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Identifying Barriers to Healthcare to Reduce Health Disparity in Zuni Indians Using Focus Group Conducted by Community Health Workers

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Abstract

The Zuni Pueblo is home to an economically disadvantaged population, which faces a public health challenge from the interrelated epidemics of obesity, diabetes and kidney disease. Efforts to decrease the impact of these epidemics have been complicated by historical, economic and cultural barriers, which may limit health-care utilization. The NIH supported Zuni Health Initiative (ZHI) conducted a study to identify barriers to health care in the Zuni Pueblo.

Community health representatives (CHRs) led 14 one-hour focus group sessions at which a total of 112 people participated posed unique questions that took into account the Zuni culture to elicit information on perceived barriers to health care. Audiotapes were translated and transcribed by bilingual ZHI staff. We reduced the text to thematic categories, constructed a coding dictionary and inserted the text into NVivo 9 program.

We identified nine themes emerged regarding the barriers experienced in receiving health care and adhering to medical advice. These included distance; transportation; embarrassment; relating to healthcare professionals; navigating the medical system; awareness of available resources; waiting times; adhering to medication; and incentives in health promotion.

In conclusion the implementation of culturally appropriate community based health promotion programs and preventive screening techniques will improve access to health care and diminish health disparities.

Keywords

American Indians; Health disparity; Barriers to health care; Access to health care; Community health representatives (CHRs); Community based participatory research (CBPR)

Introduction

The National Institutes of Health defines health disparities as differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist

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among specific population groups (1). Adverse health outcomes experienced by racial/ethnic minorities attributable to broad historical and contemporary social and economic inequalities, often impact access to and delivery of healthcare (2–4). Native Americans have long experienced lower health status than other Americans. They have a lower life expectancy, and an excessive disease burden, amplified by their low utilization of healthcare services. Current Indian Health Service (IHS) funding provides only 55% of the financial support necessary to assure adequate health care to beneficiaries (Indian Health Service strategic plan, 2010, <http://www.ihs.gov/PublicAffairs/IHSBrochure/QuickLook09.asp>).

The Zuni Pueblo, located in a rural portion of western New Mexico, is home to approximately 11,000 members (Census, 2000). More than 90% of all Zunis live in the Pueblo. This economically disadvantaged community faces a major public health challenge from the growing interrelated epidemics of obesity, diabetes, and hypertension and kidney disease. Changing lifestyles have led to decreased physical activity and increased caloric intake with high consumption of fast food, soda pop and alcohol. The Zuni have experienced considerable historical and cultural trauma, which have created fear of participating in health screening and health care (5, 6). The resulting low utilization of healthcare is further complicated by concerns about accessing health services provided by non-native health providers. There are also considerable concerns about potential loss of confidentiality resulting from receiving healthcare by Zuni providers. The combination of low health care utilization and the high rates of chronic diseases are creating the conditions for “the perfect storm” of an unrecognized epidemic of cardiovascular disease. In response to increasing concerns about these conditions, the Zuni Pueblo, in collaboration with the University of New Mexico Health Sciences Center (UNMHSC), IHS and other health programs, formed the community based participatory research (CBPR) program called Zuni Health Initiative (ZHI) to identify perceived barriers to accessing healthcare and take steps to minimize or neutralize these and thereby increase the utilization and effectiveness of healthcare. The ZHI is an integrated model of community, family and clinic-based education, lifestyle modification and healthcare, which will facilitate the translation of validated national guidelines for screening and treatment of chronic disease and improve the public health of the high-risk Zuni population.

A major goal of the ZHI is to design and implement the stress-coping and lifestyle intervention models of Walters and Simoni (7), which have been modified taking into account the uniqueness of the Zuni culture and traditions. We believe that the interventions developed by engaging the community through participatory research will increase healthcare utilization and improve adherence with prescribed therapies. This manuscript describes the process and outcomes of this research.

Methods

The University of New Mexico Health Sciences Center Human Research Review Committee and the Indian Health Service Institutional Review Board approved this study. We recruited individuals (n=112) to participate in 14 one-hour focus group discussions. Recruitment strategies included visits by community health representatives (CHRs) to Zuni households; presentations at tribal health programs, at healthcare centers, and Zuni public schools; distribution of flyers and posting notices at civic centers and local businesses. We did not design our recruitment strategy to obtain a randomly selected sample of respondents. However, by using a variety of recruitment strategies and conducting the focus groups in four groups stratified by age and gender we obtained diverse viewpoints and experiences.

The focus group sessions were conducted at the ZHI office by four CHRs, trained by DLH, who facilitated and recorded the focus groups. A series of culturally specific questions about

potential barriers to healthcare, developed in consultation with the community members and from a literature review, were presented and used to encourage discussion among the participants. Focus group participants were asked to respond to the following Zuni culturally specific questions: “Do you believe your health care needs are being met? If not, why not?”; “What help do you need to address these problems?”; “What are the barriers/problems that you experience in getting the care you need?”; “Do you think your diet and food have something to do with you getting diseases (such as diabetes or cancer)”; and “How do you think exercise is related to one’s health?” Probes and follow-up questions were used to explore dominant themes and expand upon the topics raised during the discussion. Many of the participants responded by speaking partly in the Zuni language, “Shiwi”, mixed with English. Participants also completed a CHR-administered survey questionnaire, which provided demographic, medical history, environmental exposure, family history and physical assessment information. All study participants provided informed consent and received \$25 for participation.

We used a systematic text-analysis procedure to ensure high quality data. Trained Zuni speaking ZHI staff transcribed the audiotapes of the focus groups. Verbatim notes were also taken during the focus group session by a Native Zuni speaker to facilitate transcription, since often parts of the tapes are unintelligible due to street noise, location of the tape from the speaker, and so on. We analyzed the transcripts using a grounded theory approach, which focuses on creating conceptual frameworks or theories through building inductive analysis from the data (8).

A qualitative data analyst was not present for the data collection. Two of the authors (VOS and SN) reviewed several individual focus groups and coded line by line. In this context, coding is defined as “qualitative codes that define what he or she sees in the data” (8). Using this methodology, a larger codebook was created from the codes that emerged during the detailed analysis as described above. Using this codebook a hierarchy of codes was created into an analytic concept” and nine large themes were identified. We incorporated these codes into QSR International’s NVivo 9 qualitative data analysis software (http://www.qsrinternational.com/support_faqs_detail.aspx?view=11) and then coded each individual focus group according to the hierarchy of codes. We wrote memos regarding the emergent analysis of larger themes and used quotes from the text to support these findings. Also, a content analysis of the major themes collapsed by each major theme was performed. The quantitative demographic, medical history, environmental exposure, family history and physical assessment information was entered into SAS ver 9.2 and descriptive statistical analysis was conducted. The percentages for many of the categorical items are shown (Table 1).

Results

We used the socio-ecological framework as reported by McLeroy KR, as way to conceptualize and organize the barriers and facilitators of healthcare utilization (9). This framework posits that a hierarchy of factors influences the behavior of individuals, their families, and community members; systems and programs are also part of the hierarchy, as is policy. The results of the research are presented using the framework as the organizing architecture: we present individual factors first, social network factors next, and structural factors last. Solutions to barriers are presented using the same framework.

Demographic characteristics are summarized in Table 1. Of the 112 participants, 57% were female and were evenly spread across age groups. Participants were recruited from a variety of locations; fewer were recruited from IHS than from other locations. There were 32% of the participants in the group reported to be artisans and 9% had received a diagnosis of

diabetes, and 17% had a history of hypertension. Only 27% of the participants reported education beyond high school; while 39% reported having high school diploma, and 34% reporting less than a high school education.

Perceived Barriers

A. Individual and Social Network Factors—“I’m just embarrassed being in public or knowing how people talk.”

In response to the high disease burden at Zuni the community has implemented a variety of health promotion programs; e.g., Dive into Prevention Strategies (DIPS); IHS programs on alcoholism and a food distribution program. The potential positive effects of these programs have been limited by low participation, which may reflect a feeling that participation would be embarrassing. This was mentioned by 28.1% of male participants and 39.1% of participants over 30 years of age

Embarrassment associated with receiving healthcare: Embarrassment is a large issue when programs or treatment centers focus on a single ailment such as obesity, since association with the programs effectively discloses the disease status of the participant. While tribal employees maintained confidentiality, being seen at the site of programs was sufficient to invite talk from other community members. As a result, community members found embarrassment to be a barrier in participating in programs. One participant who works for the tribe talked about how employees strive to maintain confidentiality: “*paperwork is confidential but when we see people – one another at the programs we know, we’ll know who’s getting what.*” She said that as administrators of the program “*it’s not our place to go out and yeah, that so and so is participating. It’s people themselves that want to criticize each other.*”

Embarrassment resulting from a perception of how other community members will react to their involvement was a common theme. One participant said about this phenomenon, “*these people just don’t get along. They just don’t want to see each other there, and people talk. These people talk about each other every day and stuff like that.*”

An ancillary to embarrassment is a perception of blame. The perception that the program will admonish the participant creates a barrier. Many of the health concerns are worsened by individual decisions. One participant stated, “*Some people are embarrassed to go because they know that they did wrong.*” The idea of not getting treatment because of the belief that the problem is the patient’s fault is creating another barrier to healthcare.

Lack of awareness of available resources: “*Talk more about what kinds of programs are offered. I really don’t know.*” One barrier to accessing available programs is that community members may be unaware of them. Tribal members were not aware of the many programs being offered and were not aware that most were free of cost. One member of the community said she was aware that programs existed but, “*I’m not really sure what they are.*” She did know that “*there are some programs that are free.*” Another participant when asked said, “*I really don’t know anything.*” A third said that he did not “*know what they’re doing with their tribal resources.*”

The role of incentives in health promotion: “*Yeah, but isn’t that like bribing the community?*” Health promotion programs in the community attempt to address many of these issues. Yet a major barrier that emerged to program sustainability is that much of the participation is motivated by incentives. A major motivating force for attending program activities was for the incentive. One participant said of a fitness program, “*I just do it for the*

T-shirt.” Another said, “*Some people just go for the incentives too, just to be a part of the crowd.*” A third agreed by saying, “*But that’s where I see that they’re actually going out there because they want that T-shirt.*” Incentives as a motivation for participating was mentioned most among the participants aged 15 to 29 (36.3%) and male participants (27.8%) compared with participants aged over 30 (0%) and female participants (15.2%).

B. Health System and Health Services Factors

Mistrust of healthcare professionals: “*I don’t think they know what they are doing up there. I don’t trust any of them.*” Perceived medical staff issues represented a significant barrier for many residents seeking care at IHS. These issues focus on three themes: perceived medical incompetence, personnel turnover and lack of social courtesy. A lack of trust in the competence, training and skill level of providers was identified. One participant summed up the issue quite succinctly, “*a lot of times they don’t really know what’s going on with you. They’re just basically trainees.*” Another participant echoed this sentiment with, “*I think that’s the biggest barrier to getting better health care because many of our doctors don’t know what’s going on.*” A reason for this perception is that IHS provides training opportunities for many clinicians and is seen as a teaching hospital: The feeling seems to be that “*we’re just a training ground for them that you know we need better care.*” The underlying issue is one of trust. Also, participants found facilities to be lacking in current medical technology. Equipment and staff were seen to be of lower quality than the facility available in Gallup, New Mexico. A female participant said “*there are limited diagnostic resources in Zuni which may be the barrier.*” The solution from a young female participant is that “*it would be better if we had more advanced technology and more educated doctors.*” One participant stated, “*All these student doctors and nurses are mainly up here. That’s why I go to Gallup, New Mexico.*” Another participant said “*they’re a little bit more advanced...*”

Another concern of focus group participants was the high turnover rate of the medical staff at IHS. Participants found difficulty in establishing relationships with providers. This created inconvenience of repeating health histories as well as perceived lower quality of care with a different provider. This stems from differing opinions of providers concerning diagnoses and treatments. One participant said: “*My big deal is the continuance of care here because the providers change so often. It is difficult to establish a relationship with a provider when they are changing; it’s really hard when we always are changing providers.*” Another participant stated, “*Different new providers coming in, the one you’re getting used to, next week it’s gone.*” A third one said, “*My main concern is keeping a doctor here for many years. You get to know your doctor and then in a year, here comes a different one, they ask you what brings you up here and you have to do the whole history again.*”

Also, providers were seen by participants to lack in social courtesy. A female participant said, “*As a part of the concern about the changing medical workforce, the lack of consistency in medical providers also leads to different diagnoses and treatments.*” A female participant said, “*Somebody would diagnose something and then a new person comes and they wouldn’t read the chart and then something else was there.*” Another provided an example of her son’s care: “*he had seen one doctor who just gave him Albuterol; and then a next different provider saw him and gave him a whole ‘Advire’ which I didn’t think was appropriate.*”

Another difficulty with providers was the perceived lack of social courtesy. One participant summarized it by saying, “*it’s not all of them but some of them can be rude.*” Another agreed by saying, “*some of the employees are so rude that you just don’t want to deal with them.*” Social niceties are not reported as being used. One respondent said, “*Well probably*

most of the nurses over there are real mean. I don't know what the problem is. They could at least smile or say hi or something." The perception that the doctors are not invested in patient care is also widespread. Another participant said, *"he doesn't care and no time to talk to us."*

Difficulty navigating the medical system: "Setting up appointments is another chronic problem at the hospital." Another barrier to healthcare was difficulty navigating the medical system. Two distinct issues emerged: appointment difficulty and challenges in applying for (health) coverage.

Arising from the focus group sessions was the perception that Participants reported that appointments at healthcare facilities are very difficult to secure. Participants voiced concerns over long waiting lists for appointments, regardless of the severity of the complaint. A female participant said, *"I've been on the waiting list for two years and never gotten an appointment."* This respondent also had problems *"with your yearly checkup. That's the hardest part is when they put you on the waiting list and by them saying they'll get back with you."* Another female participant said she had difficulty finding her diabetic children appointments, *"when it comes down to it they tell you (hospital) you have to be on a waiting list. The [doctors, practitioners, etc...] give you a bottle of Tylenol and send you home."* One participant said, *"And both me and my husband are going blind. And I keep trying to get into the clinic here but they're just so booked."* Only 3.12% of male participants mentioned this theme, compared with 9.09% in the female and 8.69% of participants in the group over 30 years of age. Another difficulty in navigating the medical system was the difficulty in applying to the federal program Medicaid. Paperwork was cited as the largest barrier.

Long waiting times: Even with an appointment, another factor keeping participants from utilizing healthcare were waiting times. *"It's taking too long, I don't want to wait that long."* Participants reported spending upward of an entire workday waiting for a single appointment. The waiting time to receive care is a large issue; even when someone has an appointment they experience waiting. One participant stated, *"The wait, I had to take the whole day off just for an appointment."* This includes waiting for appointments, waiting at the appointment itself and during emergencies.

C. Structural and Policy Barriers

Distance to healthcare facilities: "Transportation is hard for people in the community." One of the most salient themes that emerged from the focus groups was the difficulty of finding transportation to get to healthcare facilities. If one does not have access to a car, finding friends or family to drive them to the nearest facility or taking public transportation were the most common options. Transportation difficulties also play a role in deciding where to seek medical care. One participant said *"I'll stay with Zuni hospital – it's closer"* even when the care is perceived to be inferior to care found in Gallup, New Mexico (the largest city within a 100 mile radius). Another participant agreed, saying, *"Yeah, going to Gallup is difficult."*

Transportation was not only a barrier to receiving medical care, but also in picking up prescription medications. One participant mentioned *"when they (pharmacy) like take too long or when they close early, usually it's hard for them to get a ride up there and trying to get their medication."*

Participants discussed their challenges in accessing pharmacies to get their prescriptions filled. A female participant mentioned, *"When they like take too long or when they close early usually it's hard for them to get a ride up there and trying to get their medication."*

Again, waiting time was a barrier for filling prescriptions, *“The wait. Thirty minutes over there just to get your medication. I think that’s why people don’t like going up there, because of the long wait.”* Both the times to wait to get the prescription filled as well as the transportation to the pharmacy were seen as barriers.

Absence of public transportation: A tribally supported public transportation program, the Zee Van, has attempted to address the transportation barrier. However, confusion over the timing and location of stops has prevented many participants from using the program. One participant mentioned difficulty reaching designated spots *“because everybody has to walk a long distance each time to get to their [stops].”* One participant said, *“Zee ride takes forever to go up there.”* The policy on designated spots has changed as well, as the *“Zee Van used to go to your house and pick you up, but right now they tell you to go here to get picked up.”* This participant found that by the time she gets there *“the van has already left and you miss your appointment.”* While the intent of this resource was to address the problem of transportation to health care facilities, logistical issues make this solution less useful than intended.

Governmental bureaucracy and paperwork: Another issue raised was the difficulty participants described in applying to Medicaid. One female participant said that she applied for Medicaid, *“it’s like okay you’re accepted for only a certain amount of months and you gotta reapply. Well, I reapplied then my husband got higher pay and now we’re denied.”* And when this participant reapplied, she was denied, *“everything’s still the same but they still rejected me. It kinda of made me upset, too. How do they do their paperwork?”*

Discussion

Nine themes emerged regarding the barriers experienced in receiving health care and adhering to medical advice. These themes included distance to healthcare facilities; absence of public transportation; embarrassment associated with receiving healthcare; difficulty relating to healthcare professionals; difficulty navigating the medical system; lack of awareness of available resources; long waiting times; and the role of incentives in health promotion. We organized these themes into the architecture provided by the socio-ecological framework.

Barriers to healthcare access limit the delivery of health services to the individual. The results are captured in the downstream disparities of health outcomes of people who experience barriers to care. (10–14). Okoro et al. reported that 9% of adults 65 years did not obtain needed medical care because of transportation problems, suggesting that they might be people living in rural areas, no longer drive, or depend on others or public transportation (11). Ahmed et al. and others have reported in door-to-door surveys that 30% of respondents had a transportation barrier to health care. Those living in poverty were disproportionately affected (12–14). The Zee Van, which was used to reduce the impact of the transportation barrier to health care access, has had only a limited impact. In contrast, transportation by friends and family was highly valued and appreciated.

Ethnic minorities and other marginalized groups use health care facilities less often than the majority ethnic group because of their limited knowledge of mainstream language and the high cost of transportation. Many studies have demonstrated that health care providers may be unresponsive to or may not understand the needs of ethnic minorities (15–21). Some focus group respondents perceived that the Zuni IHS staff often delivered lower quality care than that available in Gallup NM. Zuni IHS staff was perceived as lacking appropriate medical and social skills, waiting times were long, schedules very inconvenient and facilities rundown. Many reports about quality care in rural and poor communities serving poor and

marginalized populations reported that conditions typically lower than of those serving non-poor populations (National Scorecard on U.S. Health system performance, 2008 –Why not the best; National Association of community health center’s primary care access report 2009; and 22). Facilities serving poor communities were less likely to have well trained staff or to be stocked with appropriate drugs and equipment than facilities located in better-off communities (23).

In closely- knit communities, there was frequently a concern expressed about the lack of confidentiality among local health providers and community members. This is a well-known issue on many reservations. As in many small communities, people know each other and are often interrelated by blood or marriage. Close-knit communities can offer enhanced support and other advantages, but the reduced privacy can be a problem for stigmatized issues such as sexual victimization. This theme is echoed in other research; including in one study, lack of confidentiality was cited as a major reason for not seeking help for another sensitive issue, drug and alcohol treatment (24, 25). Stigma is a concern for many American Indian populations (26). Although most advocates attempt to maintain confidentiality, even the perception of limited confidentiality can prevent people from seeking help.

The challenges navigating the health system are not unique to the Zuni population. Our healthcare systems are complex and confusing. This is especially true for patients of low literacy (27). This presents opportunities for interventions that improve health care systems, including waiting times, appointments, helping patients to apply for health insurance coverage, and getting prescriptions filled and renewed.

The prevention discussion focused on community- rather than individual-level factors that impact behavioral problems. The literature about community-level interventions suggests that these problems are influenced to a large degree by social norms and community attitudes and beliefs. For example, teenage pregnancy prevention, although impacting individuals, is often thought to be a community-level problem. Communities in which teenage pregnancy is not accepted have lower teenage pregnancy rates than those in which teenage pregnancy is not a focus of prevention programs.

Participants very thoughtfully provided ideas to solve their community problems. Included in those strategies were those about eating and exercise, environmental protection, social support, disease prevention/health promotion programs, social support, programs to bring people together for mutual problem solving, identifying additional transportation solutions and most importantly, increasing awareness of the programs that do exist and those which might evolve from this research.

Participants were strongly supportive of having research done in their community but they advocated for the researchers to come back to share the results and to engage the community in arriving at ways to use the data for the benefit of the community. The CTSA manual, “Principles of Community Engagement” (2011) describes the most appropriate approach for research - to engage the stakeholders from the beginning in a mutually responsive and respectful partnership. What the focus group participants asked for suggests that the research that has been done on the Zuni has often not been in partnership – or with the community – but rather “on” or “in” the community.

Summary and Conclusions

We collaborated with Zuni community members to evaluate the contextual barriers and facilitators to health care utilization. We identified behavioral, socioeconomic and cultural factors that play a role in the contextual influences on the creation of chronic disease disparities in the Zuni Pueblo. We now have an opportunity to address the related to health

promotion and disease prevention and incorporate these factors into a broadly focused intervention. Ultimately this information will add to the armamentarium of clinicians and health care policy makers and help them to prioritize investments in prevention and management of chronic disease. In conclusion, development of a modified indigenous CCM that addresses these perceived barriers may significantly improve community access to health care and decrease the impact of interrelated epidemics of obesity, diabetes and kidney disease. Improved health-care access, better preventive screenings, and culturally appropriate community-based health promotion programs and policies should be examined as possible ways to reduce health disparities.

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Table 1

Focus group participant characteristics (n=112)

Demographic	Percent
Gender (% female)	57
Age (% of those > 16yrs)	
16–18 yrs	13.4
19–29 yrs	14.3
30–50 yrs	15.2
50+ yrs	13.4
Participant distribution	
Participants from IHS	7.1
Participants from Tribal Administration	14.3
Participants from Zuni School	9.8
Participants from Other health programs	12.5
Education	
Less than high school	34
High school diploma	39
At least some college	27
Occupation	
Artisan	32
Clinical Phenotype	
Overweight	26
Obese	28
Hypertension	17
Diabetes	9