

Lessons Learned From a Community-Based Participatory Research Mental Health Promotion Program for American Indian Youth

Sarah E. Langdon, MPH, CHES¹
 Shannon L. Golden, MA¹
 Elizabeth Mayfield Arnold, PhD, LCSW¹
 Rhonda F. Maynor¹
 Alfred Bryant, PhD²
 V. Kay Freeman, MA³
 Ronny A. Bell, PhD¹

Background. American Indian (AI) youth have the highest rates of suicide among racial/ethnic minority groups in the United States. Community-based strategies are essential to address this issue, and community-based participatory research (CBPR) offers a model to engage AI communities in mental health promotion programming. **Objectives.** This article describes successes and challenges of a CBPR, mixed-method project, *The Lumbee Rite of Passage (LROP)*, an academic-community partnership to develop and implement a suicide prevention program for Lumbee AI youth in North Carolina. **Method.** LROP was conducted in two phases to (1) understand knowledge and perceptions of existing mental health resources and (2) develop, implement, and evaluate a cultural enrichment program as a means of suicide prevention. **Discussion/Results.** LROP implemented an effective community-academic partnership by (1) identifying and understanding community contexts, (2) maintaining equitable partnerships, and (3) implementing a culturally tailored research design targeting multilevel changes to support mental health. **Strategies formed from the partnership alleviated challenges in each of these key CBPR concept areas.** **Conclusions.** LROP highlights how a CBPR approach contributes to positive outcomes and identifies opportunities for future collaboration in a tribal

community. Using culturally appropriate CBPR strategies is critical to achieving sustainable, effective programs to improve mental health of AI youth.

Keywords: American Indian youth; community-based participatory research; mental health; health disparities

American Indian (AI) communities in the United States are disproportionately affected by a myriad health conditions, particularly evident in the area of mental health (Gone & Trimble, 2012). AI youth often experience multiple risk factors that contribute to mental illness and suicidal ideation, including depressive symptoms, low self-esteem, substance use, hopelessness, poverty, forced acculturation, and lack of social support (Gartrell, Jarvis, & Derksen, 1993;

¹Wake Forest School of Medicine, Winston-Salem, NC, USA

²University of North Carolina, Pembroke, NC, USA

³Healthy Start CORPS, Pembroke, NC, USA

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Olson & Wahab, 2006; Yoder, Whitbeck, Hoyt, & LaFromboise, 2006). They also experience high rates of suicide, suicide attempts, and suicidal ideation compared to their non-Latino White counterparts. Studies show that nearly one quarter of AIs have attempted suicide at some point during their lifetimes (Borowsky, Resnick, Ireland, & Blum, 1999; Chino & Fullerton-Gleason, 2006; Howard-Pitney, LaFromboise, Basil, September, & Johnson, 1992; Novins, Beals, Roberts, & Manson, 1999).

Programs guided by tribal communities are greatly needed to raise awareness and develop strategies to address risk factors for mental illness and suicide among AI youth. In February 2009, the U.S. Senate Committee on Indian Affairs held an oversight hearing on youth suicide in Indian country calling for community-based interventions to reduce this growing concern. Historically, however, AI communities are often resistant to research participation, due to distrust of researchers and the “Western medical model”; results not being shared with/owned by the community; and receiving few actual or perceived benefits from participation (Burhansstipanov, Christopher, & Schumacher, 2005).

Previous studies show that among AIs, enculturation is protective against suicidal ideation and other factors linked to suicidality, such as depression, alcohol abuse, and alienation from family and community (Grossman, Milligan, & Deyo, 1991; Whitbeck, Adams, Hoyt, & Chen, 2004; Whitbeck, McMorris, Hoyt, Stubben, & LaFromboise, 2002; Yoder et al., 2006). Among Lumbee Indian youth specifically, despite a dearth of literature, results from a longitudinal study by Smokowski, Evans, Cotter, and Webber (2014) showed a positive relationship between strong ethnic identity and self-esteem.

Community-based participatory research (CBPR) offers a model to engage AI communities in mental health research. CBPR is recognized as an effective mechanism of engaging underserved minority communities to address and improve health-related risk factors and outcomes (Stacciarini, Shattell, Coady, & Wiens, 2011; Wallerstein et al., 2008), particularly mental health. CBPR is defined by Israel et al. (1998) as a “. . . collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.” In using this model, “. . . research is seen not only as a process of creating knowledge, but simultaneously, as education and development of consciousness, and of mobilization for action” (Gaventa, 1988).

The National Congress of American Indians White Paper on CBPR (Sahota, 2010), along with other studies (Burhansstipanov et al., 2012; Johnson et al., 2010;

Subrahmanian et al., 2011), show that CBPR is an effective tool for health promotion and health disparities research in AI communities. CBPR enables AI communities to be active participants on multiple levels, because they can guide how research partnerships are created, implemented, maintained, and disseminated in culturally appropriate ways.

This article describes successes and challenges of using a CBPR approach, through an academic-community partnership, for developing and implementing a suicide prevention program for AI youth in Robeson County, North Carolina (NC). This work provides support for the importance of meaningful research collaborations that enhance the practice of health promotion among a disadvantaged AI population.

► METHOD

Lumbee Rite of Passage (LROP)—a suicide prevention model for AI youth was a pilot study funded by the National Institute of Mental Health and approved by the Wake Forest School of Medicine (WFSM) institutional review board. LROP evolved from an existing health education partnership between the Maya Angelou Center for Health Equity (MACHE) at WFSM and the Lumbee Tribe of North Carolina. LROP was conducted in Robeson County, North Carolina, the traditional homeland of the Lumbee tribe. The Lumbee tribe is state-recognized with approximately 55,000 members, one of the largest tribes in the Eastern United States. While there is limited information available on the health of Lumbee youth, statewide data indicate that AIs in North Carolina have significant health and economic disparities (North Carolina State Center for Health Statistics, 2010; Smokowski et al., 2014). Robeson County is the poorest of the 100 North Carolina counties, with 31% of its residents living in poverty (U.S. Census Bureau, 2012). Due to the success of the existing partnership, the tribe initiated discussions regarding significant concerns about adolescent mental health, stemming from several recent suicide attempts and completed suicides among Lumbee youth. The partners wanted to identify ways to elucidate and address suicide risk factors.

LROP used a collaborative study team structure consisting of the Principal Investigator/MACHE Director, an enrolled tribal member with 20 years of research experience in the Lumbee community; coinvestigators/staff at MACHE/WFSM; a Lumbee coinvestigator, a faculty member in the Department of Counseling at the University of North Carolina at Pembroke; a Lumbee field coordinator; and the tribal Youth Services Directors.

To further guide the study, we developed a community advisory board (CAB). CABs provide structure

through which community members actively guide the research process, assure that the process is responsive to and respectful of communities, and create partnerships to enable sustainability and expansion (James et al., 2011; Newman et al., 2011). We invited community members working either with youth, in mental health services or both; also invited were youth who previously participated in tribal cultural education. Of the approximately 40 individuals invited, 22 accepted, and 17 remained involved for the duration of the study (excluding tribal staff). CAB membership included health care providers, community-based organization representatives (including faith-based organizations), tribal staff and leadership, school personnel, academicians, and Lumbee youth. CAB objectives were (1) provide feedback on the cultural appropriateness of study instruments, (2) assist with participant recruitment, (3) work with the study team to develop and participate in LROP dissemination and sustainability plans.

The overall goals of LROP were to (1) assess perceptions of suicidal behavior and other factors associated with suicide, (2) examine mental health needs among and services for Lumbee youth (age 11-18 years), (3) elicit perceptions regarding existing services, and (4) determine the impact of an enhanced 6-month, tribally run cultural enrichment program on suicide ideation and risk factors. LROP was implemented in two phases.

Phase 1 focused on the following: cultivating existing relationships between the community and academic partner, CAB development, and focus groups and gatekeeper interviews to address aims 1 to 3. We conducted four focus groups with Lumbee youth (age 11-14 and 15-18 years in separate groups to allow for differences in maturity and life experiences) and gatekeeper interviews ($n = 16$) with professionals working in mental health and/or with youth. Interviews and focus groups were transcribed and a codebook was developed after preliminary transcript review. Codes included core concepts based on project objectives and were supplemented by emergent codes as analysis proceeded. We imported transcripts into ATLAS.ti Version 6.2 (Humboldt, Germany), a software program designed to manage qualitative data. The study team (SG, SL) cross-coded text using a collaborative, iterative process; after coding, segments of text were abstracted by code and reviewed by the study team (SG, SL). We determined themes according to (1) the level of consensus of a concept, (2) strength and depth of a concept, and (3) frequency of a concept throughout the discussions; and analyzed data by comparing and contrasting themes (Patton, 1990). Phase 2 included development, implementation, and evaluation of the cultural enrichment program. We used Phase 1 themes to work with the culture class instructors to

design and implement an enhanced program consisting of 6-months of specific, structured curriculum that provided cultural education in the context of the importance of maintaining mental and emotional health. Based on the recommendations of others (Goldston et al., 2008), LROP aimed to acknowledge and integrate Lumbee values and strengthen the cultural identity of participants. During this phase, the partners also worked to garner trust from a community cautious of research, by using CBPR to inform research practices and sustain community involvement.

In this work, we focus specifically on our successes and challenges, which are described using the conceptual model by Wallerstein et al. (2008) that guided LROP. The model characterizes the CBPR process with four main concepts: Contexts (socioeconomic, cultural, geographic, historical, community capacity/readiness), Group Dynamics/Equitable Partnerships (structural, relational, and individual dynamics), Intervention/Research (culturally tailored, appropriate research design, reciprocal learning), and Outcomes (system and capacity changes, improved health). These concepts are placed along a continuum, each informing the next and continuing in a cyclical fashion to improve current and develop new programming, accounting for the community's changing capacity and needs.

► RESULTS

Contexts

During LROP, we came to better understand the sociocultural setting of the project and adjusted expectations accordingly. Paradoxically, at the time of project development, recent suicides among Lumbee youth created a supportive atmosphere for suicide prevention programs, however, LROP faced recruitment challenges due to the sensitive topic of mental health.

In this tribal community, poor mental health and related issues carry significant stigma. During Phase 1, gatekeepers revealed that for many, it is extremely important to receive care for mental illness outside the community, due to fears about other members learning that one is seeking treatment. In addition, Christianity is an important aspect of Lumbee culture, and therefore, churches are integral components of the local community (Dial & Eliades, 1996). Our data collection revealed a potential conflict between beliefs about mental illness and Christianity. Participants in Phase 1 disclosed that many believe that mental illness/symptoms are not medical issues, but spiritual ones. For some, mental illness is not recognized as a disease, but a by-product of lack of faith or unrighteous living. This belief perpetuates stigma

and hampers treatment seeking (Pargament & Lomax, 2013). Understanding and respecting these aspects of our population were crucial to maintain community trust, recruit youth, and implement the intervention.

A challenge to our envisioned recruitment strategy was that recruiting from the public school system was not feasible. We were unexpectedly advised not to try to collect data from public schools due to concerns about data usage and past negative research experiences. However, we combatted this challenge by relying on the strengths of the relationships with other community groups, including the local Boys and Girls Clubs (owned and operated by the Lumbee Tribe) and local churches, to garner substantial support for recruitment. We relied on our field coordinator and CAB to guide recruitment efforts, which included the involvement of local church-based youth programs. We succeeded in nurturing and improving the academic-community relationship by tapping diverse facets of the community to work around recruitment challenges.

Taking into account the local cultural context was also critical component for success in Phase 2. The cultural education program in Phase 2 was part of the Lumbee Tribe's Department of Youth Services' programming, and as such, the premise of the intervention came with an existing level of cultural appropriateness. The original 6-week program was designed to teach Lumbee youth about their culture, including tribal history, art, beadwork, regalia-making, music, and drumming/dancing. Despite being in place for some time, there was a need to implement a formal, structured curriculum, and evaluate program's effectiveness.

In the enhanced cultural education program, rather than specifically targeting suicide, leaders used the cultural activities, including drumming, dancing, singing, and beadwork, to enhance enculturation, provide social support, and improve participant self-esteem as a means of suicide prevention. The youth services staff and Lumbee elders conducting the classes were seen by the youth as role models and confidants. Additionally, as Phase 1 youth noted the important role of parents/family with regard to mental health and enculturation, families were encouraged to attend, which provided families exposure to the same cultural and mental health programming as the participating youth.

Group Dynamics/Equitable Partnerships

LROP supports the theory that, for legitimacy in the field, all or part of a study team should represent the priority population (Wallerstein et al., 2008; Wallerstein & Duran, 2006). In addition to involving Lumbee investigators, an experienced Lumbee field coordinator brought engrained trust in programming and was necessary for

successful recruitment. Our field coordinator is a life-long Robeson County resident who has significant previous experience working with WFSM. She co-moderated the focus groups, conducted the gatekeeper interviews, and is widely known as a community advocate. She is familiar with dynamics of various Lumbee communities, which include differences based on the unique culture of each part of the county and variation in socioeconomic status and community norms. Due to the field coordinator's expertise in previous research and the community, she was successful in nurturing community relationships, recruiting, and interacting with participants; and exercised a strong understanding of the importance of confidentiality. We found many community members, including participants and others, were comfortable enough to share personal stories about their experiences with mental illness.

One unanticipated change early in the project, was that tribal leadership underwent significant internal division, resulting in the resignation of the tribal chairman and changes in the administration of tribal youth services. The Youth Services Department limited the number of classes they conducted due to reduced staff and funding. This created temporary confusion for the study team about who our tribal partners would be during the completion of the project. Our field coordinator maintained relationships in tribal administration and kept the study team and the new Youth Services Director informed and linked. To provide continuity for LROP youth and implement the program as planned, the team met as appropriate with new tribal leadership and staff to maintain tribal engagement.

To ensure communitywide representation, an important aspect of our plan was to involve Lumbee youth in the CAB. In particular, input from these youth was crucial in guiding the study team how to best collect data from peers on sensitive topics. However, when their attendance waned at CAB meetings, these youth were not all replaced once the intervention was underway. Our failure to readdress youth involvement in the CAB likely cost us opportunities for project improvement. During Phase 2, we surveyed CAB members ($n = 22$) to get a better understanding of their perspective of their CAB role, to ensure continued consistency with LROP study goals. CAB members indicated an understanding of their role and viewed it as including (1) provision of feedback on program components/activities, (2) participation in the dissemination of LROP educational efforts targeting local community members and stakeholders aimed at increasing awareness of existing issues, and (3) provision of support for LROP goals and community at large work to improve the mental health of Lumbee youth. This mutual understanding between the CAB,

study team and tribe allowed for a continuous cycle of feedback and improvement.

Intervention/Research

One of the benefits of our on-going collaboration with the tribe was the adaptation of an existing program. However, as the project moved forward, one important issue was ensuring that new content, and the research methods, were culturally appropriate. Using Phase 1 data to develop the Phase 2 intervention was key. While suicide was a documented problem, prevalence of certain risk factors emerged during the focus groups. Specifically, we found that the following were very problematic for Lumbee youth: (1) nonsuicidal self-harm, particularly cutting, (2) bullying, (3) stigmatization of mental illness, (4) negative impact of violence and addiction in many homes, and (5) economic stressors. We also became aware of the important role of religion in diagnosis and treatment-seeking behaviors and the critical impact of tribal cultural activities on adolescents' self-esteem and self-worth. The LROP culture class curriculum extensively integrated these themes to (1) educate youth about how the identified issues can affect one's health and (2) provide strategies to address these issues in ways that incorporate Lumbee culture, including spiritual and tribal resources as means of support. The majority of the current literature regarding AI youth mental health describe protective and/risk factors; the curriculum achievements show LROP as innovative in its target population and in developing an intervention with these components.

As previously mentioned, the CAB was a critical component of LROP, working with the study team to ensure study methods were culturally appropriate. Collaborative efforts were instrumental in disseminating study results and broader information on AI youth mental health issues, including a community forum cohosted by the CAB and the Lumbee tribe. The forum included a study results presentation and a youth panel who shared their thoughts about the mental health of their generation. Hosts facilitated small group discussions focused on (1) ways Lumbee youth cope with bullying and daily stress, (2) ideas about how the community can develop resources and create "safe zones" to protect their children from harm, and (3) strategies for the community to use to respond to the mental and behavioral health needs of local AI youth.

Opportunities for reciprocal learning were present throughout both phases and contributed to a culture of mutual respect. For example, during both phases participants shared their knowledge of available resources, the study team also shared and as a result the facilitator and the participants learned about resources of which

they were previously unaware. The study team used this information to enable resource provision for participants and help providers understand factors that affect care seeking and cultural nuances of which they should be aware to provide more culturally tailored care.

Outcomes

LROP demonstrated that using a CBPR approach to implement a tribally based suicide prevention program is a feasible endeavor that was well-received by local youth. The culture class monthly evaluative surveys indicated a high level of connectedness to Lumbee culture among youth, with the mean rating of 9.1 from a 10-point scale across all evaluation intervals. Regarding program activity enjoyment, youth had a mean rating of 9 from a 10-point scale, and stated qualitatively that teachers, elders, and peers were supportive of their engagement in cultural education. In addition, an average of 90.1% of participants at each evaluation interval stated they wanted to continue involvement in cultural activities. Although not statistically significant, participants with regular attendance (at least two thirds of classes) showed a decrease in suicidal ideation and increase in protective factors. Significant findings are limited due to the small sample size and lack of randomization; topical results on bullying (Bell et al., 2014) and depression and nonsuicidal self-harm (Arnold et al., 2013) are presented elsewhere. Culture class evaluation data supported program importance and was used by the tribe to support the continuing need for youth-focused programs. Most powerfully, the enhanced classes are sustained by tribal youth services, and mental health has become an important component in all tribal youth programming.

After the official study portion of this project ended, the work with the cultural classes and the other gains from the work around mental illness in the local community was sustained, but at a lower than desired level. Despite the positive benefits of the CAB, notable challenges of the CAB moving forward continue to be long-term sustainability and community buy-in. Others have noted similar challenges associated with keeping a project going when a grant is completed (Wallerstein & Duran, 2010).

► DISCUSSION

In this article, we attempt to capture both the successes and challenges inherent in CBPR projects using an existing conceptual model. Although many studies and programs have used the CBPR process to target youth in underserved and minority communities, few have directly engaged the youth in the process outside of being study participants. Additionally, this project

focused on a population of youth for which there are few known effective interventions to prevent suicide. LROP was innovative as it was designed with Lumbee social/cultural landscapes in mind; the intervention tailored carefully using an existing framework and weaving components of mental health throughout; and targeted AI youth, which is vastly underserved with regard to suicide prevention programming. A systematic review by Clifford et al. (2013) cites only two other culturally tailored suicide prevention programs for AI adolescents.

The LROP project team was sensitive of the need to fully understand the challenges that Lumbee youth face and the most appropriate strategies to address these challenges. Actively involving the community, in the CAB and more broadly, helped develop realistic strategies for change. Youth participating in the community forum were very open about their experiences, which made a significant impact on the effectiveness of this event and future endeavors. Future youth-focused CBPR projects should strongly advocate for active engagement of youth in all project stages and work diligently to maintain their engagement in all phases of execution.

An important lesson learned throughout this process was that enlisting study team members from the community was essential in developing and maintaining trust. These study team members brought valuable insight into (1) community dynamics, (2) establishment of relationships, and (3) historical events that have a continued impact on the community's interactions with academic-based entities. As Sadler et al. (2012) describe, using community dynamics, current and historical context to inform the iterative process for the community-academic collaboration was crucial in creating positive, ongoing relationships. Despite the significant tribal changes that occurred during study implementation, engaging multiple community partners was essential to successful LROP recruitment as well as creating a strong support base for future programming. Having "buy-in" from the community engendered trust and ownership in the locally run program to benefit Lumbee youth. Working with the community to create capacity for multilevel change, including knowledge, awareness, and action, is vital to program sustainability.

Also vital to sustainability is capitalizing on momentum generated during the course of the study to ensure maximum impact and continued effort to address the focus issue of the research collaboration. Practically, this means focusing activities during the study and beyond on developing capacity for programming that achieves sustained, multilevel change. During both phases, LROP discussed and evaluated individual, group, and community factors that created both successes and challenges. In this study, we learned that it is essential that all stakeholders work together during all stages and beyond to

improve programming for future youth. Similar successes and challenges in CBPR conducted in AI communities are described in cancer screening/prevention (Burhansstipanov et al., 2012) and substance abuse (Thomas, Rosa, Forcehimes & Donovan, 2011), particularly the necessity of cultural tailoring; the importance yet challenging nature of maintaining mutually beneficial relationships/communication; and need for effective community advisory committees/boards. However, due to the sparse literature, even more so for youth-focused programming, further CBPR work and dissemination is greatly needed to advance evidence-based practice and create long-term, meaningful change.

► CONCLUSIONS

LROP was successful in laying the groundwork for future cultural connectedness-based programming to address Lumbee youth mental health. CBPR offers a means through which tribal and academic partners can create equitable partnerships and can be a particularly beneficial methodology for targeting mental health and related outcomes in AI communities as it strengthens connections between ethnic identity and culture as a means to develop self-esteem, self-respect, and cultural connectedness. Data gathered from these types of CBPR projects will contribute to the development of research that is both culturally tailored and effective in targeting communities affected disproportionately by youth suicide and other public health concerns.

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