Community-Based Participatory Research: Conducting a Formative Assessment of Factors that Influence Youth Wellness in the Hualapai Community

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Objectives. Using a community-based participatory research approach, a tribe–university team conducted a formative assessment of local factors that influence youth wellness to guide the design of a culturally and locally relevant health promotion program.

Methods. Open-ended interviews with key informants, a school self-assessment using the Centers for Disease Control's School Health Index, and a locally generated environmental inventory provided data that were triangulated to yield a composite of influential factors and perceived need within the community.

Results. Family involvement and personal goal setting were identified as key to youth wellness. Supportive programs were described as having consistent adult leadership, structured activities, and a positive local and regional image. Availability of illicit drugs and alcohol, poor teacher attitude, and lack of adult involvement were significant negative factors that impact youth behavior.

Conclusions. Local/native (*emic*) and university/nonnative (*etic*) perspectives and abilities can be combined to yield a culturally relevant formative assessment that is useful to public health planning. In this collaborative effort, standard means of data collection and analysis were modified in some cases to enhance and build upon the knowledge and skills of community researchers. (*Am J Public Health.* 2006;96:1623–1628. doi:10.2105/AJPH.2004.054254)

Historically, health research and intervention studies in indigenous communities have been designed according to an *etic* (outsider's) perspective.[1] This approach is reminiscent of the long-standing, paternalistic federal policies designed to change and marginalize native people and is largely responsible for native people's distrust of research.[2,3] Recent studies of indigenous communities in the United States, Canada, and Australia have demonstrated the value of participatory research to support and engage the *emic* (insider's) perspective in public health research and intervention.[4–7] In 2001, the Hualapai Tribal Health Department and the University of Arizona (UA) Mel and Enid Zuckerman College of Public Health used a community-based participatory research (CBPR) approach to assess the sociocultural context of youth wellness and community perception of local youth programs. This research was the initial phase of a primary prevention–intervention program that was being developed to reduce chronic disease risk factors in local elementary-school children.

Formative Assessment and Community-Based Participatory Research

Formative assessment is research conducted before program development to understand the context in which the intervention will take place, identify specific behaviors of concern, learn about the determinants of these behaviors, identify community attitudes that might inhibit or promote program goals, and identify resources that are available to the program.[1] Formative assessment is key to improving the relevance, sustainability, and effectiveness of community-based public health programs.[8]

Understanding the local context of a health behavior requires meaningful community involvement. Yet oftentimes, community members are relegated to such tasks as setting up interview appointments and serving as translators. This level of involvement undervalues the *emic* perspective and skills of community members, and perpetuates a subservient relationship between the community members and the research community.

CBPR engages community members (insiders) and scientific researchers (generally, outsiders) in a collaborative process of scientific investigation, co-learning, and social action. CBPR can be a process of empowerment through which communities can improve their capacity to address problems by developing solutions that use local assets and control their own destinies.[8] The CBPR approach facilitates community members to (1) become researchers who address issues important to their community, (2) develop locally relevant research questions, and (3) identify local factors that influence the context and shape targeted behaviors.

It would be a mistake to assume that formative research is not necessary if community members are involved in the planning of an intervention. Community members do not know all things about their own community. The assumption that 1 person can impart the intricacies of their sociocultural context in an objective, systematic fashion, fails to appreciate the complexity of social systems and ignores community members' own roles and relationships within the community. Furthermore, the opinions, perspectives, and behaviors of community members who are willing to collaborate with outside researchers may be very different from their less receptive peers.

Community members are experts in using the local formal and informal information networks and in negotiating local systems of influence and power. As researchers, community members' knowledge and skills can guide the domains of investigation and shape data collection protocols. Their guidance and

input are key to developing and implementing an assessment process that will portray the true resources, attitudes, and behaviors of the community. Without community involvement, formative research runs the risk of being superficial, by documenting only behaviors and attitudes that are easily explained to outsiders and by describing only observable resources (e.g., facilities and programs) and overlooking intangible resources, (e.g., social cohesion and the power of social reciprocity). This level of documentation can miss subtle cultural and social assets that are reflected in internal systems of communication and social interaction as well as local controversies that can undermine intervention plans. If community members are not experienced researchers, outside experienced researchers can contribute their skills and knowledge to the partnership. Scientific expertise is needed to develop an objective investigative approach and a systematic plan to document local factors that influence behaviors and attitudes.

The Hualapai Community

In 2000, the Hualapai tribal census reported 1923 enrolled members.[9] Linguistically and culturally, the Hualapai are a Yuman-speaking group and are related to the other Pai peoples in Arizona, southern California, and the Baja peninsula of Mexico.[10] The tribe's rural 1-million-acre reservation, located in northwest Arizona, is home to approximately 1300 residents. More than 95% of the community members are native, enrolled tribal members or are members of other tribes who married into or work within the community. Peach Springs, the only residential–commercial center on the reservation, is approximately 15 miles in diameter. Commercially, the community has a convenience store, a gas station, a Laundromat, and tribally owned tourist enterprises (e.g., a river running company and a lodge). Educational and medical services consist of 1 elementary school, a combined junior–senior high school, a tribally managed emergency medical response unit, and an Indian Health Service (IHS) out-patient clinic. The clinic staff includes three physicians, three clinic nurses, two public health nurses, 1 health educator, and 1 pharmacist. The Tribal Health Department has more than 25 employees and offers behavioral health services, home health care, and health promotion programs.

In 2001, the prevalence of diagnosed type 2 diabetes mellitus was >40% in people older than 21 years.[11] Diabetes risk factors, such as obesity and low levels of physical activity, are prevalent: more than 85% of the population has a body mass index greater than 25.[11] Perhaps more alarming, the age of diabetes onset is decreasing and 8–10 adolescents have been diagnosed with the condition.[11]

METHODS

The Community-Based Participatory Research Team

The CBPR team consisted of 3 native community members and 1 nonnative public health practitioner who had worked with the community for more than 20 years. The community members were the Tribal Health Department director who was trained as a public health nurse, a former elementary-school teacher, and a former coordinator of youth programs; each had lived more than 25 years in Peach Springs. To prepare for their role as researchers, the community investigators were exposed to a variety of research methods through their collaboration with the university partner, completed the university's human subject protection instruction and examination, and participated in several research methods workshops offered by the University of Arizona, Inter-Tribal Council of Arizona, and IHS.

The team developed the formative assessment research questions: "What has our community been doing to support youth wellness?" and "What factors influence youth wellness in our community?" The team recognized the absence of adequate written documentation about past events and practices and the fact that the type of inquiry would shape how reflections of past events were shared. As a result, they selected data collection methods that provided formal and informal, public and private forums for expressing thoughts. Open-ended, semistructured interviews provided a formal and private way to collect oral histories. A formal and public forum for collecting data was supplied by the School Health Index (SHI),[12] a structured, school-based self-assessment instrument, which was completed by both tribal and nontribal members who were school employees. An inventory of local facilities and practices that promote healthy and unhealthy behaviors in youth was created informally in a public meeting. Through these methods, a variety of people familiar with the community were able to contribute to the formative database.

Interviews

Open-ended, semistructured interviews allowed people to use their own words to share their experience, attitudes, and perceptions.[1] Inclusion criteria were tribal enrollment and at least 18 years as a resident in the community. Three sets of interview questions were designed by the CBPR team: "Youth Programs," "Stayed in School," and "Dropped Out of School." Youth Programs questions asked about the purposes, resources, challenges, and community involvement associated with various programs. The school-related interviews expanded on community researchers' knowledge that attainment of a high-school degree or equivalent was reflective of wellness. Academic success required youth to avoid or overcome numerous social and behavioral obstacles (e.g., substance abuse, peer pressure, and disenchantment with the nonnative education system). Respondents were asked the set of questions that applied to their graduation status. The school-related interview questions required respondents to reflect on factors that supported or detracted from their academic achievement, accomplishments after leaving or completing school, and career goals.

The three community researchers relied on their collective knowledge of community members' involvement in local activities, and used a sampling design to identify potential "information-rich" interviewees.[13] The school-related interviews required that researchers identify community members who had graduated and members who had quit high school. Before the construction of a local high school in 2000, community members had attended more than 5 different off-reservation high schools. It could have been a formidable task

to collect lists of graduates and "drop-outs" from those schools; however, the community researchers' familiarity with their peers and neighbors precluded the task. As they stated, "We don't have to [contact schools], we all know each others."

Interviews were conducted by a pair of community researchers, 1 man and 1 woman. One person served as the interviewer and the other person took notes. The role interviewers assumed was determined by their relationship to the interviewee. Researchers did not interview their own relatives, former co-workers or other close acquaintances. Excluding relatives would have significantly reduced the pool of potential interviewees in this small community and biased the sample. The 25–45 minute interviews were not tape recorded to assure anonymity in the small community where voice recognition is high. Immediately after each interview, the interviewers reviewed the notes and added any information recalled by either of the researchers that had not been recorded. The extensive handwritten notes were typed by the note taker within 1 week of the interview.

An independent-consensus method of analysis was developed by applying the theoretical framework provided by Patton.[13] The two interviewers and the university researcher independently analyzed the interview notes for content and pattern. Content analysis involved extraction of actual phrases used by respondents that were reflective of core concepts expressed in the interviews. Patterns were determined first independently by each investigator by reading through the content phrases and identifying recurring words, concepts, or ideas. The three members of the analysis team then shared their patterns. When patterns differed, the team members discussed their rationale and through consensus agreed upon a single set of patterns. Themes that had more of a categorical or topical form were built from a collective review of the patterns.

School Health Index

The faculty, teacher aides, and administrators of the local elementary school completed the SHI as a consensus group.[14] The 2002 edition of the SHI is an eight-module, self-assessment tool used by schools to evaluate their environment and policies related to the promotion of physical activity and healthy food choices.[12] The assessment engages school personnel in a discussion of school health policies, practices, and programs, and provides a structure to develop an action plan for change.

Two community investigators, assisted by the university investigator, facilitated four 1-hour work sessions with a group of volunteer school personnel to complete the SHI. This approach had been approved by the school board and principal.

Inventory of Environmental Factors

An inventory of environmental factors was compiled to produce a broad picture of the context of youth wellness. Drawing on their collective knowledge, the CBPR team drafted a list of local institutions and behaviors that promote healthy and unhealthy behaviors. The list was presented to the Community Wellness Team, a nonpartisan, grassroots coalition of 22 regular members who represent all sectors of the community (e.g., tribal council members, tribal employees, school employees, and concerned parents). The Community Wellness Team serves as an advisory board to several local health promotion programs. By consensus, the group modified the list by adding and refining factors to accurately portray the community.[14]

RESULTS

Interviews

The sample of 48 respondents, 16 for each interview set, represents approximately 10% of the total population 18 years or older (Table 1). The research team contacted 49 community members to achieve this sample. The 98% response rate highlights the community researchers' ability to rely on established trusted relationships to successfully recruit fellow community members. The mean age of the "Dropped Out of School" interviewees was lower than that of the other participants. Many older community members who did not complete high school but eventually attained a high-school equivalency diploma were not identified to participate in this interview set.

Respondents identified consistent adult leadership and structured organized activities as key features of successful youth programs. A more subtle feature was the community's support of programs that yield a positive local and regional image of the tribe. These programs generate local pride and challenge negative stereotypes of native people. Several interviewees attributed the local sustainability and popularity of the Hualapai 4-H Youth Livestock Program to statewide publicity that reported how community youth successfully entered prize-winning livestock in the county and state fairs.

TABLE 1—Emergent Themes of Community Member Interviews Addressing Youth Wellness (N = 48)

Interview Question Set	Gender (M/F)	Age in Years, Mean ± SD	Themes
Youth Programs	7/9	45.7 ± 13.2	Consistent adult leadership
			Structured, organized activities created a positive image gaining community support and generated community pride
Stayed in School	6/10	43.0 ± 11.6	Encouragement from family members, especially mothers
			Personal goal setting
			Desire to support their family, help their tribe, and educate people on the language and culture
Dropped Out of School	7/9	26.3 ± 9.3	Family responsibilities and relationships
			Poor teacher attitude
			Alcohol and drug abuse

Family was a dominant theme in the two interview sets that considered school outcome. Individuals who stayed in school identified supportive behaviors, words, and expectations of family members—especially mothers—as important motivators. Mothers were most frequently recognized as "making sure I got up and made the bus" or as not allowing an absence when "I pretended I was sick." Mothers, fathers, aunts, uncles, children, husbands, wives, and even "the community" were described as providing encouragement throughout high school and for some, college. Community support was identified as financial support from the tribe's scholarship fund or as inquiries of progress from unrelated community members (e.g., "How's your schooling going?"). The value of family and community support was coupled with the importance of personal strength and a sense of responsibility to the community. More than half of the respondents who stayed in school discussed their desire to gain skills to help the tribe become self-sufficient or to enhance cultural or educational opportunities for youth. Sample responses include, "I want to get my ESL [English as a Second Language] certificate," and "I want to own a business to help youth[s]."

Respondents who dropped out of school discussed becoming a new parent before the completion of high school and meeting the request of a spouse or partner to drop out. Women most frequently expressed the latter sentiment; their partners had wanted them to quit school to take care of a new baby. For some, unheeded family advice and support was a secondary theme in these interviews. Respondents acknowledged that "all my relatives," "parents and family," and "the community" "encouraged me to stay in school."

Non–family themes, such as school environment and problems with drugs and alcohol, also emerged. When recalling experiences in off-reservation public schools and boarding schools, respondents described teachers as "having a bad attitude" and as "prejudice." A secondary theme was school structure. Respondents described school as "like a jail" and as having "stupid rules." In contrast, some respondents who stayed in school actually credited the rules and teachers as factors that contributed to their success: school "taught me rules and structure"; "the dedication of the teachers motivated me." Half of the respondents reported that "drugs and alcohol" had contributed to their decision to discontinue school or to the school's decision to expel them.

School Health Index

Thirty-five or 72% of all elementary-school personnel participated in the four SHI work sessions. Because of the size of the community, this group included parents and grandparents who were also school employees. The group answered the 10–12 questions within each of the eight modules by consensus, which yielded a score for each topic area. Three areas, Physical Education (PE), other Physical Activity (PA) Programs, and Family and Community Involvement were scored at a level deemed unacceptable by the group.

Low scores in PE and PA programs were attributed to the lack of a PE teacher and little time and formal training for teachers and aides to offer regular PE classes. The group proposed hiring a certified PE teacher to implement activities that would meet state standards for physical education. This solution was countered by the principal who spoke of the shortage of certified PE teachers in the state. The group offered few solutions to the poor family and community involvement. Teachers reported frequent attempts to draw family and community members into the school through scheduled open house events and parent–teacher conferences. Several reasons for poor school involvement were discussed: parents' own unfavorable experience with the school when they were students, and parents' apprehension about interacting with school personnel who may highlight their child's poor achievement or disruptive behavior. Yet, periodic parent and community interest was evident by high attendance at the school Christmas pageant and graduation.

Community Inventory

Table 2 lists social and physical environmental factors that promote healthy and unhealthy behaviors in local youth. The community gym is open to all community members in the afternoons and evenings; lights have been installed recently around the ball fields and playgrounds; and a series of summer camps are coordinated by various tribal programs. Other healthy resources include the annual events that unite the community in celebration of their native identity and survival, despite historical and contemporary challenges. Intermittent school and community sports teams, particularly basketball, are popular; however, poor school attendance and grades prevent some youth from maintaining their position on school teams.

As they considered unhealthy environmental factors, the Community Wellness Team discussed the passive acceptance of several undesirable behaviors. Adults model unhealthy behavior through lack of community and parent involvement, and through substance abuse. The preponderance of unhealthy food selections at the local store and the absence of healthy local alternatives also reinforce undesirable behavior.

Application

The formative assessment guided the design of the Hualapai Youth Wellness Program (HYWP), a school-based and family-outreach

TABLE 2—Local Factors That Motivate Youths to Have Healthy Versus Unhealthy Behaviors

Healthy	Unhealthy
Community gym	Lack of healthy choices at the local store
Community playgrounds	Lack of parental involvement
School activities/sports	Lack of volunteerism
Sports tournaments (intracommunity and intertribal)	Inconsistent youth programs
Community events (Indian Days, La Paz Run, Sobriety Festival, etc.)	Visible substance abuse
Ball fields for softball	
Churches	
Summer camps	
Ropes challenge course	

TABLE 3—Formative Assessment Outcomes and Responding Components of Hualapai Youth Wellness Program (HYWP) Design

Community Successes, Interests, and Challenges	Responding Component
Youth Programs	
Adult leadership	3 community members employed full-time to design and lead all program activities
Structured, organized activities	Implement activities from SPARK and *Physical Best*
Yield local pride and positive publicity	Report program outcome at local, regional, and national conferences
Stayed in School/Dropped Out of School	
Family involvement	Family Events (games and healthy meals)
Community Support	Local reports of activities and outcomes
Responsibility to the community	Youths recruit their families to the family events
School's Self-Assessment	
Lack of trained PE/PA personnel	Gain SPARK and *Physical Best* training for 3 project-employed community members and school personnel
Local lack and state shortage of certified PE teachers	Trained community members providing PA sessions during school hours
Poor family involvement	Family Field Events and Fun Nights
Measurable and reportable outcomes of progress	Biannual evaluation using select components of *Fitnessgram*
Community Inventory	
Gym, sports fields, and camp facility	Resources used for family events and school break activities
Community events	Project staff facilitate youth-adult games at communitywide events
Lack of positive adult role models	3 community members implement all project activities
Few healthy foods at local store	Offer healthy meals at family events and school break activities

Note. SPARK = Sports, Play, Action, and Recreation for Kids; PE = physical education; PA = physical activity.

intervention program. Table 3 illustrates the core formative research outcomes and the corresponding elements of HYWP design. Program staff comprises three community members who plan and implement intervention activities. They provide positive adult role models and adult leadership, features identified as key to supporting youth wellness. Program staff receive training in SPARK[15] (Sports, Play, Action, and Recreation for Kids), a structured national curriculum that meets state standards, and *Physical Best*,[16] to fill the local void created by a statewide teacher shortage. The HYWP can meet the school's request for measurable outcomes with select components of *Fitnessgram*,[17] a youth-oriented fitness assessment. Intervention strategies build upon the importance of family involvement and community support by implementing family events and by reporting program outcomes locally, regionally, and nationally. The HYWP uses community resources (e.g., the gym, sports fields, and camp facility), and addresses the low availability of healthy foods by featuring games and healthy meals when it coordinates school breaks and family events.

DISCUSSION

CBPR holds promise as a particularly valuable approach in indigenous communities where (1) distrust of research is high, (2) reaction to culturally incompetent programs is apathy, and (3) the relegation of community members to nondecisionmaking tasks within research-intervention projects has disempowered and exploited communities. The Alaska Native Science Commission,[18] Fisher and Ball,[19] and Macaulay et al.[20] provide some of the few published descriptions of CBPR projects in native communities and offer frameworks for building research partnerships between indigenous and scientific communities. They stress the importance of engaging the community and incorporating cultural knowledge in all phases of the research. The Hualapai–UA team contributes to the slowly growing body of CBPR literature on American Indian communities by (1) highlighting the importance of conducting a formative assessment in a CBPR project, (2) describing the modification of research techniques, and (3) offering a project-generated method of qualitative data analysis.

No published CBPR report describes the development, implementation, analysis, and application of a systematic formative assessment within tribal communities. This step is critical to the initiation of the research process because it allows the CBPR team to integrate the community members' knowledge of the local history and social behaviors with the scientific researchers' skills in objective systematic data collection. Together they yield a shared picture of the sociocultural context. The process builds on the strengths of the *emic* and *etic* perspectives the investigators bring to the project. Furthermore, a formative assessment acknowledges the internal heterogeneity of native communities often perceived by outsiders as somewhat homogeneous. Community researchers are not burdened with the task of representing the range of beliefs, attitudes, and experiences within their diverse communities.

In their description of the Indian Family Wellness Project, Fisher and Ball[19] note the importance of adapting evaluation measures to include culturally relevant domains. Other advocates of participatory research within American Indian communities call for the inclusion of traditional knowledge in research design but provide little description of methods.[18] The Hualapai–UA formative assessment demonstrates how community members' knowledge guided the selection of data collection methods. On the basis of these members' argument that public and private forums were needed to document the range of opinions and experiences within the community, consensus groups and individual interviews were used. Community members' knew that academic success was key to local perception of youth wellness, and this knowledge guided the design of the interview questions.

Perhaps the most difficult to implement recommendation of participatory research in

American Indian communities is to integrate indigenous and scientific knowledge into the interpretation of research outcomes. The independent-consensus method of analysis developed by the Hualapai–UA team assured that the analytic abilities and perspectives of native and nonnative researchers contributed to the research results. The method integrates group opinion with individual interpretation.

Traditionally, public health in indigenous communities has taken an approach that involves surveillance, needs assessment, and expert-controlled service. The community is passively involved and receives services without taking responsibility for program outcomes. This approach tends to ignore sociocultural knowledge and behaviors, and creates a dependency on outside experts and agencies.[20–23] The experience of the Hualapai–UA team demonstrates how community and scientific research partners can contribute their *emic* and *etic* perspectives and knowledge to the design, implementation, and application of a formative research effort. ■

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This article was accepted September 29, 2005.

Contributors

N.I. Teufel-Shone and S. Irwin developed the application for funding. All authors collaborated in the planning of the research process and in the selection and modification of the methods. T. Siyuja and H.J. Watahomigie led the data collection phase. T. Siyuja, H.J. Watahomigie, and N.I. Teufel-Shone analyzed the data. All authors interpreted the findings and reviewed drafts of the article.

Acknowledgments

This research was supported through a Native American Research Center for Health grant (6U269400011) awarded to the Inter-Tribal Council of Arizona. The authors acknowledge the community members who participated in this project and the Hualapai Tribal Council who approved the public dissemination of the outcomes.

Human Participation Protection

The study was approved by the institutional review board of the University of Arizona. The Hualapai Tribal Chairperson signed an Assurance of Compliance with DHHS regulations governing the protection of human research subjects.

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