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Building a Tribal–Academic Partnership to Address PTSD, Substance Misuse, and HIV Among American Indian Women

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Abstract

Objectives—To describe our partnership and research infrastructure development strategies and discuss steps in developing a culturally grounded framework to obtain data and identify a trauma-informed evidence-based intervention.

Method—We present funding strategies that develop and maintain the partnership and tools that guided research development. We share how a community research committee was formed and the steps taken to clarify the health concern and develop a culturally tailored framework. We present results from our needs/assets assessment that led to the selection of a trauma-informed intervention. Finally, we describe the agreements and protocols developed.

Results—We produced a strong sustainable research team that brought program and research funding to the community. We created a framework and matrix of program objectives grounded in community knowledge. We produced preliminary data and research and publication guidelines that have facilitated program and research funding to address community-driven concerns.

Conclusions—This study highlights the importance of bidirectional collaboration with American Indian communities, as well as the time and funding needed to maintain these relationships. A long-term approach is necessary to build a sustainable research infrastructure. Developing effective and efficient ways to build culturally based community research portfolios provides a critical step toward improving individual and community health outcomes.

Keywords

American Indian and Alaskan Native; cognitive processing therapy; CPT; post-traumatic stress disorder; PTSD; HIV; community-based participatory research; CBPR; partnership development

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INTRODUCTION

American Indian (AI) communities have experienced exposure to trauma over the past several centuries that has led to devastating consequences for their health and wellness (Brave Heart, 2003; Myhra, 2013). AIs are exposed to violence at more than twice the national rate, 101 versus 41 per 1,000 persons (U.S. Department of Justice, 2004), with AIs suffering higher lifetime rates of PTSD, 11% to 13% higher compared to 4.5% among non-AI (Beals et al., 2005), and AI women being 2.5 times more likely to be sexually assaulted than women of all other racial backgrounds (Amnesty International, 2007). Responses to historical and lifetime trauma exposure among AIs include posttraumatic stress disorder (PTSD), substance use disorders (Beals et al., 2013), and HIV exposure (Bartholow, Doll, Joy, & Douglas, 1994). The interdependence of trauma exposure, PTSD, and substance use results in a perpetuating cycle of risk (Hayman & Crandall, 2009). Despite the high need for mental health care, there are currently no programs available to AI clients that concurrently address PTSD, substance use, and HIV risk for AI communities.

Treaty agreements between tribal nations and the federal government established requirements for the federal provision of health care to AIs. The Indian Health Service (IHS) was established to fulfill this obligation (IHS, 2015). IHS is, however, extremely underfunded (Bernard, 2016), with per capita expenditures less than half those for Medicaid and lower than all other federally funded health systems including federal prisons (Roubideaux, 2005). Limited access to resources and culturally informed services result in many AI women never receiving services for serious mental health problems (Burgess, Ding, Hargreaves, van Ryn, & Phelan, 2008). With only approximately 101 mental health care professionals per 100,000 AIs (vs. 173/100,000 for White persons), significant barriers to accessing counseling and treatments exist (IHS, 2011). A review of 19 culturally tailored substance abuse treatment programs found that clinicians were able to reduce or eliminate substance use problems and improve client wellness in 74% of studies (Rowan et al., 2014). Culturally tailored intervention strategies are especially critical for this population to promote cultural acceptability and effectiveness (Dixon et al., 2007).

Given the high rates of exposure to traumatic events and related negative sequelae in AI communities, it is not surprising that trauma exposure and its associations with substance use disorders, PTSD, and HIV risk have been highlighted as areas in need of attention by many AI communities (Libby et al., 2007; Pearson et al., 2015). A Pacific Northwest AI community identified this need, and community educators, health care providers, and community members assembled a coalition to identify innovative, culturally based solutions to reduce health disparities. Named the “Sacred Journeys Women’s Initiative,” the goal of the project was to promote the resiliency and health of AI women, girls, and families. To this end, we used Intervention Mapping (IM), a planning and development tool that provides steps for taking an ecological approach for health promotion interventions (Bartholomew, Parcel, Kok, & Gottlieb, 2011). We developed community research protocols and followed the IM process Steps 1 and 2 to clarify the problem and to identify an intervention to holistically address women’s wellness around trauma symptoms, substance misuse, and HIV risk behaviors.

In this article, we: (1) describe the partnership and research infrastructure development, (2) discuss steps in developing a culturally grounded framework to obtain community assessment data and identify a trauma-informed evidence-based intervention (EBI), and (3) illustrate how a strong community-based participatory research (CBPR) partnership can foster an AI community's research capacity. We provide a description of effective procedures that can be applied to build community research infrastructure and foster mutually respectful community-academic partnerships aimed at reducing health disparities for AI communities.

To address these aims, we describe our partnership and setting, present funding strategies used to develop and maintain the partnership, and describe the tools used to guide research development. Specifically, we share how a community research committee (CRC) was formed, as well as the steps taken to clarify the health concerns of focus, program goals, objectives, and ways to develop a culturally tailored framework. We present results from our needs and assets assessment and the selection of a trauma-informed intervention. Finally, we describe the agreements and protocols developed for this community-academic partnership.

PARTNERSHIP DEVELOPMENT

The community partnership was established in 2007 when tribal women from a Pacific Northwest Tribal community reached out to the Indigenous Wellness Research Institute at the University of Washington for assistance in obtaining local data and funding to address community social and behavioral health concerns. The institute identified the academic researcher to partner with the community, and a meeting was brokered by the institute's community outreach director, an enrolled member of the same tribe. Initial discussions centered on who each person was as an individual. This included each member sharing his or her personal story and the skills and knowledge each individual uniquely brought to the collaboration. The sharing of personal histories and the exchange of small gifts were culturally respectful means of honoring the formation of these new relationships and establishing a partnership for future collaboration.

Issue Selection

On a monthly basis spanning a year, the academic researcher and the Indian education director formed an informal coalition of approximately 20 tribal leaders in order to discuss research strategies to address community concerns. Attendees included directors of tribal programs (e.g., adult and child social and health services, Indian education programs), school counselors, community volunteers, and parents. Meetings focused on teaching core concepts of CBPR, defining roles and expectations for community members and the academic partner, discussing the differences between program and research grants, and reviewing potential funding sources. This coalition reviewed their risk and protective profiles at the school district, local, and county levels. Reports presented data on the Community Domain (i.e., availability of drugs, extreme economic and social deprivation, transitions and mobility, adult antisocial behavior, low neighborhood attachment, and community disorganization), Family Domain (i.e., family problems), School Domain (i.e., academic achievement, school climate), Individual/Peer Domain (i.e., early criminal justice

involvement), and Problem Outcomes (i.e., child and family health, criminal justice, substance use). Numerous priorities were discussed from safe affordable housing, academic achievement, environmental issues, homelessness, loss of culture and language, and a need for tribal council and program support. Although the most pressing concern was risk factors among youth, members felt the larger community needed time to develop skills to address youth issues, and that beginning with young adults would be more acceptable. After considering all community priorities, the community decided to address trauma, substance use, and HIV risk among young adult women.

Community Research Committee

The Coalition selected 15 women to serve on the CRC to guide the development and implementation of the academic-led research projects. These women were community leaders, culture and language teachers, elders, health care providers, and young women (17–19 years), all of whom shared a dedication to promoting wellness across their community. The CRC promoted a logo contest across the reservation that would help “brand” the study to (1) promote recognition of the coalition’s guiding principles promoting wellness among Native women and families, (2) create identity and establish trust in the coalition efforts, (3) support advertising and recruitment efforts, and (4) inspire and mobilize the community.

Funding Strategies

The partnership first applied for program grants to support the coalition, produced data to sustain programs, and provided preliminary data to develop research proposals. During the first year (2008), the partnership received a small federal grant from the Native American Center of Excellence to evaluate a local program. The application, written together, was led by a community principal investigator. The academic partner provided oversight and training to the community members in program evaluation skills. This grant allowed both partners to understand each entity’s financial documentation and reporting requirements and produced data to obtain additional funding in order to sustain the program. In the second year (2009), the partnership obtained a larger federal grant, the Substance Abuse and Mental Health Services Administration’s Drug Free Community program, which establishes and strengthens collaboration among communities to support coalitions working to prevent and reduce substance abuse. Funding went directly to the community with a subcontract to the academic partner to provide the required program evaluation support. This funding established the Community Wellness Coalition and formalized the monthly meetings.

Research Development Strategy

We used Belansky’s modified IM for CBPR to guide the selection of theory and measures for the needs/assets assessment and to identify an EBI (Belansky, Cutforth, Chavez, Waters, & Bartlett-Horch, 2011). IM is not a theory but rather a process that uses an ecological approach and best practices to guide early planning for evaluation, adoption, and sustainability of intervention strategies. The first two steps of IM were used: (1) create a framework and matrix of program objectives based on links between individual behaviors and their physical and sociocultural environments and (2) based on community data, select a theory-based EBI. Belansky et al.’s IM approach was selected as it modifies the iterative and lengthy process of IM for a CBPR approach where each partner leads a different aspect of

the process. The academic partner accomplished the technical aspects of IM prior to meetings (i.e., reviewing the literature for theories, selecting measures, listing EBI, programming data collection tools, analyzing the data, and bringing findings to community), thereby leaving community meeting times for brainstorming and decision making (Belansky et al., 2011). The community reviewed and revised the measures, collected the qualitative and quantitative data, interpreted the findings and requested additional analyses, and ultimately selected the intervention.

INTEGRATING COMMUNITY INFORMATION

IM Step 1. Creating a Framework and Matrix of Program Objectives Based on Links Between Individual Behaviors and Their Physical and Sociocultural Environments

Over the course of two years, 3- to 4-hour meetings were held monthly. To identify core intervention components and guide data collection efforts (IM Step 1), we developed a theoretical framework grounded in Western and Indigenous knowledge, and identified community risk and protective factors. Our ecological framework (Figure 1) is based on social cognitive (Bandura, 1986), indigenous stress coping (Walters & Simoni, 2002), and social-ecological models (Bronfenbrenner, 1979). The framework highlights how culture, politics, social, and environmental factors influence level of risk for substance use, violence and trauma exposure, trauma-related symptoms, and HIV. Also noted is that spirituality and ceremony, community and family, connection to land, and cultural knowledge envelop all other factors providing strength, healing, and resiliency. This formative study captured a socioecological perspective identifying HIV/STI risk and protective factors at three levels: (1) individual (knowledge, attitude/motivation, risk perception, self-efficacy, and coping skills), (2) social environmental (social norms, social network, culture, support), and (3) physical environmental (access, venues, environment factors). The academic partner identified risk and protective indicators that mapped onto the framework. The CRC reviewed and revised the measures to incorporate community specific beliefs, rules and concerns.

Logo Contest Result—Figure 2 (the center image) is the logo selected by the CRC and was designed by a tribal youth. The image's symbolism represented the study's goal and principles and is interpreted as follows: The eagle flies toward the spiritual world, representing the essence of our work. On one wing are a cougar and a woman with her head held up, symbolizing the strength and courage to ask the hard questions, to seek and hear the truth. On the other wing are a hummingbird and a woman's head downcast, to remind us to walk with humility and graciousness. Underneath each wing are the dancers who represent the many helpers and those who guide us. In the tail is an image of a baby and cradleboard, as our work with women extends to family. In the heart of eagle is the world. It is the hope that the work we do will benefit not only the women in the community but also the women of the world. Also included in Figure 2 are the funding strategies used to maintain the partnership and further research efforts.

Identifying Population Specific Factors to Guide the Selection of an EBI—In full collaboration with the CRC, the academic partner obtained federal research funding to conduct a mixed-methods assets/needs assessment to help inform each section of the EBI.

Focus groups included ($n = 36$) women across three generations (young women 15–25 years, “moms,” and “grandmothers”), semistructured in-depth interviews ($n = 9$) conducted with community and spiritual leaders and health care providers, and a cross-sectional survey of young women age 18 to 35 years ($n = 146$). The survey included a respondent-driven sample, which is an advancement of snowball sampling in which “seeds” were identified based on diverse locations, ages, and risk factors; seeds were interviewed, and then asked to recruit others in their network. We also used venue-based recruitment methods (i.e., tribal housing areas, local powwows, maternal health clinic, schools, and the local college). Women responded to questions via audio computer-assisted self-interviews and received \$40 as compensation for participating. The protocol received community review and academic institutional review board approval.

Using Needs/Assets Assessment Findings to Guide Intervention Selection and Development—

The CRC and academic partner found strong agreement from community leaders and focus group participants on the intersecting risks of trauma, sexual risk behavior, and substance use (Pearson et al., 2015). At all socioecological levels, the community expressed pain and anger around trauma and micro aggressions. They shared concerns of “broken families” and “intergenerational childhood sexual and physical trauma co-occurring with substance use.” Micro aggressions were also systemic. Participants discussed at length the anger they felt from being followed around in stores, used as mascots, and harassed by nonnatives at schools, by the police, and by employers. Most said they were “very bothered” by these events and think of the incidents often or daily and were “unsure how to move beyond” the feelings engendered by such events. At the individual level, some described PTSD symptoms and post-trauma reactions, that is, having feelings of guilt, blaming themselves, and describing behaviors of avoidance and hypervigilance, and reexperiencing trauma memories. Substance misuse and sexual risk behaviors were discussed as avoidance behaviors, described to “kill the pain,” with a few referring to substance use and sex at an early age as rites of passage (“drugging and sexing then going through recovery”). Women expressed little control or autonomy over sex, and a lack of opportunities for personal growth (e.g., describing lack of employment and sports opportunities and independent housing).

A lack of opportunities was also identified by community leaders who provided powerful descriptions of the burden their women carry and the severe lack of supportive resources. This particular tribe is a matriarchal society; as such, the wellness of the tribe’s women is an integral part of healing the community. Similar to the qualitative assessment, the community survey illustrated evidence of the burden these women carry: 54% reported some form of PTSD (16% PTSD diagnosis, 18% subthreshold PTSD). Moreover, women with high PTSD symptoms and more binge drinking were at higher risk for having sex without a condom than those with low PTSD scores (Pearson et al., 2015). Although women’s current partnerships were likely to be monogamous or practicing safe sex, sexual behaviors with previous partners included greater sexual risk behaviors (e.g., frequent alcohol use prior to sex, inconsistent condom use, and having sex in riskier settings such as bars; Pearson & Cassels, 2014). The young women also exhibited resiliency, as psychological well-being

scores were high (Walls, Pearson, Kading, & Teyra, 2016). The CRC emphasized breaking the cycle of intergenerational trauma with the resultant hope of healing families.

As a result of the assessment, the tribal community formalized, with a tribal resolution, “Sacred Journey: The Women’s Wellness Initiative,” with the goal of promoting the “resiliency and health of young American Indian families, women and girls” and providing “culture-based counseling, social support and education to empower young women and girls to transform their lives through personal growth and well-being.” Additionally, the CRC developed and ratified the research protocol, publication guidelines, and a data-sharing agreement.

IM Step 2: Selecting the Intervention

Driven by the needs/assets assessment findings, the CRC reviewed trauma-informed interventions, assessed underlying theory, core components, and determined where and with whom the intervention was developed, cultural considerations, and perceived feasibility of implementation. The CRC identified cognitive processing therapy (CPT; Resick & Schnicke, 1992) as the intervention most appropriate for their community. They felt the individual sessions would address the unique needs of each person’s situation and provide a safe place to disclose traumatic experiences and sensitive information about their histories. The focus on trauma resonated with what they believed to be the underlying cause of avoidance and high-risk behaviors. Moreover, CPT had been adapted for low- and middle-income countries, as well as for Bosnian refugees in the United States (Schulz, Resick, Huber, & Griffin, 2006). CPT’s main therapeutic technique of Socratic dialogue would be flexible enough to incorporate specific intervention adaptations that would work for this community. It allowed for adaptation while still maintaining core treatment elements of (1) psycho-education about PTSD and related symptoms, (2) identification of thoughts and feelings, (3) learning skills to challenge maladaptive cognitions, and (4) generating more adaptive cognitions. The CRC encouraged the inclusion of addressing sexual risk behavior and using community counselors to deliver the intervention. Using community counselors to deliver the intervention would enhance the skills of community members and build infrastructure and trust within the community. The CRC also believed that most tribal members would feel more comfortable working with an AI counselor as they would have a better understanding of the situations AIs face than a non-AI counterpart.

To help guide the adaptation process, in 2012 the academic partner and the CRC invited an expert in clinical treatment of PTSD, substance use, and adaptation of CPT for low- and middle-income countries to join the partnership (Bass et al., 2013; Kaysen et al., 2013). Together, the partners obtained a grant from the National Institutes of Health to adapt and evaluate CPT with the community.

Study Approval—The CRC presented its CPT proposal to tribal council and the grant submission was supported by a tribal resolution. On notice of funding, the academic partner was granted a 6-month delay to review the grant expectations with the community and confirm engagement. The partners revisited and updated the proposed protocol to facilitate the project’s success without the pressure of meeting project time-line expectations. The

academic partner worked with the tribe to obtain its Federal-Wide Assurance for entities engaged in nonexempt human subject research (Office for Human Research Protections, 2016). The tribe delegated institutional review board review of the study protocol to the University and maintained community review through the CRC.

Protocol and Research Development—Over the course of 10 years (see Figure 2), the partnership built research infrastructure; developed and ratified research partnership guidelines; obtained both program and research funding; developed skills, and fostered understanding of each organization's financial and reporting requirements; and developed working relationships with tribal administrative and grants and contracts personnel. The partnership adopted the National Congress of American Indians research partnership protocol that set forth principles, obligations, and responsibilities that guided the partners throughout all phases of the research process. The partnership produced a legally binding data-sharing and publication agreement. This agreement regulates all facets of study data and clearly states that the tribe owns the data and grants the university a royalty-free, nonexclusive right to use the data to publish reports and other academic publications in furtherance of the aims of the project. It set forth regulation of data access, collection, protection, storage, use, and reporting requirements and describes dispute resolution terms. De-identified templates are available on the institute's website at <https://iwri.org/research-area/research/>.

REFLECTIONS

Community-academic partnerships have increasingly emerged as a viable strategy to increase external validity (Glasgow, 2009), yet often require long-term time commitments and can be difficult to maintain during funding gaps (Drahota et al., 2016). Although these barriers are a concern, community-academic partnerships have been shown to reduce health disparities (Cyril, Smith, Possamai-Inesedy, & Renzaho, 2015) and increase implementation and dissemination across diverse communities (Wallerstein & Duran, 2010), supporting their importance and the contribution they can provide.

In our community-academic partnership, we took a CBPR approach to identify goals and strategies to improve health outcomes in an AI tribal community. We spent time in the first year discussing community-wide concerns that helped develop the partnership and a common language to engage CBPR research, and planned a long-term approach to address ecological factors that facilitate or create barriers to wellness. The first small community-driven grant allowed the group to develop trust and understand financial systems. An essential initial step was obtaining funds that established the community coalition and created a logo and "branding" that facilitated community-wide acceptance of program efforts. Research led by the academic partner began in the third year, providing the time for the partnership to develop research, data sharing, and publication guidelines. In the subsequent year, additional program and research funding was leveraged to address community-driven concerns.

As we have illustrated, community-academic partnerships are a viable strategy to fulfill AI communities' expectations that researchers honor community knowledge and provide

research that addresses community concerns (Ball & Janyst, 2008). When tribal partners take ownership of the research process by guiding the development, implementation, interpretation, and dissemination of findings (Thomas, Donovan, & Sigo, 2010), collaborations have the greatest likelihood of producing lasting change (Fisher & Ball, 2002; Stubben, 2001).

We encountered several challenges in forging this community–academic partnership. In identifying a trauma-informed intervention, discussions around intergenerational and lifetime trauma at the personal and community levels were present in every meeting. Unresolved trauma issues among some community members led to tensions between time management and project goals. Another tension was around respecting the privacy of cultural knowledge and spiritual practices, which precluded incorporating traditional stories and healing practices in the treatment manual. Concern of knowledge misappropriation by nontribal members restricted the sharing of medicines or stories in any other setting except traditional settings. Moreover, the CRC recognized that individual differences in upbringing resulted in varying religious and spiritual practices. The intervention needed to be relevant for members from other tribes who resided on the reservation. Navigating these challenges as a group also served as a way to further solidify trust and reciprocity between community and academic partners.

SHARING OUR LESSONS

This process may provide a road map for building community–academic research infrastructure and identifying other interventions for AI communities. Interventions that can target multiple problem areas at once, especially in low-resource settings, are appealing. This study highlights the importance of bidirectional collaboration with communities, the time needed to create these collaborative relationships, the multistep process necessary, and inclusion of multiple key stakeholders. Developing effective and efficient ways to culturally build community research portfolios provides a critical step toward improving individual outcomes and community health.

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FIGURE 1.
Community Developed Ecological Framework to Identify Core Intervention Components
and Guide Data Collection Efforts

FIGURE 2. History of Program and Research Funding and Logo for the Sacred Journey Women's Initiative

NOTE: SAMSHA = Substance Abuse and Mental Health Services Administration; NIDA = National Institute of Drug Abuse; NIMH = National Institute of Mental Health; NIMHD = National Institute of Minority Health and Health Disparities. Dates represent funding cycle.