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Community Sharing: Contextualizing Western Research Notions of Contamination within an Indigenous Research Paradigm

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Abstract

Báa nnilah is a chronic illness self-management program designed by and for the Apsáalooke (Crow) community. Arising from a collaboration between an Indigenous non-profit organization and a university-based research team, Báa nnilah's development, implementation and evaluation have been influenced by both Indigenous and Western research paradigms. Báa nnilah was evaluated using a randomized wait-list control group design. In a Western Research Paradigm (WRP), contamination, or intervention information shared by the intervention group with the control group, is actively discouraged as it makes ascertaining causality difficult, if not impossible.

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To enact critical methodology and pedagogy, scholars and educators recommend using identifiers preferred by specific Indigenous communities (e.g., Crow). However, such usage can be complicated, since individuals within those communities may not identify using the majority affiliation and/or they may prefer a more general term (e.g., Native). We use "Indigenous" and "Native" to encourage solidarity across Nations and to advance broad scale action as well as tribal affiliations when speaking about specific nations (e.g., "Crow" and "Apsáalooke"). Although we occasionally use "Indian" or "American Indian" to align with policy language, we recognize these terms are problematic given their history. Throughout this paper, we use various terms deemed appropriate for specific contexts by our Indigenous partners and mentors. Furthermore, we defer to these partners for advice regarding specific spellings of traditional names (e.g., Apsáalooke). We also use the Apsáalooke language throughout as a purposeful way to respect the community and bring it into and Indigenize a colonizing space. (Adapted with permission from Stanton et al., 2020).

This approach is not consonant with Apsáalooke cultural values that include the encouragement of sharing helpful information with others, supporting an Indigenous Research Paradigm's (IRP) goal of benefiting the community. The purpose of this paper is to address contamination and sharing as an area of tension between WRP and IRP. We describe how the concepts of contamination and sharing within Báa nnilah's implementation and evaluation are interpreted differently when viewed from these contrasting paradigms, and set forth a call for greater exploration of Indigenous research approaches for developing, implementing and evaluating intervention programs in Indigenous communities. (Improving Chronic Illness Management with the Apsáalooke Nation: The Báa nnilah Project.:NCT03036189)￼ClinicalTrials.gov:NCT03036189)

Keywords

contamination; sharing; Indigenous research methods; randomized control trial

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The purpose of this paper is to address contamination and sharing as an area where a Western Research Paradigm (WRP) and Indigenous Research Paradigm (IRP) come into tension. We seek to ask critical questions that deconstruct elements of a WRP and contextualize the term contamination within the context of a randomized control trial (RCT) in an Indigenous community. In a WRP, one of the primary goals of an RCT is to establish causality (Schrag, 1992). It does so under the assumption there is no contamination (components of one study arm of an RCT received by participants in other study arms) between the study groups. The threat of contamination within an RCT has important implications for study design, sample size estimation, study implementation, and analyses (Parfray & Barrett, 2015). High levels of contamination can mean that researchers are less likely to: (a) discern positive results; (b) reject the null hypothesis; or (c) find a strong impact of the program (Keogh-Brown et al., 2007; Parfray & Barrett, 2015). Consequently, much has been written about methods to avoid contamination in RCT research designs.

In an IRP, the primary goal of research is to benefit communities: "knowledge creation carries with it a moral purpose" (LeFrance & Nichols, 2010). Within an IRP, researchers have a responsibility to use methods that uphold relational accountability to each other and to communities (Hart, 2010; Wilson, 2008). An integral part of upholding relational accountability is through sharing; the more information is shared, the more the community benefits. In a broad context, "sharing" can refer to the relay of beneficial knowledge or skills among *any* community members at *any* time. We are using the term contamination, as used within a WRP, to refer to sharing that occurs within a waitlist RCT when intervention group participants relay intervention information to waitlist participants prior to their taking part in the intervention. To sum, the exact same actions of study participants deemed as contamination within a WRP are contextualized within an IRP as sharing. Western and Indigenous research paradigms flow from fundamentally different epistemologies. However, rather than constructing WRP and IRP as monolithic and opposing binaries, we wish to situate our inquiry within a more nuanced acknowledgement of the complexity of each paradigm. Researchers engage in science to build knowledge from different paradigm orientations (Varpio & Macleaod, 2020) with varied research ontologies, epistemologies, methodologies, and axiologies (Daly, 2007). Much has been written on the wide continuum of approaches to building knowledge within a WRP. We define WRP as including approaches ranging from positivism, post-positivism, constructivism, and critical approaches to postmodernism (Daly, 2007; Park et al., 2020; Varpio & Macleod, 2020; Young & Ryan, 2020). An IRP is conceptualized as being simultaneously distinct from these WRPs as well as, in some cases, complementary to some approaches on the WRP continuum. For example, Indigenous scholar Maggie Kovach (2010) created a Venn diagram that illustrated areas where qualitative methodologies grounded within WRP's constructivist or interpretive approaches overlap with some approaches within an IRP. This represents how methodologies rooted in different paradigms can sometimes complement or co-constitute novel approaches to doing research.

Kovach (2010) described community-based participatory research (CBPR) as an approach to research that utilizes components of a WRP but also holds up an IRP's expectation that research has a moral purpose of action. It is considered a best practice approach for research with Indigenous communities (Fisher & Ball 2003; Wallerstein & Duran, 2010; Whitesell et al., 2018, 2020), but does not include all aspects of an IRP. CBPR overlaps with the goals of an IRP with its focus on issues important to the community and its goal of creating research that benefits the community directly. Within this context, community members and university researchers are equal partners who collectively build capacity. This equitable relationship encourages everyone to acknowledge their personal and institutional histories, be present to fully listen and receive, understand and acknowledge the expertise that is all around, and help each other to understand what's important in each other's community (Christopher et al., 2008). The CBPR relationship also encourages research teams to honor and respect each other's backgrounds and histories. Walters et al. (2020) recently introduced the term "Indigenist Community-Based Participatory Research" to describe community-based research that incorporates a CBPR approach in an IRP and highlights additional overlaps between a CBPR approach situated within WRP and IRP. We recognize and honor the work of many Indigenous scholars throughout this paper whose focus of scholarship has been within and between WRP and IRP.

Because the purpose of this paper is to explore contamination and sharing as an area of tension between WRP and IRP, we examine elements of a WRP to contextualize the term contamination itself. We accomplish this through: (a) a description of the Apsáalooke (Crow) Nation, our CBPR partnership and the Báa nnilah program; (b) a discussion of sharing in the Apsáalooke cultural context; (c) a description of Báa nnilah's participants and research design; (d) data analysis and findings of contamination and sharing in the Báa nnilah intervention; and (e) a reflection on lessons learned, their implications, and our recommendations for future work.

Our CBPR Partnership within an Apsáalooke Context

Messengers for Health (Messengers) is an Indigenous non-profit organization located on the Apsáalooke Reservation in southeastern Montana dedicated to improving the health of the Apsáalooke "through community based projects designed to strengthen the capacity of communities and empower them to assess and address their own unique health-related problems" (Messengers, 2021). The Apsáalooke Reservation is the largest of seven Indian reservations in Montana, encompassing approximately 2.3 million acres and includes multiple distinct communities. Although Indian Health Services provides a hospital and two health clinics/stations on the reservation, many community members travel to larger cities for their health care, which can be up to two hours away. There are approximately 11,000 enrolled tribal members with the majority (7,900) residing on the reservation (Messengers, 2021).

Messengers began in 1996 as a partnership with Montana State University that used a CBPR approach to address women’s cancer awareness and prevention. Our CBPR partnership works together to prioritize the health of the community. We focus on health topics determined by our Community Advisory Board (CAB) and use a strengths-based approach that is grounded in Apsáalooke values and culture to create impactful and sustaining programs. Messengers’ CAB came to a consensus in 2013 that providing support for community members who have a chronic illness (CI) would be the focus of our next CBPR project.

The Báa nnilah Program

Báa nnilah refers to an Apsáalooke cultural strength of providing personal stories of guidance for life or advice to others. When entering into a new area of research, Messengers reviews the literature for existing programs that may inform local efforts or could be adapted for local use. We identified a number of available programs and the evidence-based Stanford University-developed Chronic Illness Self-Management Program (CDSMP) emerged as a highly used gold standard in the field (Lorig et al., 2001).

Although testing evidence-based interventions in a new setting is considered best practice, Western-based CI management programs such as the CDSMP have been shown to be impractical and difficult to sustain within Indigenous communities due to their lack of cultural consonance (Narayan et al., 1998; Jernigan, 2010, Barnett & Kendall, 2011). Furthermore, forcing Western-developed interventions onto Indigenous communities is felt to be a colonizing, patronizing and aggressive action that is evocative of past practices of forced assimilation (Bartlett et al., 2007; Donatuto et al., 2011; Duran, 2011; Duran & Firehammer, 2015). The authors of this paper agree with this perspective. In light of this, we felt there was a need for an Indigenously rooted CI self-management program deeply grounded within Apsáalooke cultural values and strengths. We hoped that if we could provide evidence of its effectiveness, it could be shared with other tribal communities to adapt to their own needs and provide a culturally consonant resource to help improve community health

Culturally relevant interventions are often developed from the ground up (Gameon & Skewes, 2019). Our program’s approach and content were co-developed by our partners after listening to, and co-analyzing 20 qualitative interviews with Apsáalooke men and women who shared their personal health stories of living with a CI (Hallett et al., 2016; Hallet et al., 2020; Held et al., 2019). This iterative, collaborative approach is similar to Kading et al.’s methodology for defining strengths from a within-culture lens (2019) and highlights how interventions can be guided by local knowledge (O’Keefe & Hartmann, 2019). Community member's experiences regarding what was helpful and not helpful in managing a CI fit with some elements of Western models of CI self-management (for example, physical activity, nutrition, understanding health conditions) as well as highlighted important influencers not included in these models (for example, spirituality, historical and current loss, resiliency, and improving relationships with health care providers) (Held, et al., 2019; Schure, et al., 2020). Aakbaabaaniilea (community members who give advice) led the seven program gatherings. For more detailed information on program development and content, please see: Hallett et al., 2016; Hallett et al., 2020; Held et al., 2019; Schure et al., 2020. Additional papers addressing our methodology, data analysis, and results are forthcoming.

Sharing within Báa nnilah's Cultural Context

A strength of Apsáalooke culture is the value placed on taking care of people in one's close-knit kinship network. To provide an understanding for those from the Western culture, those who are considered immediate family in Apsáalooke culture are considered in the Western culture as extended family such as aunts, uncles, cousins and second/third cousins. The clan system is an active and important part of the culture, with individuals being called upon to provide spiritual support, encouragement, and strength to others.

Apsáalooke culture sees power in words and in good conversation, and one way of taking care of each other is by sharing good words and good advice with each other. Thus, when someone receives something of value, sharing is encouraged with those in your kinship network. Sharing within the Apsáalooke culture is an act of love and care for others. The Báa nnilah program centered this cultural value and strength of sharing. Báa nnilah was facilitated by Apsáalooke community members (Aakbaabaaniilea) who were managing a CI. The Aakbaabaaniilea were fundamental to the program's integrity as they developed a safe space and shared their struggles and successes of managing a CI with program participants. A highlight of each gathering was a sharing circle, where the Aakbaabaaniilea and participants learned and grew together by sharing personal stories related to the topic of the gathering (such as navigating the healthcare system, healthy communication, eating healthy, and exercising). Sharing was integral to the gatherings and included sharing meals, sharing stories, sharing circles, and supportive partnerships. In these partnerships, participants provided support and encouragement to each other both within and outside of the gatherings. A culturally consonant goal setting tool, Counting Coup, was developed where participants gathered feathers (achieved goals) for their metaphorical coup stick. Participants created and shared health goals informed by what would help them fulfill their Apsáalooke role within their family and community grounded within their connections and relationships with culture, identity, story, history, survivance, language, ancestors, and family clans. These goals included, but also naturally extended beyond the specific CI self-management content. See Iitáa Dáakuash et al. (2020) for a description of the development and details of this tool.

Although there are some broad cultural norms regarding who speaks in public or shares in a group based on age or gender, those did not pertain to our gathering contexts specifically. Aakbaabaaniilea opened each gathering by saying "We are here as equals. We are here to support and encourage one another. No one knows more than any other person." This created a safe space and allowed everyone to share based on who felt comfortable doing so rather than other norms. Because this was the first time Messengers invited men and women to be together in a health program, it also overcame a barrier to talking about one's health more openly as part of one's healing within the community for both men and women. This built on Messengers' past work in talking about women's health issues and indicates the strength of Messengers' relationship with the community.

During the final gathering of the Báa nnilah program, Aakbaabaaniilea encouraged graduating participants to share the information they learned from the program with others with this statement, "Understand that you can all be mentors within the community with the support and tools you have gained through Báa nnilah. Serving as a role model will improve the health of the community now and in the future." In summary, the cultural value and strength of sharing was infused throughout many elements of the intervention. These elements of the program centered culture in ways that distinguish it from traditional Western self-management programs. For example, CDSMP facilitators are required to follow the program manual and "not add, change or delete material or activities" (Self-Management Resource Center, 2016). This leaves little room for local knowledge, expertise, or community knowledge sharing strategies to flourish.

Báa nnilah Participants and Research Design

Participants in the intervention ranged in age from 24 to 82 years old (mean = 52.09 years), with females comprising 72%. Nearly half (48%) were married or living in a marriage-like relationship and 67% reported an annual household income of less than $25,000. All participants had at least one ongoing CI with 70% indicating comorbidities. Common CIs reported include diabetes (57%), high blood pressure (56%), chronic pain (35%), and arthritis (34%) and 6% of participants indicated they had cancer (breast, lung, etc.).

This pragmatic clinical trial used a cluster randomized trial (CRT) design (Cook, et. al., 2016), where each cluster consisted of participants who belonged to the same family/clan. A total of 211 participants were randomly assigned to either an intervention group (n = 104) or a wait-list control (WLC) group (n = 107). The intervention included seven gathering which occurred over approximately four months. Health survey and physical test data were collected at baseline, post-intervention, 6-month follow-up, and 12-month follow-up from participants in the intervention group, and at pre-baseline, baseline, post-intervention, 6-month follow-up, and 12-month follow-up from participants in the WLC group. Longitudinal response rate at each of the subsequent waves was 80%, 69%, and 66%, respectively, among intervention participants, and 84%, 70%, 68%, and 69%, respectively, among WLC participants. Additional qualitative interviews assessing the impact of the program with both the Aakbaabaaniilea (10) and participants (13) were completed at the end of the quantitative data collection. There was no active Institutional Review Board (IRB) on the Apsáalooke Reservation at the time of this study. The Montana State University IRB approved this study prior to any data collection.

There were multiple factors that influenced the choice to use a cluster-randomized trial design (Eldridge & Kerry, 2012), also known as a group-randomized trial, with a wait-list control group. The first factor was our hope that the intervention could be designated as “evidence-based,” which we believed required that it be evaluated from the perspective of a WRP. Within a WRP, health intervention research frequently uses the RCT design, which remains the gold standard study design for evaluating causality and for establishing an intervention as evidence-based (Ginsburg & Smith, 2016). Establishing our program as evidence-based would help other tribal communities obtain access to, and funding for, an Indigenous-rooted CI program they could adapt and implement within their own communities (Gameon & Skewes, 2019). Health programs that achieve the designation ‘evidence-based’ are usually those that have access to the most funding. For example, under the American Recovery and Reinvestment Act of 2009, $27 million was made available to deliver evidence-based self-management programs (Tilly, 2010). Communities were not allowed to use programs that did not have the evidence-based label. This limits Indigenous communities’ program choices because there are no self-management programs developed in, with and for Indigenous communities that are deemed evidence-based.

The second factor for selecting an RCT was that we were influenced by the accepted concepts of rigor embedded within WRP to be eligible for funding of grant applications submitted to the National Institutes of Health (NIH). At the time we were looking for opportunities to fund this project, NIH had a funding opportunity for projects using community-based approaches, which fit with our CBPR approach. From our experiences with this agency, we perceived that there was a positive bias toward RCTs in the NIH grant review process.

The third factor influencing design decisions related to the use of a wait-list control group so that all community members involved in the research could receive the intervention. It would not have been appropriate to have some community members benefit from the intervention while others were left out. Doing this would have broken the community’s trust, harmed the integrity of the partnership that took years to build and led to failed future projects because community members would stay away. Having a control group that received usual care or an alternative intervention that did not directly address CI self-management would not only be culturally inappropriate, but also unethical because the CAB selected CI as a vital area to address.

Data Analysis

Within the context of an RCT, contamination is most likely to occur: (a) in trials conducted in settings where participants work, live together or interact closely; (b) where interventions are desirable, simple or easily transferable or have the purpose of increasing knowledge; and (c) with interventions that are based on broadcast media, audiovisuals or written information (Howe et al., 2007; Keogh-Brown et al., 2007). The context of our RCT included all three of these components due to the close-knit nature of the Apsáalooke community, the natural way community members relate with one another and share valuable information with each other, the use of local mentors to recruit and lead participants, and the nature of program content and delivery. Consequently, we took steps to measure the extent to which sharing occurred.

We did this in three ways: (a) analyzed 2 questions relating to sharing from a quantitative questionnaire assessing the amount and extent of sharing, (b) thematic content analysis of an open-ended question from that same questionnaire, and (c) thematic qualitative analysis of audio-taped and transcribed interviews with 10 Aakbaabaaniilea relating to the nature of sharing within their gatherings.

Analysis of the open-ended question was done by two team members who performed a content analysis to discover the most prevalent and common themes found within the responses (Braun & Clarke, 2008). After identifying and selecting the core themes and illustrative quotes in the data, findings were then taken back to the research team for their feedback. This iterative process resulted in a refinement of final core categories and representative quotes. An in-depth thematic qualitative team analysis was done with the Aakbaabaaniilea interviews. For more detail on this, please see Allen et al. in press.

Findings Related to Sharing/Contamination in the Báa nnilah Intervention

After the intervention group completed the intervention and prior to the wait-list control group taking part in the intervention we asked wait-list control group participants (*n* = 93) about sharing. We first asked, “Have you taken action for your health because of something you have heard or learned from a friend or family member who has attended the gatherings?” About 80% (*n* = 74) responded “yes.” Those who answered “yes” were then asked to assign a number on a scale of 0 (not at all) to 10 (a lot) that best described the extent to which they took action based on what they learned from a friend or family member who attended the gatherings. The mean was 7.46 (*SD* =1.97), with 71% (*n* = 53) choosing a score of 7 or higher and nearly a quarter of the participants (24%) choosing the highest possible level of taking action (10). These numbers indicated high levels of sharing between the intervention and control groups, and action taken based on that sharing within the control group.

Participants were then invited to "Please share what actions you have taken or changes you have made in your life because of what you heard or learned from a friend or family member who has attended the gatherings.” Of the 51 open-ended responses, 7 themes emerged, including: (a) improved diet; (b) increased physical activity; (c) better emotional, behavioral, and spiritual health; (d) better collaborative/relational/social health choices; (e) increased education seeking; (f) increased active medical care; and (g) better self-care awareness and action. Improved diet and increased physical activity were mentioned most often (see Table 1).

These findings indicate sharing is central to the success of the Báa nnilah intervention and to its impact in the broader community. When Aakbaabaaniilea were asked to describe what successful mentorship looked like to them in the in-depth qualitative interviews, the idea of taking care of others through sharing information and words of advice was frequently expressed. One Aakbaabaaniilea said they knew they were successful “when your participants…want to utilize the information they received to help their family, their friends, and even their community at large.” Another one said, “[it’s] not just the person you’re treating. You’re also treating the family.”

A majority of Aakbaabaaniilea talked about the importance of participants sharing the health information learned in the gatherings with their friends, family, and the larger Apsáalooke community. This was referred to as a “ripple effect.” One Aakbaabaaniilea said of the Executive Director of Messengers, “she was the drop of water that we yearned for and this drop of water came down and actually hit the big puddle of water and I’m the first ripple… and so, my participants are the next ripple. And so, you know, how the water has the rippling effect. I encourage my participants, ‘When you go home, if you encounter a family member going through something, you know, feel free to share some information with them.’” To the Aakbaabaaniilea, sharing indicated that participants understood the material and were applying information and skills learned from the program into their lives.

The value placed on sharing is present in a story from one of our participants who is a kaale (grandma). She shared the importance of limiting sugar intake with her family members, including her grandson. She said that in addition to saving money, the grandson lost 15 pounds and his skin cleared up. This example highlights both how program information was shared through story by participants with their relatives and how it was implemented in actionable ways to become a healthier Apsáalooke Nation. The Aakbaabaaniilea demonstrated that sharing is a central component of the IRP methodology. They said of sharing: “it is in our blood,” “it is just natural,” “it is a natural Indigenous methodology.”

Reflections

Although we used a CBPR and IRP approach to develop the intervention, we used a WRP approach to evaluate it. This integration of multiple research paradigms and methodologies presented challenges and conflicts familiar to other researchers. For example, two of our co-authors described the conflicting tensions between rigorously testing the effectiveness of a different NIH-funded intervention with Indigenous families and promoting the sharing and integration of that intervention within the community (Belone et al., 2017). The first aim of rigorous testing was informed by WRP methods and the second aim of promoting the sharing and integration of the program in the community was informed by an IRP. This highlights how sharing/contamination can be an area of conflict between the WRP and IRP paradigms. From a WRP perspective, contamination (sharing across study groups) is seen as participants going against a research protocol that results in a negative impact on the outcomes and evaluation. From an IRP perspective, sharing is a positive action of participants which is done for the good of the community. A strength of the Apsáalooke culture is the positive value of sharing and mutual support. Thus, the WRP-based RCT design’s attempt to minimize contamination is directly challenged by the IRP-based and, more specifically, Apsáalooke value of sharing useful or important information.

While we anticipated sharing across the intervention and wait-list control groups, we did not anticipate the level of sharing that occurred prior to the wait-list control group receiving the intervention. Not only was information shared, community members in the wait-list control group proactively took action to improve their health and the health of their families. From a WRP perspective, this constitutes a high degree of contamination and makes it less likely to obtain statistically significant findings that would provide evidence for effectiveness of the intervention. From a community perspective, it is a positive showing of cultural strengths within a cohesive community that facilitated our ultimate goal of community benefit. Using a wait list control group did not work as intended because the requirement of the design (no sharing between intervention and wait-list control) was incongruent with Apsáalooke cultural values. In essence, Apsáalooke cultural values and the IRP purpose of research benefiting community took priority over the WRP-based study design.

Implications and Recommendations for Future Work

We learned many lessons in the process of doing this research including: a) what happens when trying to bridge paradigms and b) the importance of contextualizing contamination. A summary of each lesson learned and implications and recommendations for future work are discussed below.

Trying to Bridge Paradigms

In our attempt to use a WRP-based wait-list RCT design to evaluate the Baá nnilah program, we learned there was a distinct challenge to bridging the WRP and IRP because of the inconsonance of the WRP value of minimizing contamination and the IRP value of sharing. By trying to integrate a WRP and an IRP, we were attempting to walk with our feet in two worlds. One foot was firmly planted in the Apsáalooke community and committed to our primary mission of benefiting the health of community members using approaches that respect and revitalize the community. Our other foot was in the world of a WRP due to these factors: (a) culture and training of non-Indigenous partners; (b) training of Indigenous partners in predominantly Western institutions; (c) wanting to receive the benefits of our intervention being established as an evidence-based intervention by the Western research community; and (d) the perception of bias towards the WRP when applying for research funding from agencies who are grounded in the WRP. The CBPR approach added weight to the foot that was in the Apsáalooke community and led us to the following implications and recommendations.

Attempting to bridge these two paradigms forced us to explore questions such as: Is it possible to integrate these research paradigms or is trying to do so making the research less beneficial or even causing harm to communities? Can we find a way to obtain funding and receive an evidence-based designation while also valuing and honoring the Apsáalooke culture? To what extent can WRP-trained researchers truly remove themselves from a WRP to better serve Indigenous communities? With these questions in mind, we offer four recommendations for researchers and funding agencies when proposing work in Indigenous communities: (a) bringing forward Indigenous voices and methods, (b) prioritizing IRP in Indigenous communities; (c) non-Indigenous partners committing to active allyship; and (d) providing funding opportunities.

Bringing Forward Indigenous Voices and Methods—Indigenous voices and methods are amplified when Indigenous people are program officers/officials of granting agencies who develop and shape grant program announcements and requests for grant applications or serve on grant review panels. By having a seat at the table and a voice in the determination of what are fundable methodologies, the methods within an IRP will flourish. Wilson (2008) stated the importance of moving past having to justify what is valid or worthy research and moving into "develop[ing] our own criteria for judging the usefulness, validity or worth of Indigenous research methods" (p. 14). Affirming Indigenous authority, expertise, and self-determination can expand the dialogue of voices in producing knowledge, honor diverse epistemologies, create methodological pluralism, and strengthen relational ethics (Quayle & Sonn, 2019).

Prioritizing IRP in Indigenous Communities—Over 20 years ago, Smith (1990) called for a prioritization of research methodologies that focused on social justice and emphasized positive outcomes and relevance to Indigenous communities. Since then, many research methods with a CBPR approach have been utilized with Indigenous communities that are grounded in Indigenous values (Belone, et al., 2020; Braun et al., 2014; Cram, 2018; Gittelsohn et al., 2018; LeFrance & Nichols, 2010; LeFrance et al., 2012). These methods call for research that is conducted and controlled by Indigenous peoples and communities, which is in line with the United Nations Declaration on Human Rights for Indigenous Peoples (United Nations, 2007). Because there is great variation among Indigenous nations, utilizing a CBPR approach can ensure local IRPs are developed and implemented that are consonant with the values and strengths of specific Indigenous nations (Belone et al., 2020; Dickerson et al., 2018; Gittelsohn et al., 2018; Whitesell et al., 2018) with support from agencies including the National Institutes of Health (Crump et al., 2017).

Non-Indigenous Partners Committing to Active Allyship.—If non-Indigenous health researchers are interested in partnering with Indigenous communities to improve community health, we recommend committing to a lifelong process of: (a) acknowledging how training and working in a predominantly white institution (PWI) that promotes a WRP creates blind spots in research approaches and committing to learning new approaches; (b) engaging with communities with love, humility, respect and a willingness to listen and learn; and (c) being an active ally for an IRP. These recommendations, in addition to others, have been voiced through documents such as the "Guiding Principles for Engaging in Research with Native American Communities" (Straits et al., 2012). When Indigenous community partners indicate that an approach isn't appropriate or provide critiques of a WRP, non-Indigenous partners must respond appropriately by having the humility to honor the critique, listen, and revise the approach. Cochran et al. (2008) suggested that academic researchers working with Indigenous communities transform to a "service role, accepting community direction regarding priorities for research, considering Indigenous ways of knowing in research methods, and sharing or giving up entirely—depending on community needs and desires—the dissemination of research findings" (p. 26). Non-Indigenous partners must also use their voice and power as an ally to change the status quo of acceptance and dependence on WRP, including teaching IRP within PWIs. Allyship work done by non-Indigenous scholars includes an acknowledgement of some of the challenges Indigenous scholars experience when acting as a bridge between their community's culture and the painful assimilative power of PWIs. Their work is hard, and sacrifices are made by trying to write about it. Non-Indigenous allies can offer support by acknowledging the daily experiences of racism Indigenous partners experience and the systemic racism that influences their daily life. We suggest non-Indigenous partners approach Indigenous communities in a culturally appropriate and respectful manner that is not pushy and to continuously find opportunities to support the community, step back and receive corrective feedback with humility, and reduce the space they take up.

Provide Funding Opportunities—Our final recommendation is to provide funding opportunities for Indigenous communities to develop health intervention programs from the ground up through the use of an IRP versus communities having to adapt or adopt existing evidence-based Western-developed interventions. There are very few Indigenous centered interventions available, which may be one reason why health disparities in Indigenous communities seem to be intractable. Modifications such as “tagging on a feather,” adapting content without fundamental paradigmatic change to the intervention relating to Indigenous epistemology and cosmology, or modifications made without community input and control cannot provide a truly Indigenized, effective, helpful intervention (Walters et al., 2020). Therefore, some researchers have utilized a culture-centeredness approach (Belone et al., 2017, 2020; Dutta 2007; Wallerstein et al., 2019) in the development of Indigenous interventions which are grounded in the local culture and knowledge systems (i.e. histories, language, healing practices, etc.).

Importance of Contextualizing Contamination within a Relational World View

One of the key lessons we learned is the need to contextualize contamination as defined by a WRP lens. This is illustrated by an Aakbaabaaniilea, who expressed the necessity and power of providing information, resources and support to *everyone* in the community, versus limiting information sharing to alleviate a WRP’s concerns with contamination. The Aakbaabaaniilea shared, “I lost my mother to diabetes and congestive heart failure. My father was an alcoholic, you know, and he died in a car accident, and my sister died because of alcohol, so it’s like gosh, we need to break the cycle. We need to help everyone.”

Our findings highlight the strength, value, and desirability of sharing. High levels of sharing led to many positive effects on individual, family, and community health, which were congruent with our desired outcome of the intervention having an impact on the larger community. From an IRP perspective, contamination between groups had positive effects which necessitated a new terminology of sharing. By contextualizing contamination, the same behaviors take on a positive connotation, suggesting it is something to encourage, rather than avoid.

Sharing increased the likelihood the intervention was successful within this close-knit community. It also indicated the intervention was functioning exactly how it was intended to work by disseminating valuable health information and knowledge widely through word of mouth. Overall, contextualizing contamination as a positive, value-added benefit of a research design makes it more congruent within an IRP and aligns with the primary purpose of research to benefit communities and a central component of IRP, relationality. As Walters and colleagues (2020) stated, “relationships can be central to healing and provide the framework for health interventions” (p. 558).

The implications of contextualizing contamination center primarily on the fallibility of a WRP in an Indigenous domain due to its cultural inconsonance. For us, this required that we shifted to a frame of reference that did not pathologize sharing. We recommend two evaluation principles that reinforce the strengths of IRP including: (a) privileging community-defined evidences and (b) measuring the diffusion of effect.

Privileging Community-Defined Evidences—There remains a false assumption in academic literature that Indigenous communities are somehow lacking from an absence of “credible evidence,” defined as data obtained from WRP. When Indigenous communities own their own research and evidence from this research is respected in the same ways that Western researchers’ evidence is respected, health inequities will change. This includes owning the evaluation and interpretation of research and the data gathered during the research. Others have voiced the need to resist “the restraints existing within Western science” (Dickerson et al., 2018, p. S34) when developing health interventions for Indigenous communities.

We recommend using a CBPR approach within an IRP that prioritizes and honors community voices regarding what is considered evidence and acceptable research methods. Evaluation methods, measures, and definitions of program success must all come from the community (Grover, 2010; Straits et al., 2019) and can be developed with a focus on measures that are culturally important (Belone et al., 2017). This means community members take the lead in designing and selecting locally specified outcome criteria and measures (Gone & Trimble, 2012) and determine as a community the criteria for evidence that the program worked. Privileging Community Defined Evidence (CDE) can shift the focus away from evidence-based practices valued within a WRP to practice-based evidences valued within an IRP. Gone and Trimble (2012) define practice-based evidences as traditional cultural ceremonial and ritual practices used since time immemorial that are “accepted as locally compelling testimony regarding their efficacy” (p. 151). They argue that “in contrast…to the recent proliferation of evidence-based practice in mental health services, many AI/ANs instead assert the therapeutic efficacy of traditional cultural practices on the grounds of practice-based evidence” (p. 151).

Measuring the Diffusion of Effect—Measuring the spread of program effects within tribal communities can better capture the sharing and integration of intervention components that resonate with Indigenous communities’ values. It can also promote the desired outcome of the sustainability of those programs after the research funding has ended. Definitions of sustainability acknowledge the need for programs that have shown to help community members be integrated into existing community institutions (Moore et al., 2017; Walugembe et al., 2019). Furthermore, it suggests a continuation of culturally consonant programming beyond external funding (Lennox et al., 2018). Thus, measuring diffusion of effect requires longitudinal process assessments as well as short- and long-term outcome assessments from program development, implementation, evaluation, spread and integration into community agencies, and ultimately community-level impacts (Walugembe et al., 2019).

Conclusion

Academic researchers generally feel pressured to adhere to the requirements imposed by academia and/or funding sources, many of which are not consonant with Indigenous communities. The WRP has a long and troubled history of failing to see Indigenous method as valid and as such, some institutions and granting agencies may insist Indigenous methodologies be validated by a Western framework (Duran & Firehammer, 2015).

Apsáalooke Voice

We close this paper with the voice of the Apsáalooke partners in this research project. The dialogue that has occurred through writing this paper has allowed for more room to explore the importance and need for IRP and to honor the voice of Indigenous partners. Co-writing has meshed ideas together in a way that has been respectful and statements in this paper have been written strongly, with appropriate and direct language. We wrote each sentence with intention to collectively advocate for IRP and voice our insights. Also, Indigenous students' voices within our team have emerged and been emphasized.

We hope to approach research in a way that cultivates connections, pride and strength among Apsáalooke people. For an Indigenous community to open their door to research is significant due to the long history of harmful research and outside interference. One of our participants said of our program, "I know this is research, but it doesn't feel like research." This is a significant statement. The program not feeling like research helped people to become engaged, receive information, gain knowledge, and apply the program into their lives for the better. As in an IRP, we believe that the purpose of research is to improve people's lives and the community at large, be built on trust, be service oriented, and create long-term sustainable programs. Relationships are the backbone to this program. If we don't have a relationship, people won't feel comfortable telling their story. Through relationships, we are rebuilding Apsáalooke ties, and creating pride in being Apsáalooke. When participants find encouragement and support at the gatherings, they feel like they can reach out and help someone else. As a result, they go out into the community and share this encouragement. This is our Indigenous research methodology.

The Báa nnilah intervention is particularly impactful because it uses our values and who we are as Apsáalooke people and because local IRP was honored and applied in its development. The Stanford CDSMP program would not have been relational with our people, which required us to develop a new program that relied on the voices of community members who experience CIs. As this is research, we needed a protocol to evaluate the program; however, the rigidity of not allowing sharing between the intervention and waitlist control group within the WRP protocol was not consonant with our culture, where sharing is a value and an impactful practice. Our nation has faced colonization, historical trauma, the impacts of non-Indigenous people who came into our territory and imposed their ways upon us and other adversities such as warring with other Indigenous nations. However, this is not what defines us because our strengths are rooted in the soil, which allows us to stand strong in our collective identity and continue to flourish as a nation.

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Table 1

Themes and Sample Open-Ended Responses

	Theme	**Examples of open-ended responses**
1	Improved diet	“eating healthier” “drinking more water” “trying to manage a balanced meal” “changed the way I eat by reading labels more”
2	Increased physical activity	“be active” “walking a bit more” “exercising more often” “always make time to take a walk” “do things manually when I can”
3	Better emotional, mental, and spiritual health	“Helping one another is a good positive outlook on life and helping our daily life and self-worth amen” “good positive outlook on life” “change my health to be happier” “I try and stay away from negative people that put my self-esteem down” “my health is important and I'm worth it” “I choose to be more through prayer and love for myself and family”
4	Better collaborative/relational/social health choices	“find a partner to walk with” “helping one another” “contribute my experience” “more…love for myself and family” “I help my sister a lot and give her my support”
5	Increased education seeking	“Read and study the binder” “read labels more” “looking forward to learning more” “helped me understand the value of health”
6	Increased active medical care	“take care of myself; get physical exam” “take medications daily” “Living better. I'm diabetic and now taking care of myself”
7	Better self-care awareness and action	“Living a better healthy lifestyle” “Taking better care of my health and body”

Note: Responses were typed into a tablet computer by participants. Some minor spelling corrections were made.