

ACTION-RESEARCH

Lessons Learned from Designing Curriculum and Fostering University-Community Collaborations to Implement a Lay Patient Advocate Training in Tribal Communities

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Health literacy is critical to enable individuals the capacity to obtain, process, and understand information to make informed health decisions, advocate for themselves and family members, and to activate collaboration in sharing responsibility for health decisions and perform self-management behaviors to help improve their quality of life. This is a particular challenge in disadvantaged groups such as the American Indian (AI) population. The purpose of this Community Based Participatory Research study was to foster university-community collaborations to develop a health literacy/self-advocacy training curriculum for laypersons in AI communities and deliver the training curriculum via classroom integration in community adult education programs. The target population for this program was adult learners in AI tribal communities across South Dakota. A committee consisting of representatives from the community and health science content experts from the university developed a four-module curriculum. The curriculum was modified following feedback from the local adult educators who, following training, then implemented the curriculum into their programs. Results suggest our heuristic health education approach to promote positive health behaviors among the AI population may be viable. By utilizing adult education specialists to deliver the curriculum to adults with educational barriers, we combined the content expertise of university health science professionals with the specialized expertise of community-based adult educators to provide the education to AI students in a familiar environment.

Keywords: health literacy; patient advocacy; American Indians; adult education; community collaborations

Introduction

Health literacy which is essential for accessing and using health care services, managing chronic conditions, and maintaining health and wellness has come to the forefront as a major public health issue. According to the Institute of Medicine (2004), 90 million Americans lack the health literacy skills to understand and act on health information and health system demands. The fact that only around 12 percent of U.S. adults have proficient health literacy emphasizes the barrier this poses to improved health. Furthermore, over one-third of U.S. adults have difficulty with very basic and common health tasks such as reading and following the instructions on prescription drug labels and interpreting childhood immunization charts (U.S. Department of Health and Human Services [HHS], 2010). By definition, health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (HHS, 2000). It involves the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives.

Health literacy is influenced by culturally-based beliefs and communication styles, English proficiency, and experiences of bias in healthcare settings (Institute of Medicine [IOM], 2004). It is not just the result of individual capacities, but also entails the health literacy related demands and complexities of the health care system (Baker, 2006). Additionally, a number of factors impact health literacy such as a patient's receipt of appropriate health communication materials, ability to accurately interpret health-related information, and communication with providers (healthypeople.gov, 2019). People with low health literacy are overwhelmed by healthcare because their abilities and skills are challenged by the complexity and demands required to navigate an incredibly complicated healthcare system.

Pervasiveness of the Problem

Inadequate health literacy is more prevalent among vulnerable populations, such as minorities, the elderly, persons with chronic disease, and persons with lower education (IOM, 2004). More than a quarter of White adults had limited health literacy, compared to almost half of Alaskan Native/Native Americans, over half of Black Americans, and two thirds of Hispanic Americans (Kutner, Greenberg, Jin, & Paulsen, 2006). In a White paper on health literacy compiled by the Indian Health Service (IHS) Health Literacy workgroup, the IHS indicated that health literacy is disproportionately burdensome for Native American people and their elders (IHS, 2009).

Native Americans are at an increased risk of health complications due to the barriers associated with communicating, understanding, and responding to health information. Studies have shown that people with limited health literacy skills report poorer health status, are more likely to be hospitalized and have bad disease outcomes, and have a greater likelihood of medication errors due to a lack of understanding of medical labels and instructions (Berkman, Sheridan, Donahue, Halpem, & Crotty, 2011; Bennett, Chen, Soroui, & White, 2009; Nutbeam, 2008). They are also more likely to utilize treatment services instead of preventative care (HHS, 2010). In contrast, adequate health literacy may increase a person's ability to take responsibility for their health and their family's health (Sorensen et al., 2012). Studies have shown that there is a positive relationship between health literacy and patient participation in health and medical decision making (McCaffery et al., 2013; Yin et al., 2012; Seo, Goodman, Politi, Blanchard, & Kaphingst, 2016).

Although being able to read does not infer health literacy, the lack of basic literacy skills will almost always result in difficulty reading and understanding basic health information. Amongst 12th grade students, 80% of Native Americans scored below proficient in reading compared to 58% of their White counterparts (National Center for Educational Statistics, 2017). The reality that a majority of minority Americans, including Native Americans, have limited health literacy should prompt reconsideration of traditional approaches to improving health literacy and inspire new innovative strategies.

Implications for Native Americans

Because health literacy is closely linked to poverty, Native Americans are disproportionately impacted. In 2017, 21.9 percent of Native Americans were living at or below the poverty level compared to 9.6 percent of non-Hispanic Whites; furthermore, the median household income was \$45,448 for Native Americans, as compared to \$65,845 for non-Hispanic White households (OMH, 2017). Additionally, level of education is linked to economic prosperity. In 2017, 83.8 percent of Native Americans had at least a high school diploma compared to 92.9 percent of non-Hispanic Whites, 19.6 percent of had at least a bachelor's degree compared to 35.8 percent, and 6.8 percent held an advanced graduate or professional degree compared to 13.8 percent (HHS, 2017). In South Dakota, Native American adults reported a higher incidence of chronic conditions, lower self-perceived quality of physical health, and more adverse childhood experiences (ACEs) compared to White adults (Moon, Roh, Yeon-Shim, & Goins, 2015). These disparities are compounded by educational deficiencies within the population, notably, 89% of Native American students entering the adult education system have basic academic skills lower than a 9th grade level (South Dakota Department of Labor and Regulation, 2015). There is limited research, however, on the topic of health literacy interventions to address this barrier among tribal populations.

Health literacy is commonly associated with health disparities (Mantwill, Monestel-Umana, & Schulz, 2015). Native Americans have long experienced poorer health status when compared with other Americans. Research has examined the negative aspects of well-being for Native Americans including high levels of poverty, substance abuse, violence, trauma, unemployment, suicide, and lower education attainment (Gone & Trimble, 2012). Native Americans experience lower life expectancy and a disproportionate disease burden rooted in economic adversity and poor social conditions (IHS, 2019). Native Americans have a high prevalence and risk factors for mental health and suicide, unintentional injuries, obesity, substance use, sudden

infant death syndrome (SIDS), teenage pregnancy, diabetes, liver disease, and hepatitis (Office of Minority Health, 2017). It is significant to note that Native Americans frequently contend with issues such as cultural barriers, geographic isolation, inadequate sewage disposal, and low income that prevent them from receiving quality medical care (IHS, 2017). As a result of the health disparities faced and implications of low health literacy on Native Americans, the Director of the IHS identified several key initiatives that could all be greatly impacted by increased health literacy to include chronic disease management, behavioral health, and health promotion/disease prevention (IHS, 2009). Currently, limited research exists on health literacy interventions to address these disparities and barriers faced by tribal populations.

Using Community-Based Participatory Research to Improve Health Literacy

In addition to the myriad of health disparities encountered, the relationship between Native Americans and non-Native Americans in the United States has been riddled with mistrust. Tribal communities have been subject to centuries of decisions impacting their health without consideration of their perspective and equal participation in the decision-making process (Shelton, 2004). This history of deceit, neglect, and exploitation has resulted in a legacy of mistrust related to outside involvement and interference with tribal communities. Consequently, this has created a dilemma for both tribal communities and academic researchers who have a genuine interest in improving the health of Native Americans (LaVeaux & Christopher, 2009). Trust between American Indian (AI) community members and academic researchers is critical to the success of intervention research within these communities (Christopher, Watts, McCormick, & Young, 2008). Research has demonstrated that projects will fail when trust does not exist between tribal community members and academic researchers (Rogers & Petereit, 2005; Christopher, 2005). Consequently, health interventions and research need to be grounded in a model that emphasizes integrating the community as full and equal partners in all phases of the research process.

Culture plays an important role in communication and is a very important piece of the complicated topic of health literacy. For people from diverse cultural backgrounds, health literacy is impacted by belief systems, communication styles, and the understanding of and response to health information. According to a study conducted by Geana, Greiner, Cully, Talawyma, and Daley (2012), Native Americans from the Midwest rely heavily on community resources, professionals, and traditional media outlets as their primary sources of health information; their data suggested that an approach using numbers, words, graphics and culturally tailored health information was important. Furthermore, Geana et al. (2012) noted that campaigns targeting Natives should be community driven and utilize existing community resources. In addition, Nutbeam (2008) noted that the research base surrounding health literacy as a personal asset is not well developed and recommended research using more personal forms of communication and community-based interventions.

Given the importance of addressing health literacy in a cultural context and history of exploitation by scientific researchers experienced by many Native American communities, an alternative to traditional programs and research is needed. Community-based participatory research (CBPR) offers that alternative as a powerful conduit for translating research into practice while building capacity for greater community change (Jernigan, 2010). CBPR has been defined as a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities" (Israel, Schulz, Parker, & Becker, 1998, p. 173). CBPR has shown promise in translating research into practice within Native American communities (Jernigan, 2010; Whitewater, Reinschmidt, Kahn, Attakai, & Teufel-Shone, 2016; Jumper-Reeves, Dustman, Harthun, Kulis, & Brown, 2014; Lonczak, Thomas, Donovan, Austin, Sigo, & Lawrence, 2013).

Using Adult Education to Improve Health Literacy

Education is a key factor and has been documented as leading to improved health literacy, health numeracy, and knowledge and behaviors (Braveman, Egerter, & Williams, 2011; LaVallie, Wolf, & Jacobsen, 2012). Enhancing education in key elements incorporated within the framework of health literacy could help equip individuals with the knowledge and skills for problem solving and provide a sense of control allowing them to more confidently engage in their own healthcare decisions. Consequently, effective educational methods of delivering health information particularly to those with low literacy and hard-to-reach disadvantaged groups, need to be established (Coulter and Ellins, 2006).

An opportunity to improve health literacy by leveraging existing community resources is to incorporate health education into established adult education programs. Adult education programs have been identified as potential settings to improve health literacy and address the health inequalities that stem from limited

health literacy (Muscat et al., 2016; Morony et al., 2018; Mein, Fuentes, Mas, & Muro, 2012). Incorporating the development of functional health literacy skills into adult education is a natural extension of the literacy skills that are already taught (Freedman, Miner, Echt, Parker, & Cooper, 2011). Adult education provides a context where meaningful learning occurs among individuals who could benefit from greater health literacy to help promote personal, family, and community health. It is a stable, nationally funded system that offers a sustainable point for intervention and contributes to a diverse approach to meeting the health needs of adult learners. However, approaches to incorporating health literacy into adult education vary widely (Diehl, 2011).

Adult education theory indicates that students prefer information that is relevant to their current situation taught in an environment that is open and encouraging (Knowles, 1980). The complexities of health and the healthcare system necessitate that health curricula be delivered in consideration of the student population's literacy. It is imperative that the content is presented in consideration of and respect for cultural beliefs (WHO, 2018). A study conducted by Muscat et al. (2016) provided evidence to understand how health literacy can be improved and health inequalities reduced through Australian adult education programs using the Being Healthy, Staying Healthy program which embedded key learning, literacy and numeracy skill development into 29 health-related topics using Functional Context Education methods. The National Action Plan to Improve Health Literacy highlights the role of adult education in the development of stronger health literacy skills stating that organizations, professionals, and policymakers should "support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community" (HHS, 2010, p. 2).

Although adult education programs have been successfully utilized to improve health literacy, few exist that incorporate and are culturally designed for Native Americans. Furthermore, a need exists to devise sustainable health literacy programs through collaborative efforts between tribal community partners and program planners/researchers. The purpose of this project was to foster university and community partnerships to develop a health literacy/self-advocacy training curriculum for laypersons in tribal communities and to deliver training curriculum via classroom integration in pilot community adult education programs. The goal of the program was to improve the ability of participants to advocate for themselves, their family members, and potentially the "extended family unit" of the tribal community. To that end, we engaged in a partnership with the South Dakota Association for Lifelong Learning (SDALL) and four tribal communities. SDALL is a private, non-profit organization dedicated to providing professional development opportunities to adult educators in South Dakota to enhance the learning opportunities for adult education students.

Methods

Target Population

This project was designed to be used with adult learners in reservation communities throughout the upper Midwest. Of the 219 adult education students that participated from three tribal communities in South Dakota, 53% were women and 47% were men. The mean age was 37 years ($M = 37.25$, $SD = 12.99$), with a range of 18–73. The adult education programs serve adult learners seeking basic education services such as GED, job readiness, basic computer skills, life skills, and job-specific training in math, reading, writing, science and social studies. These classes represent the only adult education services available in these tribal communities. The adult educators within these classrooms were recruited as instructors. These instructors were trained in the delivery of the health literacy curriculum and subsequently integrated the lessons into their classroom instruction. Students in these classes gave consent to receive the curriculum and to participate in the follow-up by completing post-intervention measures.

Development of Health Literacy/Self-Advocacy Training Curriculum

Since the goal of the project was to increase the ability of the adult learners participating in the program to advocate not only for themselves but also for others in their community, support within the tribal community was vital to the success of the project. Integration of the curriculum into an existing community-based adult education program and seeking guidance from the Native American community fit this model of community involvement. The program and instructors had long-standing relationships in the community, which brought an inherent level of trust when securing support and recruiting participants for the project.

A curriculum committee was convened at the University of South Dakota (USD) consisting of representatives from the tribal communities, content experts (faculty of the USD School of Health Sciences and the Sanford School of Medicine), and other key stakeholders. Native American community members included (a)

an MSW with extensive practice experience in the area of Indian child welfare, expertise in trauma-informed care, and numerous positive connections with the tribes throughout the state; (b) a member of a central South Dakota Sioux tribe and student leader at the university; and (c) a faculty member that had over 30 years of experience working with members of various tribes and participating in tribal events. The aim was to develop a curriculum that was culturally sensitive and culturally relevant. The committee consulted with experts in tribal health disparities within the Collaborative Research Center for Native American Health (CRCAIH) and adopted several of their recommendations, the most significant of which was to utilize the Circle of Courage as a framework for discussing health issues with tribal populations (Brendtro, Brokenleg, & Van Bockern, 2009). The Circle of Courage is a model of positive youth development based on the principles of belonging, mastery, independence, and generosity. The model integrates the cultural wisdom of tribal peoples and findings of modern youth development research.

Within traditional Native American culture, identity is tied closely to one's family or tribe membership. Much attention is placed on family relationships, and family consists of parents, grandparents, aunts, and uncles. It has been suggested by researchers that Native Americans tend to more likely be collectivistic (Hossain, Skurky, Joe & Hunt, 2011; Beckstein, 2014). Consequently, the curriculum was developed through the lens of collectivism with the consideration of the potential impact on the family. Additionally, there is an emphasis on learning by doing and watching. As a result, the curriculum was designed with flexibility to incorporate stories and experiences that extend beyond a structured classroom environment.

A literature review was then conducted, which yielded a number of existing resources from organizations including the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and the United States Department of Agriculture. In a study addressing engaging stakeholders in the development of culturally competent curriculum, Kamaka (2010) found that focus groups were effective tools. Consequently, we integrated sessions similar to focus groups into the development of the curriculum; these consisted of discussing the proposed curriculum with the adult instructors at each of the reservations to receive input prior to finalizing the curriculum.

The curriculum committee initially decided upon a heuristic Health Literacy/Self-Advocacy Training Curriculum (TC) comprised of five lessons in the following order of delivery: (a) Becoming an Advocate; (b) Finding Health Care Resources; (c) Medications; (d) Maintaining Your Balance-Healthy Eating; and (e) Maintaining Your Balance-Physical Activity. The content experts devised the lessons utilizing existing resources on each topic (Brendtro et al. 2009; CDC, 2018; CDC, 2019; FDA, 2013; USDA, 2013). The final lesson plans were shared with the curriculum committee to receive input prior to implementation. All lessons and supplemental resources were printed in binders and stored as online modules through USD's learning management system. The curriculum committee and instructors had access to the online curriculum throughout the entire course of the project.

Training of the instructors who would ultimately be teaching the curriculum was conducted by the lead project manager who was one of the content experts (an Assistant Professor of Health Sciences), in conjunction with representatives from the priority population in the community. Training for the adult educators, who would be teaching the curriculum via classroom integration at the site, included an overview of the scope of the project, curriculum, and corresponding research questionnaires. Each of the five modules was discussed in detail. The trainings were informal allowing discussion of and input on each lesson plan.

Revisions were made to the curriculum as a result of the feedback received from the adult education instructors within each of the tribal communities. The initial five lessons/modules were condensed into four to include (1) Becoming an Advocate, (2) Medication Administration and Prescription Drugs, (3) Maintaining Your Balance: Healthy Eating, and (4) Maintaining Your Balance: Physical Activity See **Table 1**. The modules covered in the curriculum included teaching outcomes, student learning outcomes, and an outline of the lesson plan activities/procedures. An optional module addressing mental health was also created. All trained instructors were given a username and password to access the revised curriculum including the lesson plans and supplemental resources through USD's learning management system.

Adult learners were recruited from the participating tribal communities as a whole by the local adult education staff working in the community. Students who were already enrolled in the adult education classrooms were encouraged, but not required to participate. Recruitment techniques relied on posters advertising the training and word of mouth. This research study was reviewed and approved by Institutional Review Boards.

Data was collected by trained staff to study our research question at three points in time: pretest (baseline, before curriculum delivered); posttest (30 days post-delivery); and follow up (60 days post-delivery).

Table 1: Health Literacy Curriculum Overview.

Module 1	Module 2	Module 3	Module 4
Becoming an Advocate	How to Read Medication Labels and Prescriptions	Maintaining Your Balance – Healthy Eating	Maintaining Your Balance – Physical Activity
The Medicine Wheel: Beyond the Tradition, Parts 1–3 (educational video) Health Advocacy within Framework of Circle of Courage	OTC Medicine Misuse Taking Medicine as Prescribed Medicine Storage and Disposal Questions to Write Down Before Visiting a Healthcare Provider Medicine Record Form What’s on the Label Adverse Reactions	Healthy Weight Management Nutrition Facts Label Food Diary Balancing Calories BMI Chart	Physical Activity and Exercise Benefits My Physical Activity Diary Let’s Move Family Activities Guide Let’s Move Family Calendar Strategies for Increasing Physical Activity

The Training Curriculum (TC) intervention was delivered four weeks after our pretest. Patient activation was measured using a valid 13 item measure Patient Activation Measure (PAM) (Hibbard, Mahoney, Stockard, & Tusler, 2005). PAM measures the extent to which a person perceives she or he is the manager of her or his health and health care. Research has shown increased levels of activation result in improved self-management behaviors (Hibbard, Mahoney, Stock, & Tusler, 2007).

Findings/Lessons Learned

Building University-Community Partnerships

The foundation of this project was building and leveraging partnerships between the university and community. As noted throughout the manuscript, many different organizations helped with the planning, implementation, and evaluation of this project. Collaboration with the South Dakota Association for Life-long Learning (SDALL) was critical, as they had the relationships with and access to the adult education programs. SDALL is the professional association representing almost 90% of the adult educators in South Dakota with a mission of promoting and providing professional growth and development for adult educators in South Dakota (SDALL, 2018). A representative from SDALL, the president at the time, was part of the steering committee to provide guidance and serve as a conduit to the adult education programs facilitating vital communication to recruit participants, organize the trainings, conduct assessments, etc. The partnership worked well with SDALL because they have people on the ground to include program administrators and classroom teachers in the tribal communities that were part of this project. Additionally, SDALL indicated that they received benefit from this curriculum given the limitations of their instructors to include a small percentage having formal science and health training, limited resources and time to write curricula, and access to students with health literacy needs. According to the SDALL representative, one of the reasons the partnership was so appealing for SDALL was because they “got to access expert curriculum writers in the field of health literacy which is a huge concern in adult education as well as health care to provide a high quality curriculum that our instructors could take and use with students already coming to our classes” (personal communication, February 2015).

The Collaborative Research Center for Native American Health (CRCAIH) was also vital to this project. CRCAIH (2018), housed within Sanford Research and supported by the National Institute on Minority Health and Health Disparities, was “designed to create a platform to bring together Tribal communities and health researchers, from multiple disciplines, to work together in the development of cutting-edge transdisciplinary research that will address the significant health disparities experienced by Native Americans in South Dakota, North Dakota and Minnesota” (para. 1). All of their projects address social determinants of health. CRCAIH provided support throughout the project by facilitating connections with leaders at the reservation communities and providing training and resources related to culture, research regulation, research methodology, community engagement, and research management.

Other vital partners included the South Dakota Area Health Education Center (AHEC), University of South Dakota School of Health Sciences, and the University of South Dakota Sanford School of Medicine. In addition to collaboratively administering the program, these entities provided valuable content, methodology,

and evaluation expertise. Representatives from SDALL, SD AHEC, and USD were part of planning, implementing, evaluating, and disseminating results related to this project. Equally important and absolutely critical were the partnerships established with the tribal communities, which included Sisseton Wahpeton Oyate, Enemy Swim, Eagle Butte, and Pine Ridge.

Trust Building between Academic Researchers and Communities

Historically, tribal communities have faced exploitation, deceit, and neglect related to health care services, interventions, and research resulting in mistrust related to outside involvement and interference with tribal communities. This has created dilemmas for both tribal communities and academic researchers who have a genuine interest in improving the health of Native Americans (LaVeaux & Christopher, 2009). This project, grounded in CBPR worked to establish trust by integrating tribal community members throughout all aspects of this project to include the development, implementation, and evaluation. Specifically, the delivery of the program was conducted by local, Adult Education instructors many of whom were tribal members. They not only had access to the priority population, but more importantly, had established trusting relationships. Despite the efforts to integrate community members and establish trust, the team indicated that this should be given greater prioritization as the foundation for future projects. Specifically, the model outlined by Christopher et al. (2008) for building and maintaining trust in Native American community-based participatory research partnerships should be utilized. They highlighted strategies that focused on the following two levels of trust building and maintaining: (1) between university and community partners and (2) between the initial project team and the larger community. For the first level of trust, they recommended acknowledging personal and institutional histories, understanding the historical context of the research, being present in the community and listening to community members, acknowledging the expertise of all partners, and being upfront about expectations and intentions (Christopher et al., 2008). All of these recommendations were attempted when designing and implementing this project; however, due to time limitations and geographical challenges, the team admits that it was not possible to be consistently present within each of the tribal communities. The curriculum trainer indicated that it would have been helpful to have more visits to and time within each community to interface with, provide curriculum guidance for, and establish trust with the adult education instructors. The four tribal communities within this project were hundreds of miles apart. As a result, the curriculum trainer was only able to visit each community one time to provide the initial training on the curriculum; follow-up was conducted via emails and phone calls.

The recommendations for the second level of building and maintaining trust are intended to assist initial partners with expanding to the greater community by not assuming people know that the project uses a CBPR approach, revisiting the first-level of recommendations with potential new partners, and matching words with actions (Christopher et al., 2008). These recommendations are important as this CBPR project is expanded and similar projects are implemented in the future.

Contextualizing Community-Based Participatory Research Principles for Tribal Communities

CBPR fosters true collaboration and partnership; if practiced according to published recommendations, it has the ability to develop trust through shared contribution, decision making, and ownership (Belone et al., 2016). In an article contextualizing CBPR principles for working with Native American communities, LaVeaux & Christopher (2009) highlighted two sets of recommendations to include Israel and colleague's (1998) "gold standard" for conducting CBPR research and a list of nine principles specific for conducting successful research with Native Americans. Israel et al. (1998) provided eight common principles for successfully conducting CBPR. These principles, including how they were integrated throughout this project, are outlined in **Table 2**.

Furthermore, LaVeaux and Christopher (2009) outlined nine additional considerations for universities using a CBPR approach with tribal communities. These considerations include (1) acknowledging historical experience with research and with health issues and working to overcome the negative image of research, (2) recognizing tribal sovereignty, (3) differentiating between tribal and community membership, (4) understanding tribal diversity and its implications, (5) planning for extended timelines, (6) recognizing key gatekeepers, (7) preparing for leadership turnover, (8) interpreting data within the cultural context, and (9) utilizing Indigenous ways of knowing. These recommendations for partnering with and conducting successful research with Native Americans were considered and integrated throughout this project.

Table 2: Application of CBPR Principles to Lay Patient Advocacy Project in Tribal Communities.

Principles	Application of CBPR Principles in this Project
Recognize community as a unit of identity.	Existing communities of identity were identified and utilized to strengthen the sense of community through collective engagement.
Build on strengths and resources in the community.	Instead of focusing on deficits and problems in the tribal communities, this project built on community strengths and resources to include the use of culture and traditions to promote health and wellness.
Facilitates collaborative partnerships in all phases of the research.	Partnerships with Native Americans to include engaging each of the tribal communities was part of all phases of this project to include planning, developing, implementing, and disseminating results.
Integrate knowledge and action for mutual benefit of all partners.	The project directly benefited the tribal communities, unlike past research where data gathering or needs assessment conducted did not have any impact on the community. This project successfully balanced providing tangible benefits to the communities while collecting the necessary research data. Additionally, tribal cultural beliefs and Indigenous ways of knowing were integrated throughout this project in effort to preserve traditional culture.
Promote a co-learning and empowering process that attends to social inequalities.	The partnership between the university and the tribal communities emphasized shared information, decision-making, power, resources, and support. University researchers put themselves in the role of the learner to accept new viewpoints and relinquish their position of sole expert in the partnership. The researchers also provided extensive education and training for the community members to implement the curriculum and engage in all aspects of the research process. Finally, the tribal partners were able to provide the researchers with an understanding and appreciation for Native ways and tribal sovereignty.
Involve a cyclical and iterative process.	The partnerships for this project were a result of long-standing relationships, which was very important. Tribal communities in particular want to establish integrity and sincerity before participating; although necessary, this can be very time-consuming. The researchers recognized the uniqueness of each tribal community, necessity for flexible plans and timelines, and importance of demonstrating a commitment to the community.
Address health from positive and ecological perspective.	The researchers utilized an ecological model to understand the context in which the tribal communities make decisions about and access resources related to their health and health care. Progress was contingent upon addressing ecological, sociological, and cultural issues.
Disseminate findings and knowledge gained to all partners.	Information on the results of the project was disseminated back to each of the tribal communities. Unfortunately, other priorities and commitments within each of the tribal communities impeded further discussion about the results.

Flexible Curriculum

Allowing for a flexible, evolving curriculum is vital. As previously noted, the curriculum was originally designed to have five modules; however, after the training with the adult education instructors, the curriculum was condensed into four modules. The fact that the curriculum was housed within an electronic Learning Management System that each instructor had access to, allowed for modifications to be quickly made and easily accessed. In addition, it was important that the classroom instructors had the flexibility to deliver the curriculum according to the needs of their students and within their individual classes. For example, some instructors chose to deliver the curriculum across a period of one month (approximately one module per week), others chose to deliver within one week (one module per day), and others delivered sequentially yet randomly based upon opportunities within the classroom. Additionally, instructors had the flexibility to enhance the curriculum. The provided curriculum served as a foundation and guide; however, instructors were encouraged to modify or enhance as needed and as appropriate for their population. For example, instructors shared that they incorporated visits to the on-site health and fitness center to orient students to the facilities and receive physical fitness assessments. Likewise, one instructor shared about inviting a local man to share about the challenges he encountered as a diabetic with severe complications and another instructor had a local woman share about her success losing weight. If the curriculum had been

too prescriptive, it would not have allowed for the infusion of local ingenuity and resources within each tribal community.

Instructor Training and Attrition

The adult education instructors were key to successfully implementing all aspects of this project. Consequently, it was very important to build trust by acknowledging their expertise throughout the process. The local instructors clearly understood that they had a voice in this process, and that valuable voice was listened to throughout the entire implementation of this project. For example, when the curriculum training was initially provided for the adult education instructors at each of the tribal communities, the training was conducted in an informal manner allowing the instructors to discuss, brainstorm, provide feedback, etc. Consequently, the curriculum was revised based upon this feedback.

One of the primary barriers to this project consisted of the constant turn-over of adult education instructors within each of the tribal communities. For example, within one of the tribal communities almost twenty Adult Education instructors were initially trained; many of them were very enthusiastic about and expressed innovative ideas for implementing the curriculum with their students. Within six months of the initiation of the program, though, almost half of those instructors had left their positions. Furthermore, one of the sites was in the process of accreditation review and lost their Adult Education Coordinator due to an extended medical leave of absence; these limitations in resources resulted in the de-prioritization of the project. Potential solutions were devised for addressing these issues with future projects to include: creating video vignettes of the training for each module for new instructors to access within the Learning Management System and providing a stipend for a lead instructor within each tribal community that can serve as a local point-of-contact and curriculum adviser for new and existing instructors. The video vignettes would also include the history and overview of the project. These strategies exemplify the important aspects of building and maintaining trust to include creating an ongoing awareness of the project history, establishing communication with new instructors, and being upfront about project expectations and intentions with new instructors.

Discussion/Conclusion

The purpose of this project was to foster university and community partnerships to develop a health literacy/self-advocacy training curriculum for laypersons in tribal communities and to deliver that training curriculum via classroom integration in pilot community adult education programs. The curriculum was developed by a committee consisting of health science content experts with input from representatives of the tribal communities and adult educators.

Implications for Practice

This project has the potential to impact practice for a variety of reasons. Our pilot collaboration and educational model shows potential as it positively impacted patient activation. It addressed Coulter and Ellins' (2006) recommendation by design of a health education/information curriculum and delivery of it in an effective way to a hard-to-reach, disadvantaged population with low literacy. It also was consistent with Nutbeam's (2008) recommendation to study community-based educational interventions. Our model was unique. By using adult education specialists to deliver the curriculum to adults with low literacy and other educational barriers, we combined the content expertise of university health science professionals with the specialized expertise of community-based adult educators and provided the education in the students' "home" environment. Previous research supports the idea that adults learn best when they are in informal and comfortable settings (Knowles, Holton, & Swanson, 2015). Furthermore, this approach proved conducive to fostering an effective learning experience. The fact that the adult educators were known and trusted within the communities assisted in giving the program credibility. In spite of the widespread and increasing use of lay health workers (LHWs) and patient navigators (PNs), relatively little is known about processes and best practices for selecting and training those from diverse backgrounds. There are several reports of individuals being trained as LHWs within African American, Latino, and Asian American communities, however, there is no known literature addressing the training of laypersons in AI communities (Gwede et al., 2013; Rhodes, Roley, Zometa, & Bloom, 2007; Han, Kim, & Kim, 2007). Often times LHWs and PNs are used specifically for the dissemination and implementation of programs. There is little research on the involvement of LHWs and PNs in the actual development of these programs such as how the adult educators from the tribal communities were involved in the planning and implementation of our intervention.

The National Research Council's (NRC) report *Improving Adult Literacy Instruction: Supporting Learning and Motivation* recommends instructional approaches that support motivation and persistence in adult learners (NRC, 2012). The report underscores the importance of linking new information to real-life events and meaningful purposes within the students' lives (NRC, 2012). This program's curriculum tied health literacy lessons to real-life student issues and, by being a part of the tribal communities, instructors were able to reinforce the applicability of the lessons to student experiences. Future programs can incorporate these strategies and the lessons learned when engaging in community-based research with Native Americans and other disadvantaged groups.

Study Limitations & Strengths

There were several limitations to our study. We did not specifically measure "health" literacy of the participants. Future programs should focus at minimum on completing a pre- and post-program health literacy assessment. Gearing more of the content toward visual learners was one of the recommendations made and will be incorporated into future programs. Although incentives were vital to insuring the ability for programs and participants to complete the study, providing incentives in the AI communities involved under the fiscal constraints of the program were challenging. Finally, while valuable qualitative data was gathered from some participants, a formal method for collecting such data would have enhanced the quantitative data.

There were several strengths to this program. In general, it helped fill the large gap in health literacy programs particularly within tribal communities. The training phase was key to insuring buy-in from the adult educators in the tribal communities. On-site trainings at the adult education programs provided the lead project trainer insight into the resources (e.g., access to technology) at each site. The willingness of researchers and curriculum developers to seek adult educator feedback and to incorporate suggestions based on educators' knowledge of their student base and their communities created a truly collegial relationship between the curriculum committee and the implementing instructors. Obtaining input from tribal community representatives also provided important insight and helped gain credibility for the program. Culturally-sensitive communication throughout all aspects and phases of the project was instrumental in securing instructors and student participants. The presence of the curriculum team with varied backgrounds and levels of experience in dealing with AI and adult education populations was key to minimizing the impact of miscommunications. Overall, this model shows promise for leveraging university-community partnerships to improve the health literacy and patient advocacy of tribal communities and beyond.

Recommendations for Future Research

There are many future studies that would be helpful in addressing the subject of health literacy and self-advocacy with disadvantaged communities that have historically faced barriers such as poverty and health disparities. Future studies within the Native American population could include a larger study within South Dakota, as well as, collaboration with other states and their tribal populations to see if the findings can be replicated. Additionally, longitudinal follow-up with participants could determine if the information taught is retained and implemented. Surveying previous participants in this pilot study to learn if and how they are using their newly gained knowledge and whether they have offered and/or are being utilized as a resource within their communities could have important implications that should be addressed. Including elders as presenters or assistant teachers within subsequent programs could strengthen the credibility of the program within the communities. Other future studies could include applying this research to other populations (e.g., refugees, other impoverished, and/or disadvantaged groups) which would allow researchers to study likely cultural differences. Finally, studies should further explore and assess the utilization of non-traditional research approaches such as community-based participatory research for designing, delivering, and sustaining culturally sensitive health literacy initiatives.

Competing Interests

The authors have no competing interests to declare.

References

- Baker, D. W.** (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21(8), 878–883. <https://doi.org/10.1111/j.1525-1497.2006.00540.x>
- Beckstein, A.** (2014). Native American subjective happiness: An overview. *Indigenous Policy Journal*, 25(2), 1–6. Retrieved from <http://www.indigenouspolicy.org/index.php/ipj/article/view/251/256>

- Belone, L., Lucero, J. E., Duran, B., Tafoya, G., Baker, E. A., Chan, D., ... Wallerstein, N.** (2016). Community-based participatory research conceptual model: Community partner consultation and face validity. *Qualitative Health Research, 26*(1), 117–135. <https://doi.org/10.1177/1049732314557084>
- Bennett, I. M., Chen, J., Soroui, J. S., & White, S.** (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Annals of family medicine, 7*(3), 204–211. <https://doi.org/10.1370/afm.940>
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpem, D.J., & Crotty, K.** (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine, 155*(2), 97–107. <https://doi.org/10.7326/0003-4819-155-2-201107190-00005>
- Braveman, P., Egerter, S., & Williams, D.R.** (2011). The social determinants of health: Coming of age. *Annual Review of Public Health, 32*(1), 381–98. <https://doi.org/10.1146/annurev-publhealth-031210-101218>
- Brendtro, L., Brokenleg, M., & Van Bockern.** (2009). *Reclaiming youth at risk: Our hope for the future*. Bloomington, IN: Solution Tree Press.
- Centers for Disease Control and Prevention.** (2018). *Healthy weight*. Retrieved from <http://www.cdc.gov/healthyweight>
- Centers for Disease Control and Prevention.** (2019). *Adding physical activity to your life*. Retrieved from <http://www.cdc.gov/physicalactivity/>
- Christopher, S.** (2005). Recommendations for conducting successful research with Native Americans. *Journal of Cancer Education, 20*(1), 47–51. https://doi.org/10.1207/s15430154jce2001s_11
- Christopher, S., Watts, V., McCormick, A. K., & Young, S.** (2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health, 98*(8), 1398–1406. <https://doi.org/10.2105/AJPH.2007.125757>
- Collaborative Research Center for Native American Health.** (2018). *CRCAIH*. Retrieved from <https://www.crcaih.org/>
- Coulter, A., & Ellins, J.** (2006). *Patient-focused interventions: A review of the evidence*. London: The Health Foundation.
- Diehl, S.J.** (2011). Health literacy education within adult literacy instruction. *New Directions for Adult & Continuing Education, 2011*(130), 29–41. <https://doi.org/10.1002/ace.408>
- Food and Drug Administration.** (2013). *Nutrition facts label: Eating healthier and feeling better using the nutrition facts label*. Retrieved from <https://www.fda.gov/food/nutrition-education-resources-materials/how-understand-and-use-nutrition-facts-label>
- Freedman, A., Miner, K., Echt, K., Parker, R., & Cooper, H.** (2011). Amplifying diffusion of health information in low-literate populations through adult education health literacy classes. *Journal of Health Communications, 16*(3), 119–33. <https://doi.org/10.1080/10810730.2011.604706>
- Geana, M. V., Greiner, K. A., Cully, A., Talawyma, M., & Daley, C. M.** (2012). Improving health promotion to American Indians in the midwest United States: Preferred sources of health information and its use for the medical encounter. *Journal of Community Health, 37*(6), 1253–1263. <https://doi.org/10.1007/s10900-012-9564-x>
- Gone, J. P., & Trimble, J. E.** (2012). American Indian and Alaska Native mental health: Diverse perspectives on enduring disparities. *Annual Review of Clinical Psychology, 8*(1), 131–160. <https://doi.org/10.1146/annurev-clinpsy-032511-143127>
- Gwede, C. K., Ashley, A. A., McGinnis, K., Montiel-Ishino, F. A., Standifer, M., Baldwin, J., ... Green, B. L.** (2013). Designing a community-based lay health advisor training curriculum to address cancer health disparities. *Health Promotion Practice, 14*(3), 415–424. <https://doi.org/10.1177/1524839912458675>
- Han, H., Kim, K., & Kim, M.** (2007). Evaluation of the training of Korean community health workers for chronic disease management. *Health Education Research, 22*, 513–21. <https://doi.org/10.1093/her/cyl112>
- Healthypeople.gov.** (2019). *Health literacy*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/health-literacy#7>
- Hibbard, J.H., Mahoney, E.R., Stock, R., & Tusler, M.** (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research, 42*(4), 1443–1463. <https://doi.org/10.1111/j.1475-6773.2006.00669.x>
- Hibbard, J.H., Mahoney, E.R., Stockard, J., & Tusler, M.** (2005). Development and testing of a short form of the patient activation measure. *Health Services Research, 40*(6), 1918–1930. <https://doi.org/10.1111/j.1475-6773.2005.00438.x>

- Hossain, Z., Skurky, T., Joe, J., & Hunt, T.** (2011). The sense of collectivism and individualism among husbands and wives in traditional and bi-cultural Navajo Indian families on the Navajo reservation. *Journal of Comparative Family Studies*, 42(4), 543–562. <https://doi.org/10.3138/jcfs.42.4.543>
- Indian Health Service.** (2009). *Indian health service: White paper on health literacy*. Retrieved from https://www.ihs.gov/sites/healthcommunications/themes/responsive2017/display_objects/documents/IHSHealthLiteracyWhitePaper.pdf
- Indian Health Service.** (2019). *Disparities*. Retrieved from <https://www.ihs.gov/newsroom/factsheets/disparities/>
- Institute of Medicine.** (2004). *Health literacy: A prescription to end confusion*. Board on Neuroscience and Behavioral Health, Nielson-Bohlman, L., Panzer, A.M., Kindig, D.A., Editors, Institute of Medicine and the National Academies. The National Academies Press: Washington, D.C.
- Israel, B., Schulz, A., Parker, E., & Becker, A.** (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202. <https://doi.org/10.1146/annurev.publhealth.19.1.173>
- Jernigan, V. B.** (2010). Community-based participatory research with Native American communities: The chronic disease self-management program. *Health Promotion Practice*, 11(6), 888–899. <https://doi.org/10.1177/1524839909333374>
- Jumper-Reeves, L., Dustman, P.A., Harthun, M.L., Kulis, S., & Brown, E.F.** (2014). American Indian cultures: How CBPR illuminated intertribal cultural elements fundamental to an adaptation effort. *Prevention Science*, 15(4), 547–556. <https://doi.org/10.1007/s11121-012-0361-7>
- Kamaka, M. L.** (2010). Designing a cultural competency curriculum: Asking the stakeholders. *Hawaii Medical Journal*, 69(6 Suppl 3), 31–34. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3123146/>
- Knowles, M.S.** (1980). *The modern practice of adult education: From pedagogy to andragogy*. Chicago, IL: Assoc. Press/Follet.
- Knowles, M.S., Holton, E.F., & Swanson, R.A.** (2015). *The adult learner: The definitive classic in adult education and human resource development* (8th ed). New York: Routledge.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C.** (2006). *The health literacy of America's adults: Results from the 2003 national assessment of adult literacy*. Washington DC: U.S. Department of Education
- LaVallie, D. L., Wolf, F. M., Jacobsen, C., Sprague, D., & Buchwald, D. S.** (2012). Health numeracy and understanding risk among older Native Americans and Alaska natives. *Journal of Health Communication*, 17, 294–302. <https://doi.org/10.1080/10810730.2011.626497>
- LaVeaux, D. & Christopher, S.** (2009). Contextualizing CBPR: Key principles of CBPR meet the indigenous research context. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 7(1), 1–26.
- Loncak, H.S., Thomas, L.R., Donovan, D., Austin, L., Sigo, R.L., & Lawrence, N.** (2013). Navigating the tide together: Early collaboration between tribal and academic partners in a CBPR study. *Pimatisiwin*, 11(3), 395–409.
- Mantwill, S., Monestel-Umana, S., Schulz, P.** (2015). The relationship between health literacy and health disparities: A systematic review. *PLoS ONE*, 10(12). <https://doi.org/10.1371/journal.pone.0145455>
- McCaffery, K., Holmes-Rovner, M., Smith, S., Rovner, D., Nutbeam, D., Clayman, M., Kelly-Blake, K., Wolf, M., & Sheridan, S.** (2013). Addressing health literacy in patient decision aids. *BMC Medical Informatics and Decision Making*, 13(S2). <https://doi.org/10.1186/1472-6947-13-S2-S10>
- Mein, E., Fuentes, B., Soto Mas, F., Muro, A.** (2012). Incorporating digital health literacy into adult ESL education on the US-Mexico border. *Rhetoric Professional Communication & Globalization*, 3(1), 162–174. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3666030/>
- Moon, H., Roh, S., Yeon-Shim, Y., & Goins, R.T.** (2015). Disparities in health, health care access, and life experience between Native American and white adults in South Dakota. *Journal of Racial and Ethnic Health Disparities*, 3(2), 301–308. <https://doi.org/10.1007/s40615-015-0146-3>
- Morony, S., Lamph, E., Muscat, D., Nutbeam, D., Dhillon, H., Shepherd, H....McCaffery, K.** (2018). Improving health literacy through adult basic education in Australia. *Health Promotion International*, 33(5), 867–877. <https://doi.org/10.1093/heapro/dax028>
- Muscat, D., Smith, S., Dhillon, H., Morony, S., Davis, E., Luxford, K....McCaffery, K.** (2016). Incorporating health literacy in education for socially disadvantaged adults: An Australian feasibility study. *International Journal for Equity in Health*, 15(84). <https://doi.org/10.1186/s12939-016-0373-1>
- National Center for Education Statistics.** (2017). Status and trends in the education of racial and ethnic group. Retrieved from <https://nces.ed.gov/pubs2017/2017051.pdf>

- National Research Council.** (2012). *Improving adult literacy instruction: Supporting learning and motivation*. Washington, DC: National Academic Press.
- Nutbeam, D.** (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67(12), 2072–78. <https://doi.org/10.1016/j.socscimed.2008.09.050>
- Office of Minority Health.** (2017). Profile: American Indian/Alaska Native. Retrieved from <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62>
- Rhodes, S., Foley, K., Zometa, C., & Bloom F.** (2007). Lay health advisor interventions among Hispanics/Latinos: A qualitative systematic review. *American Journal of Preventative Medicine*, 33(5), 418–427. <https://doi.org/10.1016/j.amepre.2007.07.023>
- Rogers, D., & Petereit, D.G.** (2005). Walking forward: The South Dakota Native American project. *Journal of Cancer Education*, 20 (1), 65–70. https://doi.org/10.1207/s15430154jce2001s_14
- Seo, J., Goodman, M. S., Politi, M., Blanchard, M., & Kaphingst, K. A.** (2016). Effect of health literacy on decision-making preferences among medically underserved patients. *Medical decision making: An international journal of the Society for Medical Decision Making*, 36(4), 550–556. <https://doi.org/10.1177/0272989X16632197>
- Shelton, B.L.** (2004). *Issue brief: Legal and historical roots of health care for American Indians and Alaska Natives in the United States*. Menlo Park, CA: Henry Kaiser Family Foundation.
- Sorensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., ... (HLS-EU) Consortium Health Literacy Project European.** (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, 12, 80. <https://doi.org/10.1186/1471-2458-12-80>
- South Dakota Association of Lifelong Learning.** (2018). About South Dakota Association for Lifelong Learning. Retrieved from <http://sdall.org/about/>
- U.S. Department of Agriculture.** (2013). *Native American nutrition education resource list*. Retrieved from <http://fnic.nal.usda.gov/resourcelists>
- U.S. Department of Health and Human Services.** (2000). *Healthy People 2010 (2nd ed.)*. Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services.** (2010). *National Action Plan to Improve Health Literacy*. Washington, DC: Author.
- Whitewater, S., Reinschmidt, K., Kahn, C., Attakai, A., & Teufel-Shone, N.** (2016). Flexible roles for American Indian elders in community-based participatory research. *Preventing Chronic Disease*, 13. <http://dx.doi.org/10.5888/pcd13.150575>
- World Health Organization.** (2018). *Social determinants of health*. Retrieved from http://www.who.int/social_determinants/sdh_definition/en/
- Yin, H. S., Sanders, L. M., Rothman, R. L., Mendelsohn, A. L., Dreyer, B. P., White, R. O., ... Perrin, E. M.** (2012). Assessment of health literacy and numeracy among Spanish-speaking parents of young children: Validation of the Spanish parental health literacy activities test (PHLAT Spanish). *Academic pediatrics*, 12(1), 68–74. <https://doi.org/10.1016/j.acap.2011.08.008>

How to cite this article: Gutierrez, C., Vogt, B., Giger, J., Lemke, J., & Memmott, J. (2020). Lessons Learned from Designing Curriculum and Fostering University-Community Collaborations to Implement a Lay Patient Advocate Training in Tribal Communities. *Collaborations: A Journal of Community-Based Research and Practice*, 3(1): 6, 1–13. <https://doi.org/10.33596/coll.48>

Published: 25 March 2020

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