Assessment of Oral Health Needs and Barriers to Care in a Gullah Community: *Hollywood Smiles*

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Submitted 16 February 2012, revised 5 October 2012, accepted 5 November 2012. This project was conducted with partial support from the South Carolina Clinical & Translational Research Institute, Medical University of South Carolina's CTSA NIH/NCRR Grant Number UL1RR029882; and from the NIH/NCRR Grant Number P20 RR017696, South Carolina COBRE for Oral Health. It was also partially supported by the MUSC Center for Oral Health Research.

Abstract

Objectives: To assess the oral health (OH) needs and barriers to OH care in Gullah African American communities.

Methods: A community advisory board (CAB) was formed to guide the research study. Five focus groups (*n* = 27 participants) were conducted to explore the OH needs/barriers. Participants completed demographic surveys and participated in discussions facilitated by open-ended questions. All sessions were audio-recorded, transcribed and analyzed using NVivo8.

Results: Facilitators of OH included positive experiences and modeling. Fear and access to care were the most cited barriers. Tooth extraction was the dental treatment of choice. Intervention recommendations included improving clinic access, using the churches to socially influence receipt of OH care, providing group educational sessions with OH specialists, and having local "lay people" to provide support and help to navigate OH care systems.

Conclusions: The design of a multilevel, culturally and locally relevant intervention may lead to a decrease in OH disparities in Gullah communities.

Keywords

Oral health disparities, community-based participatory research, focus group, Gullah African Americans, barriers to oral health care, community oral health promoter, community partnership

Despite national improvements in OH status over the past decade, profound disparities remain in some population groups as classified by gender, income, age, and race/ethnicity. Low socioeconomic status non-Hispanic Blacks have among the poorest OH of racial groups in the United States.[1] Poor OH is associated with oral cancer and linked with other cancers (gastric, lung, pancreatic).[2] There is increasing evidence that poor OH, especially periodontal disease, increases the risk of a variety of systemic conditions, such as coronary heart disease, adverse pregnancy outcomes, hyperglycemia control in diabetics, stroke, and hyperlipidemia,[3] and negatively impacts social life and dentofacial self-confidence.[4]

The African American (AA) Gullah population along the Southeastern U.S. sea coastal regions are a direct descendant population of rice plantation enslaved Africans from West Africa.[5] *Gullah* refers to several things: language, people, and a culture. The Gullah today have a considerably lower level of non-African genetic admixture compared with other AA groups,[6] which is thought to be owing to their longtime geographical, social, and cultural isolation.[7] When compared with other AAs, the Gullah face profound OH disparities. Fernandes and colleagues[8] found significantly higher prevalence rates of periodontal disease among Gullah with type 2 diabetes mellitus (70.6%) compared with national estimates

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of type 2 diabetes mellitus in AAs (31.3%). The mean total number of missing teeth among the Gullah with type 2 diabetes mellitus who were sampled is significantly higher at 8.3[8] compared with means reported in the National Health and Nutrition Examination Survey 1988–1994 and 1999–2002 among non-Hispanic Black adults of 6.9 and 5.8, respectively ($p < .01$).[9]

Hollywood, South Carolina, is a rural town of 33 square miles, located in Charleston County, with a total population of 4,714 residents composed of about 55% (2,610) AA, mostly Gullah.[10] According to the 2000 census, one fourth of the AA population lives below poverty levels[11] and among those 25 years and older, only 36% completed high school or equivalent.[12] Despite these challenges, the Gullah population of Hollywood, South Carolina, has a strong sense of community and is interested in improving their health and the health of their future generations.

This article discusses a community-based participatory research (CBPR) approach to assessing the OH needs and barriers to OH care faced by Gullah citizens residing in Hollywood, South Carolina. CBPR interventions and research establishes a mutual trust that enhances both the quantity and the quality of data collected.[13,14] The CBPR approach strengthened the relationship between researchers and the community and has been instrumental to inform a culturally sensitive and community preferred intervention in this community. The use of a qualitative method (focus groups) to identify barriers to OH care and to inform the development of an OH intervention allowed the investment of community members in the problem identification process and design of a future, planned intervention.

DESIGN

A total of 27 participants were enrolled and participated in five focus groups (range, 4 to 6 participants) to assess (1) OH needs of Gullah residents in Hollywood, South Carolina, (2) barriers to OH care, and (3) recommendations for intervention strategies. After initial analysis of four of the focus groups, we identified data collection saturation and conducted one more focus group session to further validate the findings. All group sessions were recorded and transcribed verbatim. The Medical University of South Carolina Institutional Review Board approved this study.

The Hollywood Smiles Research Team

Through the Community Engaged Scholars Program, offered by the Medical University of South Carolina (MUSC) Center for Community Health Partnerships, a partnership between the College of Dental Medicine at the Medical University of South Carolina, and the Hollywood, South Carolina, mayor's office was initiated. The academic partner, a dentist and assistant professor at the College of Dental Medicine, had been conducting research in a different Sea Island region and recognized the need for CBPR. The community partner, the Hollywood mayor's assistant and community leader, agreed to partner with the research team because of her passion for the community and desire to improve the quality of life for the citizens. The Community Engaged Scholars Program was the catalyst for the new partnership and provided 12 months of didactic training on CBPR, mentorship, and pilot funds for newly established community–academic partnerships. In sustaining the CBPR approach, the community partners elucidated the problems and needs of the community, while working with the academic researchers to develop a culturally preferred study design, determine recruitment methods, implement the study, and collect and analyze the data.

To gain representation of community perceptions, preferences, and priorities in the development of a research agenda and research processes, an eight-member CAB was formed.[15,16] Recommendations from the community partner at the onset indicated that this was a very religious community with influential pastors, and their support and endorsement would be vital for any new partnership and/or project in this community. The community had an existing advisory group of church pastors, known as the Spiritually United Neighbors. Volunteers from Spiritually United Neighbors and other formed community groups were invited to join the Hollywood Smiles project, and serve as the CAB. The Hollywood Smiles CAB includes one town administrator, one community leader, and five church leaders, all of whom are Gullah AAs. The CAB met once a month and provided oversight of the study, assisted with developing the questions for the focus groups, identified potential research participants, recommended a moderator for the focus groups, and assisted with the analysis of the findings. This CAB continues to meet quarterly and serves in a partnering role, sharing decision-making power regarding

conduct of research and use and ownership of the products.

Participant Identification and Recruitment

CAB members provided a list of possible participants, who were screened over the phone, by the community partner, to ensure they met the inclusion criteria. If interested and met inclusion criteria, they were invited to participate in the focus groups, conducted in the Hollywood town hall, and a choice of days and times were offered. Inclusion criteria included (1) adult (18 years of age or older), (2) AA, (3) one of the parents born in the Sea Islands (Sea Islands is defined as South Carolina coast from Beaufort to Georgetown, 35 miles inland), and (4) no health complications that would unable possible participants to be present at the focus group sessions.

Participants from different churches in Hollywood were purposively invited to participate. In the earlier focus groups, most of the participants who attended were female. Therefore, for the last focus group, an effort was made to recruit male participants, and the CAB reached out to the local fire department and the town hall to assist in the recruitment process. Refreshments were provided and participants were compensated with a $20 gift card for their time.

Protocol Development and Data Collection

For the focus group protocols, we (academic and community partners) first drafted open-ended, semistructured questions pertaining to OH care and the barriers to care, which would allow participants to use their own words to share their experiences, attitudes, and perceptions. These were piloted with the CAB and we found they had difficulty understanding the meaning of some of the terms used, which resulted in limited responses. Following the CAB's recommendations, questions were modified to employ simple terms, allowing participants to tell their best and worst experiences in a dental chair and the main reasons they thought people in their community go or do not go to the dentist on a regular basis.

As advised by the CAB, a Gullah female, who is a nurse researcher and has experience with focus group moderation, led the focus group sessions. Discussions lasted on average 1 hour, and were audio-recorded. The moderator encouraged storytelling, and then probed to provide clarification on perceived barriers as needed. Once the barriers to OH care were identified, participants were asked how to overcome them and improve the OH of their community as a whole. To ensure accuracy of participants' responses, notes were taken by two Institutional Review Board–approved members of the research team, which included the academic partner, and a researcher dental professional. At the end of each session, participants were given an opportunity to ask the dental professional questions concerning OH care. Recordings from all five focus group sessions were professionally transcribed verbatim. Based on the field notes taken during the discussions, the transcripts were carefully reviewed and corrected accordingly to ensure accuracy.

The questionnaires used for the quantitative data collection (demographics and OH habits) had been previously used by the principal investigator in another project with this population[17] and was reviewed and approved by the Hollywood Smiles CAB.

Data Analysis

Data analysis and the interpretation of the qualitative data followed processes that are described in the literature for exploratory investigations[18] and have also been described for testing of concepts and messages.[19] Using QSR NVivo 8, the research team analyzed the transcripts for recurrent themes and patterns in the responses. The focus was on understanding the participants' personal experiences. The research team looked for specific categories to sort and distinguish pieces of data, also known as coding.[20] As analysis progressed, codes were revised and new codes were added when appropriate.

Through multiple reviews, common themes were discovered among the categories, which generated specific findings. Coding was initially done by one coder and then reviewed by a second coder. These findings were then discussed with the CAB, ensuring accuracy and understanding (by the research team) of the cultural approaches taken by some of the community members.

RESULTS

As shown in Table 1, the participants were predominantly female (n = 20 [74%]), and 100% were Gullah AAs (n = 27). The age range was 39 to 68 years old. Most participants (74%) had an income of less than $29,000 per year.

Even though 74% of participants reported brushing twice a day, and 51.8% reported flossing once a day (Table 2), the majority of participants (52.38%) indicated they only sought

dental care when there was a problem. In general, the participants (96.3%) had a history of toothaches, which often resulted in tooth extractions. The three broad themes identified were (1) facilitators of OH, (2) barriers to OH care, and (3) recommendations for intervention strategies.

Facilitators of OH: Positive Experiences and Modeling

Participants that reported having a "good" experience in the dental office were more likely to seek preventive regular care, independent of the possible barriers present. Having a dental provider who cared about their well-being and general health and listened to their concerns was important. Participants wanted to be treated with respect, understand what is being done to them, and have pain minimized during procedures (Table 3).

For self-management of OH needs, participants indicated they learned by modeling of their parents and support systems. They managed OH as they were taught as a child, heard about in school, or from a local dental provider. Positive early experiences with dental providers during childhood for some participants, as well as positive sharing of recent experiences by close relatives or friends, facilitated and reinforced self-management and seeking routine dental care (Table 3).

Barriers to OH Care: Fear, Access, and Cultural Beliefs

Fear and access to care were the most cited barriers to OH. Fear was caused by emotional issues such as anxiety associ-

Table 1. Sociodemographic Background of Focus Group Participants in a Gullah Community (*N* = 27)

	n (%)
Age (yrs)	
35–44	3 (11.1)
45–54	8 (29.6)
55–64	12 (44.4)
≥65	4 (14.8)
Gender	
Female	20 (74.1)
*Highest grade**	
9–11	1 (3.7)
12	9 (33.3)
Some college or technical school	10 (37.0)
College graduate	6 (22.2)
Marital status	
Single	7 (25.9)
Married	9 (33.3)
Divorced	6 (22.2)
Widowed	4 (14.8)
Common law (living with partner / not legally married)	1 (3.7)
Income (US$)	
≤5,000	5 (18.5)
5,000–9,999	2 (7.4)
10,000–14,999	6 (22.2)
15,000–24,000	5 (18.5)
25,000–29,000	2 (7.4)
≥30,000	7 (25.9)

*Numbers do not equal to 27 owing to missing data.

Table 2. Dental and Social History Background of Participants (*N* = 27)

Question	Response	*n* (%)
How often do you brush your teeth?	>2 times a day	7 (25.9)
	Twice a day	13 (48.1)
	Once a day	6 (22.2)
	Less than once a day	1 (3.7)
	Never	0
How often do you floss your teeth?	>2 times a day	2 (7.4)
	Twice a day	1 (3.7)
	Once a day	11 (40.7)
	Less than once a day	8 (29.6)
	Never	5 (18.5)
How often do you go to the dentist?	More than once a year	6 (22.2)
	Once a year	7 (25.9)
	Only with a dental problem	14 (51.9)
	Never	0
Smoking status	Past	5 (18.5)
	Current	3 (11.1)
	Never	19 (70.4)
Alcohol consumption	>3 glasses per week	3 (14.3)
	1–2 glasses per week	2 (9.5)
	<1 glass per week	8 (38.1)
	Never	8 (38.1)

ated with pain, as well as perception of dental experiences. The majority of the participants, especially those who reported a previous bad experience and/or those who did not receive dental care during childhood reported fear. They shared their fear of needles, fear of pain, and fear of the "other things" the dentist may find (Table 3). Other participants indicated they felt dentists were rough, had no patience, and/or did not explain what they were doing. Many reported they did not trust dentist providers.

Access to care factors, mentioned by participants, included financial concerns, lack of transportation, lack of a community dental clinic, time constraints, and attitudes of the dentist and dental staff members toward patients. Participants also reported perceived value of OH and understanding the importance of OH as important factors (Table 3).

Table 3. Participants' Quotes

Facilitators of Oral Health	Barriers to Oral Health Care	Recommendations for Intervention Strategies
Positive Experiences	*Fear*	
"Another dentist that I went to before. He was really gentle. He let me know exactly what he was doing. It hurt, but I knew what he was doing."	"And, I haven't had a real bad experience. I made the experience bad for myself. Cause I had a fear of going to the dentist."	"Good visual aids as far as to be able to show them actual pictures or me personally if I see something then I'll understand."
"I really just didn't want to look at any dentist, you know because with having the problem with the teeth, it was causing me to have bad breath, I stopped, I was very upset until the other day when finally I find someone relief in a dentist that I am going to now."	"I just had the fear of dentist. And I knew if I took care of my teeth the way it should, get it done, cleaned every 6 months. Then that would keep me from the dentist."	"I mean you don't just give this long reading from this paper and yaddydya and using these words we don't understand. Instead of getting up there and tell what you have to do. Brush here, floss there. And don't take too long."
"Yea, my, the best experience I've ever had? I don't know, any of'em is good [All my experiences were good]."	"Well, my fear is needles. I'm terrified of needles. That's my problem."	
"My best experience going to the dentist as a younger person was getting a lollipop when I get into the office."	"Cause I had a fear of going to the dentist. I would have a toothache and I wouldn't go to the dentist. I'd doctor it myself."	"I would prefer someone with the training, a professional versus somebody in the community."
Modeling	*Access*	
"Maybe if you start taking children [to the dentist] at a young age and let them grow up in it [in the dental office]. I went as a child, and I was always afraid of needles when I used to go to a dentist, but I go back, cause it's important, I know it's important"	"That's a big thing out here. A lot of people don't have transportation. They can't get there themselves. They can't get the children there, so nobody goes. "	"I think somebody here [from the community] trained [in oral health]. Cause we know our people, and we relate better to our people. Cause getting other folks [from outside the community], we're afraid sometime."
"I think children follow by example if they know mommy and daddy goes to the dentist; mommy and daddy brush. Well, I'm going to do the same thing. Most kids follow what the parents do, whether it's good or bad."	"Sometime, it's the distance that they have to go to make it to the dentist."	
	Cultural Beliefs	
	"Culturally, and growing up at my grandmother's house, there's always a philosophy, if not broken, don't fix it. And a lot times they just don't go if nothing is bothering them. And that's just a cultural thing. And I believe that's the biggest thing that keeps a lot of people from going."	

Table 4. Principles of Community-Based Participatory Research

Principle 1	Principle 2	Principle 3	Principle 4	Principal 5	Principle 6	Principle 7	Principle 8	Principle 9
Establish clear goals	Become knowledgeable about the community	Establish relationships	Develop community self-determination	Partner with the community	Maintain respect for community diversity	Mobilize community assets	Release control	Maintain community collaboration
To develop a model to improve the oral health of rural Gullah community	Meetings with local leaders and historians to learn more about the culture and habits. Created study specific community advisory board; Academic partners participated in multiple community events; Community members hired as part of the research team.	Partnerships were slowly formed with different community / church leaders; Partnership established with community clinics.	Participated in multiple cultural events, educating the community on how to take better care of their oral health needs; Research team became involved in other projects, led by the community.	Formal partnership established with the Mayor's office; multiple churches in the Sea Island communities and with the Community Advisory Board.	Smaller community advisory boards formed in each participating community / church; Hired community members to be part of the research team; Used different recruitment/ intervention strategies, based on community input.	Used community's strengths (i.e., people assets and current infrastructure (church, community dental clinics) to improve different aspects of the projects.	Community and academic partners are Co-PIs in different projects. Community organization is funded by grant support.	Community is involved in every aspect of the project, from problem identification, through finding possible solutions to results dissemination Research team involved in community led projects.

Participants across all groups mentioned using a wide range of home remedies to alleviate pain and other dental problems, such as self-extractions, placing teabags and/or ice on the tooth or affected area, massaging the gums, applying liquor to the tooth and drinking it as well, and applying substances to the tooth, such as kerosene, castor oil, alcohol, and the "scrapings of a black frying pan."

Recommendations for Intervention Strategies: OH Promoters, Church Delivery, and Access

The use of a trusted, local community person to help their peers overcome their fears, improve their knowledge on OH, and navigate the system was the most common recommendation on how to possibly overcome the barriers to OH care. This is a small community with "word of mouth" as the major communication channel.

Participants also recommended intervening through the churches as a means to socially influence the community to act on improving their OH needs. The church is part of life in this community, and was perceived as the most organized and structured mechanism to gain support and to implement any new initiative. Gaining the pastors' endorsement and involvement with the project would be necessary for the community to endorse and participate.

Participants, although recommending a lay community person to support and help them navigate, preferred having specific OH education from professional OH specialists who had OH expertise and could answer their questions. Although they trusted key leaders in the community, it was recognized that professionals were trained and could provide the latest, evidence-based recommendations.

Others recommended improving access to dental clinics, including public transportation. Several leaders in the community had a goal to establish "their own" community dental office/clinic in the area of Hollywood, South Carolina, that was staffed with local, indigenous people they could trust and where they could receive local care.

DISCUSSION

CBPR has been suggested as a strategy to develop trust and build on the strengths of partners from various settings to address significant health issues, particularly those persistent health issues that reveal disparities among minority popula-

tions.[21] An expert task force convened by the NIH reported nine key principles of community engagement[22] (Table 4). Table 4 also highlights the adoption of the established principles during the research continuum.

The initial partnership between the MUSC College of Dental Medicine and the Hollywood, South Carolina, Mayor's office has been expanded with the CAB and several local churches. The CAB has been very instrumental in initially bridging the communication and overall exposure between the academic investigators and grassroots community. Trust and mutual respect has developed over time, and has been nurtured by academic partners participating in weekend church, civic, and social events, as well as community partners (i.e., Mayor's staff, church pastors) participating in academic forums and meetings. The partners have identified mutual interests in the health of the community, and over time have embraced the diversity of expertise, resources, and skills of that the partnership as a whole provides, which is larger than individual contributions.

Formative assessment, in this case done through focus groups, is a description of the process whereby the community informs the interventions that are being developed. It is essential for developing interventions in new and diverse cultural settings for which existing information is limited. The assessment data are also vital in identifying the barriers to and opportunities for intervention and the community strengths that will contribute to the development and implementation of an effective and culturally sensitive intervention.[23]

In accordance with other reports, participants identified a number of reasons for using alternative "strategies" rather than visiting the dentist when suffering from tooth pain or other dental problems.[24-26] The majority of the participants, especially those who reported a previous bad experience or who did not receive dental care during childhood, were more likely to express fear. According to Gilbert and associates,[27] self-care behaviors are common and can act as substitutes for or supplements to formal health care services. The phenomenon of dental self-extraction is real and is not limited to residents of developing nations or geographically isolated areas; because of potential complications, such as prolonged bleeding or bacterial endocarditis, community health clinicians and officials should be cognizant of this behavior.[28]

Discussion of the advantages of dental care can encourage individuals to act, but decreasing/eliminating barriers to change is more likely to make action a reality. This is in agreement with our participants' recommendations on using an indigenous person to help them to move into action, by giving participants an opportunity to talk about their fears and hear positive experiences and facts, therefore increasing participants' OH literacy. At the same time, barriers to oral care need to be eliminated to facilitate positive behavior. Offering affordable dental services in the area of Hollywood removes the financial barrier for those who cannot afford it; providing other supportive services such as transportation in the community can also make it easier for people to get to the dentist. Positive encounters at the dental office, either with staff or dental providers, can encourage them to accept dental care as well as to return for subsequent care. The interpersonal interactions and communication between participants and dental providers are crucial to establish a trusting relationship at the time that care is rendered and influence the acceptance of subsequent care.

In the *Hollywood Smiles* formative phase, an assessment of the community OH needs and barriers to OH care was successfully conducted and the results will form the basis of a multilevel intervention to improve OH outcomes, not only in this particular community, but among other rural Gullah minority communities as well. Although it is impossible to generalize the information gained from this self-selected population, this community presents similar related research challenges observed in other minority, rural communities in the United States, which will likely make our intervention model possible to be extrapolated and generalized.

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