of surface MTM sites relative to underground mines. Surface coal mines require fewer employee hours per ton of coal than underground mines (Freme, 2008). Corresponding to an increase in surface mining practices, the number of mining jobs in Appalachia has declined by more than 50% between 1985 and 2008 (Freme, 2008). These declining economic opportunities place the population at greater risk for layoffs, job loss (with corresponding multiplier effects through local economies), and poverty.

Appalachian health disparities are well recognized but not all Appalachians are exposed to the same socioeconomic or environmental risks. Previous studies have documented health disparities in mining areas of Appalachia in general or in West Virginia specifically (e.g., Hendryx, 2008; Hendryx & Ahern, 2008; 2009; Hendryx, O’Donnell & Horn, 2008; Hitt & Hendryx 2010; Hendryx & Zullig, 2009) but these studies have not examined effects specific to MTM. The current study examines whether the Appalachian subpopulation residing in MTM areas experiences greater poverty risks than other areas, and whether both poverty and MTM risks are related to health outcomes as measured by mortality rates. Results of the study have implications for efforts to reduce disparities and promote environmental justice for a vulnerable population.

METHODS

Design. The study is an analysis of the associations among county-level poverty rates, coal mining, and mortality rates for the four-state region of Kentucky, Tennessee, Virginia and West Virginia. Some but not all of the counties in the four states included in this study are in Appalachia.
Appalachian counties were defined by Appalachian Regional Commission designations in place in 2006. Some analyses, described below, examine trends over the years 2000-2007, and some analyses collapse mortality rates across years.

**Data and Variables.** Coal mining data were obtained from the Energy Information Administration (EIA) (Freme, 2008) and from satellite imagery to identify MTM areas (Skytruth, 2009). Coal mining activity was recorded from the EIA for the years 2000-2007 based on any coal mining (surface or underground) over that time. MTM occurs in a contiguous geographic area that includes parts of southern West Virginia, eastern Kentucky, western Virginia, and eastern Tennessee. MTM is identified from satellite imagery as a surface mining site that crosses over a ridge or mountain peak, and that either 1) spans at least 320 acres including at least 40 acres of removed ridge top or 2) spans 40-320 acres and contains at least 10-40 acres of ridge top (Skytruth, 2009). A county was classified as an MTM county regardless of the number or size of MTM sites or whether the site was historical or active over the study period. The satellite imagery was last updated in 2005. Each county was thus classified into one of three groups: MTM county, coal-mining county but outside the MTM area, or non-mining county. Figure 1 presents a map of the four state area with county mining designations.

![Figure 1. Coal mining areas in Central Appalachian states, 2000-2007.](image)

The primary focus of the study was on poverty and MTM. However, I examined a set of additional covariates as well. The choice of which covariates to include was based on previous research on this topic, and on additional prior evidence that the selected variables (poverty, high school and college education rates, smoking rates, African American race, metropolitan setting, and obesity rates) exert the strongest influences on population health outcomes including mortality (Muennig, et al., 2009; Woolf, Johnson, & Geiger, 2006; Woolf, Johnson, Phillips, & Philipsen, 2007). I did not include other race or ethnicity groups in addition to African Americans because of small population sizes of these groups in most parts of these states.

Poverty and other demographic data were taken from the 2008 Area Resource File (ARF, 2008) which in turn is based on US Census data and Census estimates. Poverty rates included those for the entire population, and rates specific to children aged 0-17, for each year 2000-2007. Education rates
and percent African American population were based on 2000 Census data. Metropolitan status (yes/no) was taken from the ARF based on US Department of Agriculture (USDA) rural-urban continuum codes in place in 2003. Adult smoking rates were obtained from Behavioral Risk Factor Surveillance System (BRFSS) survey data for 2003 and 2006 as reported on the BRFSS website (CDC, 2007) and on state-specific public health department websites. Adult obesity rates as measured in 2007 were obtained from the USDA's Food Atlas (USDA, 2010).

Total age-adjusted mortality rate per 100,000 was found for the years 2000-2007 from CDC public data (CDC, 2008). Rates were age-adjusted to the US Standard 2000 population. Mortality from all internal causes was included; mortality from external causes (injury, homicide, and suicide) was excluded.

I included poverty for the period of time 2000-2007 because earlier poverty figures were calculated differently on the ARF and did not seem consistent when compared to more recent figures, and 2007 was the most recent year available. I included mortality for the period 2000-2007 to begin with the same year as the poverty data and ending with the most recent data available on the CDC public database. I included mining data for 2000-2007 to coincide with these other data. There were eight counties that had small amounts of non-MTM mining in the years 1994-1999 but no mining during 2000-2007; these counties were classified into the non-mining group for the current study. The timing for the various measures are not the same, but were collected to represent the same time period as much as possible given data availability.

Two alternative classifications of counties were created to examine mining-related effects. The first consisted of three groups: MTM counties, other coal mining counties, and the remaining non-mining counties. The second consisted of three groups: the same MTM counties (all of which are in Appalachia), other Appalachian counties, and the remaining non-Appalachian counties. These alternatives provide a test of MTM effects relative to 1) other mining and 2) general Appalachian effects. Although most mining in these four states occurs in Appalachia, there is a non-Appalachian mining area in western Kentucky, and there are areas of Appalachia without coal mining.

**Analysis.** Analyses included least squares models using the SAS GLM (General Linear Models) procedure to examine total and childhood poverty rates each year for the years 2000-2007 by county groups, and to examine total age-adjusted mortality rates for the years 2000-2007 by county groups. Overall F values were found for each year and each comparison, followed by post-hoc Ryan-Einot-Gabriel-Welsch multiple range tests to compare the three group means controlling for Type I error.

The second major analysis examined total age-adjusted mortality as the dependent variable, with mining and poverty as the primary independent variables of interest, controlling for other covariates. Mining was treated as a categorical variable (MTM, other mining, and non-mining as the referent.) These models were run using SAS Proc Mix, with mining as a random variable nested within a fixed state effect. This nested structure allows for possible within state correlated effects that may relate to state differences in environmental or health policies. A sandwich estimator was used to calculate robust standard errors. Prior to conducting these models, covariates were examined for multicollinearity and high-school education was dropped from further analysis because it correlated highly with poverty. Models examined the mean age-adjusted mortality rate for the combined years 2000-2007 in relation to MTM county (yes/no), non-MTM mining county (yes/no), total mean poverty rate for the years 2000-2007, percent African American, adult obesity rate, adult smoking rate, college education rate, and county designation as metropolitan or non-metropolitan. Three models were examined. Model 1 included only MTM and non-MTM mining as the independent variables, Model 2 added poverty, and Model 3 added other covariates.
RESULTS

A total of 403 counties with complete data on the measures of interest were included in the analysis. Divided into groups on the basis of mining, there were 37 MTM counties, 44 other mining counties, and 322 non-mining counties. Divided into groups based on Appalachian status, there were the same 37 MTM counties in Appalachian areas, 148 other Appalachian counties and 218 non-Appalachian counties.

Poverty rates in the MTM areas were significantly higher in every year 2000-2007 compared to other areas (Table 1). This was true for both total and child poverty rates, and when the comparisons were based on other mining or on other Appalachian areas. Age-adjusted mortality rates were also significantly higher every year 2000-2007 in MTM areas for both comparisons (Table 1). The model F value for every test was significant at p<.0001, and group differences described in the Table were based on post-hoc means tests controlling for Type I error rates. Figure 2 provides an example of one of these results over time, for the data at the bottom of Comparison 1 concerning mortality rates for MTM, other mining, and non-mining counties; this figure shows that non-MTM areas were not different from non-mining counties, but illustrates the significantly higher annual mortality rates present in MTM areas compared to both other groups.

Table 1. Adult poverty rates per 10, child poverty rates per 100, and total age-adjusted mortality rates per 100,000 for mountaintop mining (MTM) areas compared to other mining, non-mining, Appalachian, and non-Appalachian counties, years 2000-2007

<table>
<thead>
<tr>
<th>Comparison 1: MTM vs Other-Mining vs Non-Mining</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult poverty rate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MTM</td>
<td>22.8**</td>
<td>23.5**</td>
<td>23.4**</td>
<td>22.1**</td>
<td>23.3**</td>
<td>26.8**</td>
<td>25.5**</td>
<td>25.4**</td>
</tr>
<tr>
<td>Other-mining</td>
<td>17.7</td>
<td>18.6</td>
<td>18.4</td>
<td>17.8</td>
<td>19.0</td>
<td>21.3</td>
<td>20.7</td>
<td>20.9</td>
</tr>
<tr>
<td>Non-mining</td>
<td>12.9</td>
<td>13.4</td>
<td>13.7</td>
<td>13.4</td>
<td>14.0</td>
<td>15.3</td>
<td>15.3</td>
<td>15.3</td>
</tr>
<tr>
<td>Child poverty rate</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MTM</td>
<td>30.9**</td>
<td>30.6**</td>
<td>32.7**</td>
<td>33.0**</td>
<td>32.0**</td>
<td>37.4**</td>
<td>35.0**</td>
<td>34.6**</td>
</tr>
<tr>
<td>Other-mining</td>
<td>24.5</td>
<td>25.1</td>
<td>26.0</td>
<td>26.1</td>
<td>26.1</td>
<td>29.4</td>
<td>28.7</td>
<td>28.8</td>
</tr>
<tr>
<td>Non-mining</td>
<td>18.1</td>
<td>17.9</td>
<td>18.6</td>
<td>19.4</td>
<td>18.9</td>
<td>21.2</td>
<td>21.1</td>
<td>21.2</td>
</tr>
<tr>
<td>Mortality rate per 100,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MTM</td>
<td>1023*</td>
<td>1037*</td>
<td>1041*</td>
<td>1021*</td>
<td>987*</td>
<td>991*</td>
<td>986*</td>
<td>950*</td>
</tr>
<tr>
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<td>950</td>
<td>926</td>
<td>931</td>
<td>923</td>
<td>877</td>
<td>892</td>
<td>854</td>
<td>833</td>
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<tr>
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<td>895</td>
<td>894</td>
<td>891</td>
<td>844</td>
<td>853</td>
<td>820</td>
<td>810</td>
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</tbody>
</table>

Comparison 2: MTM vs Other Appalachian vs Non-Appalachian

<table>
<thead>
<tr>
<th>Comparison 2: MTM vs Other Appalachian vs Non-Appalachian</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
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<tbody>
<tr>
<td>Adult poverty rate</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MTM</td>
<td>22.8**</td>
<td>23.5**</td>
<td>23.5**</td>
<td>22.2**</td>
<td>23.3**</td>
<td>26.8**</td>
<td>25.5**</td>
<td>25.4**</td>
</tr>
<tr>
<td>Other-Appalachian</td>
<td>16.1</td>
<td>16.8</td>
<td>16.8</td>
<td>16.1</td>
<td>17.0</td>
<td>19.1</td>
<td>19.0</td>
<td>18.9</td>
</tr>
<tr>
<td>Non-Appalachian</td>
<td>11.8</td>
<td>12.1</td>
<td>12.5</td>
<td>12.5</td>
<td>13.0</td>
<td>14.0</td>
<td>13.9</td>
<td>14.0</td>
</tr>
</tbody>
</table>
Poverty and Mortality Disparities in Central Appalachia • Hendryx

<table>
<thead>
<tr>
<th>Child poverty rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>MTM</td>
</tr>
<tr>
<td>Other-Appalachian</td>
</tr>
<tr>
<td>Non-Appalachian</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mortality rate per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>MTM</td>
</tr>
<tr>
<td>Other-Appalachian</td>
</tr>
<tr>
<td>Non-Appalachian</td>
</tr>
</tbody>
</table>

* MTM significantly higher (p<.05) than other two groups, and other two groups not significantly different from each other.
** All three groups significantly different (p<.05) from each other.

Figure 2. Age-adjusted mortality rates per 100,000 for the years 2000-2007 for counties in MTM areas, other mining, and non-mining counties, Kentucky, Tennessee, Virginia and West Virginia.

Table 2 shows the results of the nested linear models with robust standard errors. In Model 1, MTM was associated with significantly higher mortality rates compared to the non-mining referent, but other mining areas were not different from the referent. When the significant effect of poverty was added to Model 2, the effect of MTM was reduced but remained significant. Adding additional covariates in Model 3 did not alter the significant effects of MTM and poverty. Although not shown in Table 2, comparing MTM to the Appalachian and non-Appalachian groups also resulted in significantly higher MTM mortality rates in all three models.
Table 2. Model results for total age-adjusted mortality per 100,000 in relation to mountaintop mining (MTM) activity, poverty, and other covariates, for Kentucky, Tennessee, Virginia and West Virginia (N=403).

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Model 1</th>
<th></th>
<th>Model 2</th>
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<th>Model 3</th>
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<td></td>
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<td>P&lt;</td>
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<td>(standard error)</td>
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</tr>
<tr>
<td>Mountaintop mining (MTM)</td>
<td>127.2 (18.3)</td>
<td>.0001</td>
<td>51.3 (18.4)</td>
<td>.022</td>
<td>63.0 (13.8)</td>
<td>.002</td>
</tr>
<tr>
<td>Mining in non-MTM areas</td>
<td>28.2 (23.4)</td>
<td>.26</td>
<td>-12.8 (14.9)</td>
<td>.42</td>
<td>-4.5 (10.1)</td>
<td>.67</td>
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<td>8.8 (1.7)</td>
<td>.0001</td>
<td>6.2 (0.8)</td>
<td>.0001</td>
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<tr>
<td>Smoking rate</td>
<td></td>
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<tr>
<td>Obesity rate</td>
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<tr>
<td>Percent African American</td>
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<td>.0001</td>
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<td>Percent with college</td>
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<td>.03</td>
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<td>-3.4 (0.3)</td>
<td>.0001</td>
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<td>18.3 (3.0)</td>
<td>.0001</td>
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DISCUSSION

Poverty is concentrated in MTM areas of central Appalachia compared to other types of mining activity, to other counties in central Appalachia, and to the non-Appalachian portion of these states. The higher mortality rates present in MTM areas compared to non-mining areas can be attributed in part to poverty, but both poverty and MTM activity contribute unique variance to understanding mortality disparities present in central Appalachia. This study does not attempt to determine whether MTM activity causes poverty, though the effects of MTM on such factors as depressed property values, employment declines and volatility, and foregone alternative economic opportunities have been previously identified (Burns, 2007; Freme, 2008; Wood, 2005). Rather, the study establishes the simple fact that MTM areas have higher poverty. Thus, residents of these areas are faced with the combined risks of differential exposures to potential environmental hazards in the context of socioeconomic vulnerability.

Limitations of the study include those imposed by the county-level ecological design. Data were not available on individual MTM exposures in relation to poverty status or mortality. However, some writers have argued that, from an environmental justice perspective, it is not necessary to prove direct causal links between specific environmental exposures and disease outcomes, and that evidence at a community level of compound disadvantages imposed by poor environmental conditions, poverty, and other factors, is sufficient to invoke action to improve those communities (Kriebel, et al., 2001; Wakefield & Baxter, 2010).

Another limitation concerns temporal and other imperfections in the data. Most covariates were measured only at a single point, such as 2000 Census data, and so do not precisely correspond with mortality observations. The temporal and spatial relationship between MTM activity and mortality is inexact as well; for example, some of the MTM activity took place years before the mortality observations, although the correct temporal specification between possible exposure and subsequent mortality is not clear and some lag would be expected, in other cases exposure could lead to acute exacerbation of an existing illness over a short time. MTM was coded as a simple yes/no
variable regardless of its scope within a county. To the extent that MTM affects air and water quality, those effects may cross county boundaries. All of these considerations (including MTM at smaller scales, including older and newer MTM activity, and cross-county MTM effects) would be expected to make observed MTM effects conservative.

The lack of significance of the smoking variable in the regression model partly reflects its overlap with other covariates but also suggests that smoking rates were imprecisely measured. (In other analyses, results not shown, I found that smoking rates were significantly higher in MTM areas versus other groups, and so to the extent that this higher smoking variability has been captured, MTM effects remained significant after controlling for the higher smoking rates measured there.) Biological mechanisms by which pollution from MTM may impact health are not assessed in this study, and in general are poorly understood. Given the evidence for impaired air and water quality involving multiple chemicals (e.g., explosive chemicals, diesel fuels, silica, coal itself and its trace elements), and the evidence for health disparities that include multiple disease states including cancer, heart disease, lung disease, and kidney disease (Hendryx, O’Donnell, & Horn, 2008; Hendryx 2008), it may be that exposure effects vary across settings; one community may be faced with toxic dust from explosives and overburden at an MTM site, while another may experience contaminated water from coal processing or mine drainage. It remains an important next research step to identify personal level exposures, doses, and resulting biological impacts.

Previous research on health disparities in relation to Appalachian coal mining has usually examined mining regardless of its type (that is, combining surface and underground), and has focused on mining either throughout Appalachia or in West Virginia (e.g., Hendryx, 2009; Hendryx & Ahern, 2008, 2009; Hendryx & Zullig, 2009). The current study is one of few to examine effects specific to MTM areas in the several central Appalachian states. The results show that not all areas of Appalachia experience the same health disparities. Disparities are concentrated in the portion of central Appalachia where MTM occurs. The National Institutes of Health has targeted Appalachia as part of the national effort to reduce and eliminate disparities based on race, socioeconomic status, rural or urban setting, region, and other variables (Zerhouni & Ruffin, 2002). To achieve the national goal of eliminating Appalachian disparities, efforts must concentrate on reducing and eliminating disparities specifically in the central Appalachian MTM region.

For these efforts to succeed, we will need to address both socioeconomic and potential environmental risks faced by area residents. Persons exposed to environmental risks are more likely to experience adverse health consequences when they are already vulnerable due to other risks, such as those imposed by poverty (Evans & Kantrowitz, 2002). Even in the face of uncertainty regarding individual-level environmental exposures, prudent and reasonable efforts to reduce environmental risks can include stricter monitoring and enforcement of air and water quality standards, and restrictions on MTM practices to ensure that they occur only when adequate environmental quality standards can be met during mining and post-mining reclamation activities. Efforts to reduce poverty can include economic diversification and job creation programs; investments in K-12, vocational, college, and adult education; and modifications to tax structures to divert public dollars to geographic areas of greatest needs. These efforts become even more important when we consider that coal reserves in central Appalachia are expected to peak and production to enter permanent decline within the next few years (Milici, 2006; Ruppert, 2001), further reducing coal’s economic contributions to the region.
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Poverty and Mortality Disparities in Central Appalachia • Hendryx


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Spiritual Care within Oncology Care: Development of a Spiritual Care Program at an Indian Health Service Hospital

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ABSTRACT

Spiritual care is essential in providing quality health care for patients and their families and is supported in the mission of the Indian Health Service (IHS). Their mission is to raise the physical, mental, social and spiritual health of American Indians and Alaska Natives to the highest level. This paper will describe the spiritual care programs at the Phoenix Indian Medical Center, an IHS hospital located in Phoenix, Arizona. Two hospital committees, the Volunteer Chaplains’ Association and the Traditional Cultural Advocacy Committee, provide spiritual care for the medical center and work to sustain a presence of spiritual and cultural awareness and well being. In this paper, particular attention is focused on the ways in which these committees have worked collaboratively with community agencies, tribes in Arizona, and academic institutions, through National Cancer Institute funded grants to raise awareness of how spiritual and cultural understandings of American Indians play an essential role in cancer care.

Key Words: Spirituality, American Indians, Traditional Indian Medicine, Chaplain, Oncology Care

The mission of the Indian Health Service (IHS) is “to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level.” It recognizes the importance of spiritual care in providing quality health care for patients and their families (Indian Health Service, 2011). In this paper, we describe the spiritual care infrastructure, history, activities and collaborative efforts with community agencies, tribes in Arizona, and academic institutions, aimed at sustaining a presence of wellbeing and spiritual and cultural awareness at Phoenix Indian Medical Center (PIMC), an IHS facility located in Phoenix, Arizona. These efforts are guided by two PIMC committees, the Volunteer Chaplains’ Association and the Traditional Cultural Advocacy Committee (TCA), both of which provide spiritual care at the medical facility. The collaborative efforts of the committees to specifically address the spiritual needs of patients and their families going through a cancer experience were funded by National Cancer Institute grants (Grant Numbers UO1 CA 86122-02 and U01 CA11469), aimed at decreasing cancer health disparities.
BACKGROUND

Indian Health Service and the Phoenix Indian Medical Center

The IHS, an agency within the Department of Health and Human Services (DHHS), is responsible for providing healthcare services to members of the approximately 564 federally recognized tribes in 35 states. Phoenix Indian Medical Center (PIMC, one of the largest facilities in the IHS with an approximate 60 inpatient bed capacity, is accredited by The Joint Commission (TJC) and the medical staff is employed in a staff-model medical practice.

PIMC provides healthcare through approximately 300,000 outpatient visits per year and offers a range of comprehensive care including pediatrics, surgery, emergency, primary care, dental, eye, behavioral health, and oncology. Inpatient care includes specializations in intensive care, general medical and surgical care, and obstetrics and gynecology. Patients live in metropolitan Phoenix, while others are transported urgently or emergently from outlying remote areas for health care unavailable at their home reservation clinic. Many patients have utilized the IHS as their primary, and often only source of health care for their entire lives, as have their parents and grandparents.

Diversity of Spiritual and Cultural Understandings

American Indian and Alaska Natives (AI/AN) look to elders, healers, practitioners, pastors and ministers when needing spiritual guidance for health and healing. Often, assistance will be sought from more than one group, as there can be much diversity as to beliefs about spirituality and healing within a family and within a tribal community. As expressed by Linda Burhansstipanov, 2001:p. 211: “…a large group are bicultural who use both Traditional Indian medicine (TIM) as well as modern western medicine for their health care problems.” An important facet of AI/AN societies and tribes is respect for individual autonomy and this includes a person’s spiritual beliefs (Ellerby, et al., 2000). Just as each tribe has its own language and culture, so it is with practices and beliefs related to spiritual and religious understandings. Trust and respect earned by spiritual leaders is highly valued among AI/AN and relationships between the leaders and those they serve are of upmost importance. There are many AI/AN for whom traditional tribal understandings and customs embody and define their spiritual worldview and identity.

Whether living on their home reservations or not, many AI/AN have close cultural and spiritual ties to their families and communities. When seeking healthcare, particularly for a hospitalization or an illness requiring specialized treatment, patients are often separated from their families, sometimes for extended periods, and enter into a technological environment, which is both isolating and intimidating (Kelly & Minty, 2007).

Spiritual ties to communities are not simply a descriptive term but can have far-reaching implications for a person’s physical and spiritual health and wellness. For example, in the Navajo tradition, one’s spiritual strength, identity and protection are found within the four Sacred Mountains where the creation stories and spiritual beings reside and form the homeland “boundaries” of the tribe (Nabokov, 2007). Being far away from one’s support system and one’s home leaves many AI/AN’s feeling vulnerable spiritually and emotionally. It is not unusual for those living in urban areas to seek out support, culturally and spiritually, through various organizations and gatherings, but also to make it a priority to get back to one’s home reservation or community for ceremonial and community events. These gatherings are not viewed exclusively as social events but can often be held for spiritual reasons to restore and maintain spiritual balance and harmony.
Provision of Spiritual Care Services

It is essential to understand that AI/AN individuals see themselves as not only a physical self, but also a mental, social, and spiritual being. Healing is described as a process that brings these parts of oneself together at a deep level of inner knowledge (Hunter, 2006). Therefore, healthcare providers must recognize and respect that the journey to wellness for the patient must not only address the physical, but must also address the spirit. The community recognizes that by restoring harmony to the person, the ceremony improves the harmony of the people as a whole (Coulehan, 1980).

Within IHS, a practitioner or provider of Traditional Indian Medicine is designated as a Traditional Medicine Practitioner, and defined to be “a person who is trained in a Native American community, and applies culturally specific knowledge and skills in the diagnosis, treatment, or referral of patients to promote their well being physically, mentally, socially, and spiritually.“(IHS Provider Class File, RPMS). Some IHS sites employ practitioners on site, while others access spiritual care providers known to the patient and their family, through community contacts.

At PIMC, spiritual care is provided for patients, families and staff through the work of two committees: the TCA and the Chaplains' Association. Both groups meet monthly, having established guidelines and procedures that meet requirements necessary to function within a healthcare facility. The authors are not aware of other IHS sites employing chaplains or utilizing a formal mechanism for pastoral care.

History of the Traditional Cultural Advocacy Committee (TCA)

Prior to 1989, requests from PIMC patients regarding their spiritual needs was addressed on an individual basis with assistance from the health care provider and hospital’s administration. In 1989, community members and health care providers, in response to inconsistencies in care, created what would later be known as the Traditional Cultural Advocacy (TCA) Committee. Currently, the committee is made up of approximately 15 individuals some of whom are hospital staff members and other individuals from the community who as Elders, “... hold[s] certain qualities and maintain a certain lifestyle and knowledge base.” (Ellerby 1999). Initially, the TCA committee was set up to address the needs of the AI/AN patients who wanted their own Traditional Indian Medicine (TIM) ways practiced but their role expanded by also providing educational programs for employees in the area of cultural competency, especially as it pertained to the spiritual needs of patients. A partnership program with a TIM provider, Mr. Monetatchchi, Jr. and an urban Catholic faith-based health system is described by Ann Hubbert. According to Mr. Monetatchchi, Jr “The intent of the partnerships and education was not to ‘learn Indian healing ceremonies,’ but rather to share the philosophy of TIM in a way that all people, including patients and healthcare professionals, could choose directions to enhance their own way of living.” (Hubbert, 2008; p. 67). The TCA established formal policies and procedures that would protect patient rights under the American Indian Religious Freedom Act of 1978. To compliment the Act, in 1994, Dr. Michael Trujillo, then director of the IHS affirmed the agency’s commitment to “protect and preserve the inherent right of all American Indians and Alaska Natives to believe, express, and exercise their traditional religions” with the inception of the Traditional Cultural Advocacy Program (TCAP). Through policies it is required that IHS staff must inform patients of their right to practice native religions and healing practices, and when a patient or family member requests the services of a TIM, every effort will be made to address this request (Ross, 2000). In that same year, the PIMC Administration formally acknowledged the TCA, and the committee now falls under the direction of the hospital’s Medical Executive Committee (MEC).

Today, the TCA continues to assist PIMC in providing educational opportunities for staff and
assisting in the coordination of a patient’s practitioner of TIM. Additionally, the members maintain a site on campus for the use of a sweat lodge, open to all and led by ceremonial elders. Elders are asked by patients and hospital staff to provide spiritual blessings that can involve the practice of burning specific botanicals to assist with spiritual healing and restore balance when there are situations involving loss and grief, conflicts and unresolved issues.

History of Volunteer Chaplains’ Association

In 1979, the PIMC administration asked an American Indian minister serving a congregation in Phoenix to work with the hospital’s Director for Volunteer Services to organize a group of local clergy to provide onsite pastoral care services at PIMC on a volunteer basis. Many of the local clergy, representing various Christian affiliations, were already serving American Indians and were willing to volunteer their time ministering to patients at the hospital. As this group became more formalized, policies and procedures were put into place for pastoral care services. Pastoral care services provided by chaplains can include the following: visiting patients in the inpatient and outpatient settings, providing religious resource materials, conducting weekly Sunday services at the hospital and hosting an annual Easter Sunrise Service open to community members, providing coverage 24/7 through an on-call pager service for emergent/urgent requests, and officiating at special occasions such as baptisms, funerals and weddings.

Oncology Care and Funding for Spiritual Care Services

Despite the tremendous volunteer support from the community clergy, a gap in the provision of pastoral care services remained. Hospital administration supported the development of a permanent pastoral care position; however, funding was not available within the hospital and attempts to accumulate sufficient outside financial support from several church denominations met with various obstacles. In 2001, funding was made available to support the work of a chaplain to develop a spiritual care program through a National Cancer Institute grant (Grant Number U01 CA 86122-02).

The PIMC chaplain works in partnership with the Southwest American Indian Collaborative Network (SAICN), the Volunteer Chaplains’ Association, TCA, and members of the medical center’s oncology staff to specifically address the spiritual care needs of those seeking cancer care at or working in the medical center. As a member of the multi-disciplinary oncology clinic team, the chaplain meets with patients during chemotherapy treatments, clinic visits and hospitalizations and assists with end-of-life discussions with patients and families, requiring careful and sensitive communication, as many American Indians do not speak directly about death.

A cancer diagnosis can provoke fear and the journey of seeking care has many challenges, physically, financially, emotionally and spiritually. These challenges are felt acutely among American Indians, as health care disparities already present before a cancer diagnosis becomes magnified can sometimes overwhelm patients, families and tribal communities. These challenges were clearly described by one of the PIMC chaplains who expressed his desire to learn not only more about cancer as a disease, but how he and other spiritual care providers could learn to respond to the spiritual and emotional needs of patients and families going through cancer. In order to provide this education, the “Spirituality and Cancer” conference was planned for February of 2002.
COLLABORATIVE WORK PROMOTES SPIRITUAL WELL BEING FOR THOSE WITH CANCER

Cancer Care Conferences

The planning of the conference, as well as the conference itself, brought together the spiritual care providers at PIMC as well as those in the communities and organizations serving American Indians. Approximately 40 patients, traditional healers, and clergy attended the one-day event which featured keynote addresses as well as panel discussions on topics such as “Traditional AI/AN Treatment and Practices for Cancer,” “Self Awareness and Self Care for the Spiritual Provider,” and “Beliefs about Cancer: Stories and Experiences.”

The conference findings reaffirmed the centrality of family and tribal community life in the spiritual healing process of the person with cancer, and, as one participant stated, “family support is your spirituality and how you live.” Despite the importance of those ties, these relationships and ties within families and community are typically the ones most challenged by cancer. The participants expressed their concern that so few resources, such as support groups on their reservations, were available. They also expressed that they felt uncomfortable participating in support groups available through other organizations, including clinics and hospitals, because of cultural differences. Others expressed their distress at loved ones being sent far away from home for oncology care without the support of family. A tribal member whose family member had cancer shared the following concern: “There was no place to go, so she was sent off the reservation to people who didn’t know Native people.”

As confirmed by Pelusi and Krebs from their findings at a National American Indian Cancer Survivor/Thrivers Conference “…healthcare providers should spend less time talking about the intricacies of cancer and its treatment and more time looking at, listening to, and trying to understand how cancer and its treatments affect the everyday lives of the people and families we treat” (Pelusi and Krebs, 2005).

The spiritual care conferences became a biannual event, with various themes, for those involved in the work of the NCI grants and for the members of the PIMC spiritual care program.

The conference, “Celebrations and Ceremonies for Life’s Transitions: Implications for Cancer Care with American Indians” which was held in 2007 and sponsored by SAICN, attracted over 200 attendees. In one of the presentations, “Cancer Care: Transitions in the Journey,” panelists shared stories about transitions of cancer from their lives or the lives of others with whom they lived and/or worked. A panelist, an American Indian physician, stated that it angers him when he hears of a doctor making the statement “I am sorry, there is nothing more we can do for you” because the patient has put their trust in that medical provider. There is always something that can be done to ease the suffering of a patient, even if a cure is not possible; being present for the patient and assisting the family throughout the dying process is healing, in and of itself.”

Cancer Education Video Projects

In order to reach a wider audience with those lessons learned and stories shared, SAICN and the conference photographers, Lizard Light Productions, a small American Indian family contract photography and multimedia business, embarked upon what would become a year long project together to produce two videos. Few educational resources exist that address spiritual and cultural aspects for American Indians and are widely available.

The first video “Cancer Has Crept Among Us” features the story of Linda Havatone, an American
Indian cancer survivor and her family’s multiple experiences with cancer in a rural reservation community in northwestern Arizona. Her story highlights cancer care disparities that are often present in American Indian communities.

The second video, “American Indian Attitudes and Values: An Integral Part of Cancer Care” features interviews with American Indian cancer survivors, family members, community leaders and providers on the importance of providing culturally and spiritually appropriate cancer care.

Both videos can be viewed via the Inter Tribal Council of Arizona, Inc. website at http://www.itcaonline.com/saicn/Resources.html. An accompanying guidebook with questions based upon the videos is currently being produced to facilitate group discussions for audiences viewing the videos and will also be made available via the Inter Tribal Council of Arizona, Inc. website.

CONCLUSION

Developing a spiritual care program that addresses the spiritual care needs of American Indian patients and their families should involve thoughtful and careful consideration of what patients express is important to them not only as individuals going through cancer but as part of a family or tribal community. Partnerships with community and ceremonial elders, pastors and other spiritual leaders as well as health care providers and organizations involved in the life of American Indian communities will be essential in laying the foundation for a responsive, respectful and relevant spiritual care program at a hospital or clinic serving American Indians.

ACKNOWLEDGMENTS

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Race and Hepatitis C Management within the Veterans Administration

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ABSTRACT

Objective: To examine black-white differences in hepatitis C treatment within the Veterans Administration (VA) and determine whether racial variation in specialty consultation explains differences in hepatitis C treatment between blacks and whites.

Methods: We performed a retrospective cohort study of 1040 veterans meeting VA eligibility criteria for hepatitis C treatment. We used multiple imputation to handle missing race data. Specialty consultation was determined from the VA outpatient medical dataset and hepatitis C treatment was determined from the VA decision support system. Conditional logistic regression was used to examine the association between race and hepatitis C treatment as well as race and specialty consultation.

Results: There was no statistical difference in specialty consultation between blacks and whites, OR= 1.23 (95% CI, 0.85-1.78). Among 505 patients who visited a specialist, there was no statistically significant difference in hepatitis C treatment between blacks and whites, OR= 0.55 (95% CI, 0.30-1.00).

Conclusions: Among veterans who met eligibility criteria for hepatitis C treatment there were no statistically significant differences in specialty consultation or hepatitis C treatment by race. There was a statistical trend towards less treatment for blacks.

Keywords: Hepatitis C, consultation, treatment, Veterans Health

INTRODUCTION

The prevalence of hepatitis C infection within the United States is 1.8%. Most people who become infected develop chronic infection, and chronic infection is the most common cause of liver failure and liver transplantation in the United States (Alter, 1999; Centers for Disease Control and Prevention,
Hepatitis C virus infection is particularly important within the Veterans Administration (VA), where the prevalence among veterans is more than twice that of the general population (Cheung, 2000; Dominitz, 2005). The VA uses nationally integrated computer information systems. These computerized systems, along with the high prevalence of Hepatitis C, makes the VA an important and excellent setting for studying hepatitis C management. Within VA medical centers, primary care physicians screen for infection among those at risk by testing patients’ serum for the hepatitis C antibody (CDC 1998; CDC, 2003; Strader, 2004), and then refer patients with positive screens to specialists trained to treat chronic hepatitis C infection, generally a gastroenterologist or infectious disease specialist. A quantitative hepatitis C RNA test is the gold-standard for confirming infection. Because most primary care physicians are not trained to treat chronic hepatitis C infection, patients typically will not receive treatment unless first evaluated by a specialist. If the specialist physician determines that a patient is eligible (Bini, 2005) for treatment and the patient agrees, then that patient is recommended for treatment. Treatment consists of weekly doses of interferon and daily doses of ribavirin (Strader, 2004).

While there are some studies to the contrary (Bini, 2005), many studies indicate blacks receive treatment for chronic hepatitis C infection less often than whites (Butt, 2007; Groom, 2008; Hall, 2004; Rousseau, 2008). This has substantial implications for health disparities for three reasons. First, among U.S. born persons six and older, hepatitis C infection is more prevalent among blacks than whites (3.2% vs. 1.5%) (Alter, 1999). Second, the incidence of hepatocellular carcinoma, a sequela of untreated chronic hepatitis C infection, is increasing faster among blacks than whites (El-Serag, 2003). Third, among patients with end stage liver disease, another sequela of untreated chronic hepatitis C infection, blacks are underrepresented on the wait-list for liver transplantation (Seaberg, 1998). If blacks receive treatment for chronic hepatitis C infection less often, then their burden of disease and disease sequelae may worsen relative to other groups. Unfortunately, there are no studies which examine the causal mechanisms of this treatment disparity despite the increased prevalence and increasing risk of hepatitis C sequelae among blacks.

HCV management involves multiple steps: access to a clinician, blood tests, specialty consultation, and treatment. Teasing out disparities in treatment therefore requires examining the steps leading to treatment. Racial differences in later steps may exist because of differences in the occurrence of previous requisite steps. If blacks receive treatment less often, it may be because blacks undergo specialty consultation less often. We therefore hypothesized that the clinical data in the VA information systems would reveal racial differences in the occurrence of specialty consultation as a cause of racial differences in hepatitis C treatment.

**METHODS**

This study was approved by the Philadelphia VA Institutional Review Board. The Philadelphia VA IRB was aware of the identification of HIV infected subjects in this study.

**Data Source**

The Veterans Health Administration is a nationally integrated healthcare system with nearly 8 million veterans enrolled. After each outpatient or inpatient encounter with the VA, the patient’s clinical record is coded, with standardized clinical information collected and stored in VA databases. Data for this study were obtained from three VA Medical SAS datasets: 1) The Inpatient Medical SAS Dataset (IMD), also known as the Patient Treatment File, which includes acute care, extended care, observation care and non-VA care records; 2) the visit and event files of the Outpatient Medical SAS Dataset (OMD) which includes all VA ambulatory care data; and 3) the Decision Support System (DSS), which includes pharmacy records. All datasets were extracted from the Austin Automation Center.
Study Subjects
Using the OMD and IMD, we identified all positive hepatitis C quantitative RNA laboratory tests generated between October 1, 1999 and March 31, 2006 from Clarksburg, WV and seven Pennsylvania sites: Altoona, Butler, Coatesville, Erie, Lebanon, Pittsburgh, and Wilkes Barre. For those with multiple tests, we consider only the first positive test, which we call the Initial Test. We only included patients who saw a primary care physician after the Initial Test. We only included patients who received at least minimal primary care. We defined minimal to be three or more visits during the study period from October 1, 1999 to September 31, 2006. Therefore, we included patients only if they had at least three primary care visits over the study period and had at least one primary care visit after the Initial Test. We call the first primary care visit following the Initial Test the Index Visit.

The VA uses standard inclusion/exclusion criteria when determining eligibility for Hepatitis C treatment (VA Centers of Excellence in Hepatitis C Research and Education, 1999), (see Inclusion/Exclusion criteria for treatment below). Using these criteria, we excluded any patient from our study who did not meet all of the laboratory eligibility criteria (except platelet count and thyroid indices as they were not available in our dataset). We also excluded any patient with evidence of previous hepatitis C treatment, patients younger than 18, and patients with HIV. The patients who met both inclusion and exclusion criteria formed the primary cohort. We examined the primary cohort for any association between race and specialty consultation as well as race and hepatitis C treatment. We also examined the association between race and hepatitis C treatment among the subset of patients in the primary cohort who received specialty consultation.

### Inclusion and Exclusion Criteria for Interferon and Ribavirin Therapy

#### Inclusion Criteria
- Anti-HCV antibody positive
- Hemoglobin ≥ 13g/dL for males, Hemoglobin ≥ 12g/dL for females
- White Blood Cell Count ≥ 3000/mm³
- Absolute Neutrophil Count ≥ 1500/mm³
- Platelet Count ≥ 85,000/mm³
- Total Bilirubin < 2.0mg/dL
- Albumin ≥ 3.2g/dL
- Serum Creatinine < 1.5mg/dL
- Thyroid Stimulating Hormone - within normal limits

#### Exclusion Criteria
- Hemoglobinopathy or hemolytic anemia
- Evidence of decompensated cirrhosis: Ascites, Varices, Encephalopathy
- Comorbid conditions that can interfere with treatment
  - CNS trauma or seizure disorder
  - Diabetes
  - COPD
  - Coronary Artery Disease
  - Congestive Heart Failure
  - Condition which require treatment with systemic steroids
- Substance Abuse
- Psychiatric Disorder
- Pregnancy
- Inability to comply with treatment
Primary exposure: Race

Patient race was obtained from the IMD and the OMD. Race coding within the VA is of two types, self-reported or recorded by clerical staff. Whenever possible we used self-reported race over that of clerical staff. Studies on the accuracy of clerical staff race coding in VA data (Kressin, 2003) indicate race is greater than 90% accurate when white or black race is coded. We included all patients identified as black or white.

Outcomes

We used clinic codes from the OMD to measure specialty consultation. We considered specialty consultation positive if it met three criteria: 1) A clinic code indicating gastroenterology or infectious disease consultation; 2) an ICD-9 code for hepatitis C (070.51, 070.54, 070.70, 070.90); and 3) date of service after the Index Visit. We used pharmacy records from the DSS to define hepatitis C treatment as follows: 1) prescription for interferon or pegylated interferon occurring after specialty consultation, or 2) interferon or pegylated interferon in combination with ribavirin occurring after specialty consultation.

Potential Confounders

We examined data generated during the year prior to the Index Visit to obtain information on baseline patient demographics, co-morbidities, and laboratory data. Age, gender, and VA service connectedness were obtained from the OMD and IMD. The VA standards for determining eligibility for hepatitis C treatment also include several exclusion criteria. VA Centers of Excellence in Hepatitis C Research and Education, 1999) Thus, we measured and controlled for these. Using ICD-9 codes from the OMD and IMD, we captured the following co-morbidities based on the presence of one inpatient or two outpatient primary or secondary diagnoses: Psychiatric Disorder including: Depression (296.20-296.39, 311), Other Affective Disorders (296.00-295.19, 296.40-296.99), Psychosis (295.00-295.90), or Neurotic Disorders (300); Comorbid illness including: CNS disease (330.00-349.00), COPD (491.00-492.99, 496.00-496.99), Diabetes (250.00-250.99), Ischemic heart disease (410.00-414.99), Congestive Heart Failure (428.00-428.99), and Hemoglobinopathy (282.00-283.99); Alcohol abuse (303.00-303.93, 291.00-291.99); Substance Abuse (292.00-292.99, 304.00-304.99); Cirrhosis (571.5); Decompensated Liver Disease (572.2-572.4, 572.8); Pregnancy (650.00); and CPT codes for Organ Transplant generated at any time between October 1, 1999 and September 30, 2006 (50380, 33945, 33935, 32851-32854, 47135-47136). HIV infection was considered positive if a patient had a positive HIV PCR test, or the pharmacy records from the DSS revealed prescriptions for HIV medication. From the OMD and IMD, we obtained serum ALT, total bilirubin, albumin, hememoglobin, serum creatinine, and white blood cell count. VA Medical Center site (VAMC) was extracted from all three datasets and defined as the site where the majority of care took place. Both internal VA sources and external studies have demonstrated the validity of VA databases for research (Kang, 1991; Kerr, 1999; Murphy, 2002).

Data Analysis

We used the t-test and chi-square test to compare demographic and clinical characteristics by race. We found no pregnant patients in the cohort. We calculated unadjusted odds ratios for the association between race and the outcomes of interest. 12.2% of the patients in our primary cohort had missing race data (127/1040, Figure 1). Using the primary cohort we performed multiple imputation with regression of all covariates onto ten imputed datasets to assign a racial classification to these subjects. We then performed conditional logistic regression to determine the association between race and specialty consultation, as well as the association between race and treatment. We also performed conditional logistic regression to determine the association between race and treatment among the subset that underwent specialty consultation. In each case, regression covariates included age, race, sex, serum ALT, alcohol disorder, substance abuse, psychiatric disorder,
and comorbid illness. We included ALT because of its importance as a marker for active hepatic inflammation and its common use in treatment decision making (Seef, 2002; Strader, 2004). We conditioned models on the VAMC site to control for any unmeasured factors that may differ by site or care. Finally, because of their potential use as exclusion criteria in the decision to treat, we also looked for modification of any associations between race and outcomes by the following terms: alcohol disorder, substance abuse, psychiatric disorder, and comorbid illness. All data were analyzed using the statistical package Stata 9.2.

RESULTS

Figure 1 illustrates creation of the study cohort. 2,118 persons had positive results for the quantitative hepatitis C test. Of these, 1,691 visited a primary care physician at least three times between October 1, 1999 and March 31, 2006, including at least one visit after the positive hepatitis C result. Of these patients, 1,058 met our inclusion and exclusion criteria. Finally, we identified 145 people whom had missing race data or could not be classified as black or white, 127 of whom had missing data. This yielded the primary cohort of 1040 subjects, 676 whites, 237 blacks, and 127 subjects whose race was subsequently imputed.

The demographic and clinical characteristics of the cohort are shown in Table 1. The average age was 52.4 years and 2.5% (26/1040) were female. Decompensated liver disease was more common among whites. Whites also had higher baseline serum Albumin, ALT, White Blood Cell counts, Hemoglobin, and Total Bilirubin levels compared to blacks. Blacks had higher serum creatinine levels, were more likely to have documented, psychiatric illness, and drug or alcohol related illnesses or comorbid illnesses.

<table>
<thead>
<tr>
<th>Table 1. Cohort Characteristics</th>
<th>Whites (n = 676)</th>
<th>Blacks (n = 237)</th>
<th>p-value</th>
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<tr>
<td>Demographic Variables</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>52.2</td>
<td>53.0</td>
<td>0.11</td>
</tr>
<tr>
<td>Female %</td>
<td>2.9</td>
<td>1.7</td>
<td>0.15</td>
</tr>
<tr>
<td>VA related variables</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service Connected &gt;=50%</td>
<td>15.5</td>
<td>14.0</td>
<td>0.75</td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cirrhosis</td>
<td>4.9</td>
<td>2.5</td>
<td>0.12</td>
</tr>
<tr>
<td>Decompensated liver disease</td>
<td>0.3</td>
<td>0</td>
<td>0.40</td>
</tr>
<tr>
<td>Alcohol disorder</td>
<td>24.6</td>
<td>41.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>20.6</td>
<td>47.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Psychiatric disorder</td>
<td>44.1</td>
<td>53.6</td>
<td>0.01</td>
</tr>
<tr>
<td>Comorbid condition</td>
<td>29.6</td>
<td>37.6</td>
<td>0.02</td>
</tr>
<tr>
<td>Laboratory values</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Albumin (g/dL)</td>
<td>3.61</td>
<td>3.86</td>
<td>0.01</td>
</tr>
<tr>
<td>ALT (IU/L)</td>
<td>73.3</td>
<td>58.8</td>
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</tr>
<tr>
<td>Hemoglobin (g/dL)</td>
<td>15.2</td>
<td>14.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Serum Creatinine (mg/dL)</td>
<td>0.95</td>
<td>1.04</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total Bilirubin (IU/L)</td>
<td>0.86</td>
<td>0.81</td>
<td>0.01</td>
</tr>
<tr>
<td>White blood cell count (x1000/μL)</td>
<td>7.48</td>
<td>6.71</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
Figure 1: Cohort Creation

2,118 with positive quantitative Hepatitis RNA-PCR result.

1,691 with three or more primary care visits.

1,479 without evidence of previous Hepatitis C treatment.

1,443 without evidence of HIV.

1,058 meeting laboratory inclusion criteria.

1040 with white or black race or missing race data: Primary Cohort.

505 underwent specialty consultation.

Examine for racial differences in specialty consultation and treatment.

Examine for racial differences in treatment.

145 patients identified as non-black, non-white or missing race. 127 of these had missing race data.
Among the 1040 patients with documented HCV infection, 505 (48.6%) subsequently underwent specialty consultation. The median time from primary care visit to specialty consultation was 16 days longer for blacks compared to whites (63 vs. 79). Overall, the frequency of specialty consultation was higher for blacks than whites, but not statistically significant (59.9% vs. 53.7%, p=0.10) (Table 2). To adjust for confounding we first imputed race for those with missing information on race. During the creation of the initial study cohort, 145 people were identified as neither black nor white, or had missing race data (Table 1). Of these, 127 had missing race data. After imputing the race for these 127 persons and performing conditional logistic regression to control for age, sex, service connection, serum ALT, psychiatric disease, alcohol disorder, substance abuse, comorbid conditions, and site of care, the adjusted difference between blacks and whites remained not significant (OR=1.22, 0.85-1.77, p=0.27) (Table 2).

In the primary cohort of veterans with documented HCV infection 130/1040 (12.5%) subsequently received hepatitis C treatment. The median time from primary care visit to treatment was 87 days longer for blacks compared to whites (221 days vs. 308 days). Also, the overall percentage of veterans receiving treatment was greater for whites than blacks (26.2% vs. 13.4%, p=0.02). After full adjustment, however, the difference between blacks and whites was not statistically significant (OR=0.64, 0.36-1.15, p=0.14) (Table 2). Among the 505 veterans with HCV infection who subsequently underwent specialty consultation, the frequency of hepatitis C treatment also was higher for whites than for blacks (34.7% vs. 21.3%, p<0.01); however, after full adjustment, statistical significance was lost and only a trend towards statistically lower odds of treatment for blacks remained (OR=0.54, 0.30-1.00, p=0.05) (Table 2).

Results of conditional logistic regression are seen in table 3. Factors associated with specialty consultation included younger age and higher serum ALT. Substance abuse was a negative predictor of specialty consultation. Cirrhosis was the only predictor of treatment, while substance abuse, psychiatric disorder, and comorbid illness were either negative predictors or indicated a statistical trend towards being negative predictors.

The results of the interaction terms are listed in table 4. In two instances, being both black and having the disorder indicated lower odds of treatment than being black alone (alcohol disorder & psychiatric disorder). In the other two instances, being both black and having the disorder resulted in a higher odds of treatment than being black alone (substance abuse & comorbid illness). However, the column entitled “p-value for interaction” indicates that race did not significantly interact with any of the factors we studied. Thus odds of treatment for blacks with the disorders are not statistically significant than the odds of treatment for blacks without the disorder.
We assumed that we would find a racial difference in hepatitis C treatment between blacks and whites. Our hypothesis was that any racial difference in hepatitis C treatment would be accounted for by differences in differences in specialty consultation. To the contrary, this cohort of veterans with evidence for hepatitis C infection revealed black and white veterans at most had differing rates of hepatitis C treatment which merely trended towards statistical significance after adjusting for potential confounders. Instead of explaining treatment differences, the opposite was true – there was no association between race and specialty consultation. If anything, blacks were more likely to undergo specialty consultation than whites. An analysis of the veterans who underwent specialty consultation further revealed only a statistical trend towards significance rather accounting for any treatment difference. These results agree with a prospective cohort study among veterans with Hepatitis C (Bini, 2005) which also showed that race was not an independent predictor of treatment.

Our study stands in contrast to two previous retrospective cohort studies showing lower treatment among black veterans within the VA (Butt, 2007a; Rousseau, 2008). However, our results agree with Rousseau (2008) who found no association between race and specialty consultation. One of the strengths of our study is the use of standard VA criteria for hepatitis C treatment to define our cohort. Unlike some of the previous studies, each person in our cohort met inclusion laboratory criteria for treatment. Those with exclusion criteria were controlled for in our regression analyses. By using standard VA criteria to define our cohort we were able to ensure that only those patients who were eligible for treatment were included. A second strength is the use of multiple imputation to address the missing race data for a significant minority of the entire sample. Many retrospective studies which analyze existing data either fail to mention or fail to account for missing race data. This can result in biased results. Our use of multiple imputation, while imperfect, is considered the gold-standard for
dealing with missing data and its potential problems.

Our finding that 55.3% of veterans had undergone specialty consultation and 12.0% were given prescriptions for hepatitis C treatment is similar to results from other studies (Butt, 2007a; Fultz, 2003; Groom, 2008; Hall, 2004; Irving, 2006; Morril, 2005; Rousseau, 2008). The high prevalence of co-morbidities among HCV infected veterans, including psychiatric disease, alcohol and substance abuse, is also similar to other studies (Butt, 2007a; Fultz, 2003; Hall, 2004; Rousseau, 2008).

Both the strength of the effect size and the p-value for the association between race and treatment increased in statistical significance between the primary cohort and the subset of patients who underwent specialty consultation, reflecting the fact that only those were seen by specialists were treated in our cohort. A closer look at those most likely to be treated revealed a trend towards significantly lower odds for blacks. We do not want to simply dismiss this difference because it is not statistically significant. The difference may be important clinically. It may be due to clinical differences between blacks and whites we could not measure, such as the severity of disease. Our results indicated that blacks were seen by specialists on average 16 days later than whites. While this difference is not large, it does suggest that blacks are seeing specialists later than whites. Several studies have indicated that blacks present for medical care with more advanced disease than whites (Mandelblatt, 1991; Roach, 1995; Swindells, 2002; Yancy, 2003). On the other hand, our data also could not account for potential differences in the degree of liver fibrosis by race. Some evidence suggests black patients progress to cirrhosis more slowly than white patients (Bonacini, 2001; Wiley, 2002). If blacks in our cohort had less hepatic fibrosis, then treatment may be have been indicated less often than for whites. Our data suggest this is a possibility, as the frequency of cirrhosis among white patients was higher than among black patients in our cohort. Another possibility is the racial difference in genotype prevalence. Many studies have shown lower treatment responses among blacks than whites (Kinzie, 2001; McHutchison, 2000; Muir, 2004; Pyrsopoulos, 2001) with this difference partly due to racial differences in genotype 1 prevalence. Blacks are infected with this difficult to treat genotype more often than whites 88% vs. 67% (Alter, 1999). Additionally, blacks appear to respond to hepatitis C treatment less often than whites regardless of genotype (Kinzie, 2001; Pyrsopoulos, 2001). Specialists, therefore, may be deciding to withhold treatment if the risk of serious side-effects out-weighs the relatively low likelihood of treatment response. Alternatively, blacks patients may decide to forgo treatment more often than whites because of the relatively low chance of treatment success and known serious side-effects of therapy (CDC, 1998; Seef, 2002; Strader, 2004). Previous research on racial disparities in health suggests blacks have lower preferences for certain treatments compared to whites (Ayanian, 1999; Oddone, 2002; Smith, 2002; Whittle, 1997). In these cases, black patients prefer less invasive treatments and at times will forgo treatment entirely. It is possible that racial differences in treatment preferences, which were not measureable in our study, may have contributed to the trend towards statistical significance in our results.

Other potential explanations include discrimination within the healthcare setting and physician bias. Racial discrimination within medical care settings is well documented (Abreu, 2001; Schulman, 1999; van Ryn, 2000; Weisse, 2001). While we could not account for this in our study, the interaction terms enable us to comment on physician bias. Uncertainty of appropriate medical care can be a cause of racial disparities. Uncertainty can lead to racial disparities because without clear management guidelines, decision making is more susceptible to subjectivity, stereotyping, and biases which often operate to the detriment of minorities (Smedley, 2003). While the VA has clearly stated HCV treatment guidelines, there are no studies that indicate how well they are followed. The decision if and when to initiate hepatitis C treatment is sometimes unclear, as are the types of patients who will benefit most from treatment (Seef, 2002). Patients with psychiatric illnesses, HIV,
alcohol or substance abuse fall into a “grey” category for which the appropriateness of treatment is uncertain. The prevalence of these disorders among hepatitis C patients is high (Butt, 2007b; El-Serag, 2002; Goulet, 2005) and was high in our cohort. We detected no significant interactions between race and any of the factors: alcohol disorder, psychiatric disorder, substance abuse, or comorbid illness. Had we noted a clear drop in treatment rates among blacks with these disorders compared to blacks without these disorders, it might suggest that uncertainty was playing a stronger role. However, we did not find this. Instead, in two instances the odds of treatment actually increased among blacks with the disorder.

We note several limitations. Our study may not be representative of the entire VA nor other care settings. Our sample included few women and thus the results cannot be generalized in this respect. Also, we could not capture patients who received hepatitis C consultation or treatment outside the VA. Veterans who have the financial means to do so may seek care both within and outside the VA. Finally, our sample size while not small is moderate in comparison to other studies.

In summary, black and white veterans in this cohort had similar odds of specialty consultation and statistically similar odds of hepatitis C treatment. A closer examination of those most likely to be treated revealed a trend towards significantly lower odds for blacks, suggesting specialty consultation is an important place to examine if treatment disparities exist. While access to specialists cannot explain any disparity, there is reason to expect that clinical differences and differences in clinical decision making by patient’s race may contribute to this disparity and require further study.

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Breast cancer screening practices among American Indians and Alaska Natives in the Midwest

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ABSTRACT

American Indian and Alaska Native (AI/AN) women currently have some of the highest mortality rates from breast cancer for any racial/ethnic group in the United States and some of the lowest screening rates. However, current data are not available for regional differences in screening, which can result in dramatically different stage at diagnosis and mortality. We conducted surveys with 120 focus group participants in a needs assessment of mammography among AI/AN in the greater Kansas City metropolitan area and parts of Northeast Kansas. We found that among women under age 40, for whom recommended screenings include only annual clinical breast examination and breast self-examination, more women reported breast self-examination than clinical breast examination (85.3% versus 55.0% in the past year). Among women age 40 and older, more women reported breast self-examination (80.0% in the past year) than either clinical breast examination or mammography (50.8% and 46.9%, respectively, in the past year). These low rates of breast cancer screening are consistent with low rates reported around the country among AI/AN and have strong implications for stage at diagnosis and prognosis for AI/AN breast cancer patients.
and Daling, 2003). Although incidence rates among AI/AN women are lower than for non-Hispanic white women (91.7/100,000 versus 123.5/100,000), more AI/AN women are diagnosed with late-stage breast cancers than other racial/ethnic groups, with 44% of newly diagnosed cases staged at regional or distant metastasis, compared to 33% among non-Hispanic whites (Smith-Blindman, et al., 2006; American Cancer Society, 2009-2010; Wampler, Lash, Silliman, and Heeren, 2005). Breast cancer incidence rates among AI/AN women differ by geographic region, with rates as high as 139.5/100,000 in Alaska and as low as 50.4/100,000 in the Southwest (Espey, et al., 2007). Recent data show that breast cancer incidence may be significantly under-reported among AI/AN women due, in large part, to racial misclassification (American Cancer Society, 2008).

Late stage at diagnosis and subsequently high mortality from breast cancer among AI/AN women are likely partially explained by low screening rates, particularly low rates of mammography that are declining (Espey, et al., 2007). Current breast cancer screening recommendations for average risk women age 40 and older are annual mammograms and clinical breast examination and monthly breast self-examination (American Cancer Society, 2007). Among AI/AN women age 40 and over, 62.7% report having had a mammogram in the past two years, compared to 68.7% among non-Hispanic whites (National Center for Health Statistics, 2007). Mammography rates also differ by geographic region, with rates lowest in the Pacific Coast (61.3%) and highest in the East (71.7%) (Espey, et al., 2007). In addition, AI/AN women living in urban areas (71.4%) are more likely to be screened than their rural or reservation counterparts (51.7%) (Schumacher, et al., 2008). Data detailing use of breast self-examination and clinical breast examination among AI/AN women are not reported in the literature.

Due to poor survival and screening rates and geographic variation in incidence, mortality, and screening rates, it is important to collect region-specific data concerning breast cancer screening behaviors. This study provides information about breast cancer screening behaviors among AI/AN women living in Northeast Kansas and the greater Kansas City metropolitan area in Kansas and Missouri.

METHOD

The data for these analyses came from a larger mixed-method needs assessment to determine needs and barriers to mammography among AI/AN. The surveys on which the data were based were conducted as a part of the focus group component of the study. The study protocols were approved by the institution’s Human Subjects Committee prior to implementation of the study.

Focus group participants were recruited through listservs and mailing lists from partner organizations in the American Indian Health Research and Education Alliance, and through posters, flyers, and word-of-mouth at local cultural events, such as pow wows. Though both men and women were recruited into focus groups to discuss issues surrounding breast cancer, only data from women are reported here. Participants were eligible for this part of the study if they were 20 years of age and older and were of AI/AN descent. Written and verbal consent was obtained from each eligible participant. A total of 22 focus groups were conducted from 11/06/2007 thru 06/19/2008. Focus groups were stratified by gender; female focus groups were stratified by age (25-39 versus 40 and older), based on current recommendations for mammography for normal risk women, and screening status if age 40 or older (up-to-date with screening recommendations versus not up-to-date with screening recommendations). Women were considered up-to-date if they had a mammogram in the last two years. Participants were provided with a meal and a $25 gift card for their time.

Prior to the start of each focus group, participants were invited to fill out a short survey asking about their breast cancer screening status as well as their knowledge about breast cancer, barriers to screening, and family history of breast cancer. For the purpose of these analyses, only surveys filled
out by female participants were included (N=120) and double data entered in a MS ACCESS database. Data entry comparisons and data analyses were performed using SAS. Discrete variables are described using frequencies and percentages while continuous variables are described using means and standard deviation. Bivariate analyses were performed using Chi-square for discrete outcomes and t-tests for continuous outcomes; significant differences were not found.

RESULTS

Table 1 provides basic demographic information obtained from 120 AI/AN women. Table 2 shows self-report breast cancer screening rates for the age categories of 20-39 and 40 and over. For the cohort aged 20-39 years, participants answered questions regarding clinical breast examination (N=49) and breast self-examination (N=47). The majority of women have had a clinical breast examination (83.7%) and more than half of these women had one within the year (55.0%). The explanation provided for most recent clinical breast examination was due to a routine women's health exam (92.9%). The remaining respondents claimed their most recent clinical breast examination took place due to symptoms or a recommended follow-up visit. Almost three-fourths of respondents have performed breast self-examination (72.3%), 85.3% of those within the year.

Table 1: Demographics of the AI/AN sample for breast cancer screening (N=120)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>Age (mean, std)</td>
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<tr>
<td>Race</td>
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<td>83.3</td>
</tr>
<tr>
<td>Multi-racial</td>
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<td>Marital Status</td>
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<td>Married/Partner</td>
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<td>Divorced/Widowed</td>
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</tr>
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<td>Never Married</td>
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<td>Education</td>
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<tr>
<td>High school or less</td>
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<td>20.2</td>
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<tr>
<td>Some college</td>
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<td>37.8</td>
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<td>College +</td>
<td>50</td>
<td>42.0</td>
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<tr>
<td>IHS</td>
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<tr>
<td>Other facility</td>
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<td>Discussed Breast cancer screening</td>
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<td>Yes</td>
<td>74</td>
<td>66.1</td>
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* In addition to IHS
Table 2: Self-report breast cancer screening practices

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<th>20-39 years old (N=49)</th>
<th>40+ years old (N=71)</th>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
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<tr>
<td><strong>Discussed Breast cancer screening</strong></td>
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<tr>
<td>No</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Yes</td>
<td>NA</td>
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<td><strong>Most recent mammogram</strong></td>
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<td>Year or less</td>
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<td>1 - 5 years</td>
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</tr>
<tr>
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<td>NA</td>
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<td>Never had a mammogram</td>
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<td>NA</td>
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<tr>
<td><strong>Reason for most recent mammogram</strong></td>
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<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Symptom/Follow-up</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Unknown</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Mammogram frequency</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every year</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Every other year</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Irregularly</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Only 1 mammogram</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Never had a mammogram</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Ever had a Clinical Breast Examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>16.3</td>
</tr>
<tr>
<td>Yes</td>
<td>41</td>
<td>83.7</td>
</tr>
<tr>
<td><strong>Most recent Clinical Breast Examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year or less</td>
<td>22</td>
<td>55.0</td>
</tr>
<tr>
<td>1 - 5 years</td>
<td>13</td>
<td>32.5</td>
</tr>
<tr>
<td>5+ years</td>
<td>5</td>
<td>12.5</td>
</tr>
<tr>
<td><strong>Reason for most recent Clinical Breast Examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Routine exam</td>
<td>38</td>
<td>92.9</td>
</tr>
<tr>
<td>Symptom/Follow-up</td>
<td>3</td>
<td>7.3</td>
</tr>
<tr>
<td><strong>Ever done Breast Self-Examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>27.7</td>
</tr>
<tr>
<td>Yes</td>
<td>34</td>
<td>72.3</td>
</tr>
<tr>
<td><strong>Most recent Breast Self-Examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Month or less</td>
<td>9</td>
<td>26.5</td>
</tr>
<tr>
<td>1 month - 1 year</td>
<td>20</td>
<td>58.8</td>
</tr>
<tr>
<td>1 - 5 years</td>
<td>3</td>
<td>8.8</td>
</tr>
<tr>
<td>5+ years</td>
<td>2</td>
<td>5.9</td>
</tr>
</tbody>
</table>
Self-reported breast cancer screening rates for women who were aged 40 years and over (N=71) are also included in Table 2. Participants answered questions regarding mammograms, clinical breast examination, and breast self-examination. The majority of respondents (81.5%) had discussed mammography with a health professional; 43.7% had a mammogram within the last year. The reason given for most recent mammogram was a routine exam. For those who have had a mammogram, half reported a yearly mammogram while one-fifth reported a mammogram every other year.

For those women who had a clinical breast examination (91.2%), half had one in the past year. Eighty-seven percent of participants had performed breast self-examination and of those, 80% had done so within the year.

**DISCUSSION**

These data indicate that women aged 20-39 years are more likely to have performed breast self-examination than to have had a clinical breast examination within one year or less and women aged 40 and over are more likely to have performed breast self-examination in the last year than to have had a clinical breast examination or a mammogram. The difference in use of screening modalities may be due to the fact that women can complete breast self-examination without a provider. We have learned from our larger study that women sometimes avoid going to providers due to mistrust issues or gender issues (Daley, Joseph, Monteau, Cully, and Kraemer-Diaz, 2010), showing that it is possible that women are more comfortable screening themselves then trusting a provider, particularly a male provider. It is also possible that women did not understand what a clinical breast examination entailed and were under-reporting their use. Additionally, women may have over-reported use of breast self-examination due to media campaigns for the technique, though studies fail to show any improved survival from performance (Hackshaw and Paul, 2003; Irwin, Artin, and Oxman, 1999; Kosters and Gotzsche, 2003). Other issues that may explain this difference in use of screening techniques are lack of knowledge about screening modalities and cultural barriers. Further exploration into reasons for disparities in screening modality is needed.

Mammography is considered the gold standard for breast cancer screening and is recommended for average risk women annually beginning at age 40 (American Cancer Society, 2008). 66.2% of the women in our sample reported annual or bi-annual mammography, indicating that a similar percentage of age-eligible AI/AN women in our sample were up-to-date with screening compared to the national average for AI/AN (66.6%, American Cancer Society, 2009-2010). Mammography rates for AI/AN in our sample, like rates for other AI/AN around the country, lag behind those for non-Hispanic whites (68.1%, American Cancer Society, 2009-2010). It is possible that self-selection into our study biased our sample and our screening rates are not indicative of the overall screening rates of women in our greater population. If there is selection bias in our sample, it is likely that our sample had more women who are up-to-date with screening recommendations than are represented in the general AI/AN community in Kansas and Missouri. Therefore, it is possible that AI/AN in our region lag behind other AI/AN around the nation in screening mammography rates. Because of our small sample size, we cannot generalize screening rates to the population level. Therefore, screening rates may be lower than the current data suggest. Preliminary results from our focus group data indicate that cost of the test, fear of the test and the potential results of the test, transportation, and access to care or lack of insurance are all major barriers.

Fifty-three of our respondents indicated that they had discussed breast cancer screening with a health professional, but 66 respondents reported having had a mammogram. It is likely that the 66 women who had a mammogram discussed breast cancer screening with a health professional. A possible explanation for this difference may be the perceived quality of health education given
by health care professionals to AI/AN women. In addition, the data rely on women's memory of the screening process.

Our data show that AI/AN women in the Heartland lag behind other women in the United States in breast cancer screening behaviors. Low rates of screening have important implications for stage at diagnosis of breast cancer, putting the women in our sample at greater risk for late stage diagnosis, similar to other AI/AN communities around the country. Barriers to screening are now being studied and should allow the development of culturally-appropriate screening interventions to decrease the disparity in screening rates and ultimately decrease diagnosis of late-stage breast cancer among AI/AN.

REFERENCES


Breast cancer screening among American Indians and Alaska Natives • Daley et al.

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