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Barriers and Opportunities: A Community-Based Participatory Research Study of Health Beliefs Related to Diabetes in a US Marshallese Community

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Abstract

Purpose—The purpose of this study was to investigate the beliefs and perceptions related to type 2 diabetes (diabetes) that influence diabetes self-management behaviors for Marshallese in the U.S. Utilizing the Health Belief Model as a theoretical framework, researchers seek to better understand the underlying beliefs that motivate or impede diabetes self-management behaviors.

Methods—The community-based participatory research (CBPR) collaborative engaged in 14 months of preliminary fieldwork and conducted two tiers of focus groups for this project as part of our long-term commitment to reducing health inequalities in the Marshallese community. The CBPR team conducted an initial round of two exploratory focus groups (n=15). Based on the knowledge gained, researchers held a second round of focus groups (n=13) focused on health beliefs regarding diabetes. All participants were Marshallese, aged 18 and older, and included men and women. Participants either had a diagnosis of diabetes or were a caretaker of someone with diabetes.

Results—The findings elucidate the structural and non-structural barriers to successful diabetes self-management for Marshallese in the US. Barriers include: eating differently than the rest of the family, social stigma of diabetes, transportation, cost, lack of access to healthcare, as well as cultural and language barriers.

Conclusions—While there are significant barriers to improving diabetes self-management, there are also areas of opportunity including family and peer reinforcement to encourage proper diabetes management behaviors and a growing community desire to lift the stigma of diabetes. The CBPR

team offers recommendations to make diabetes management interventions more culturally appropriate and effective for the Marshallese population.

The purpose of this study is to investigate the beliefs and perceptions related to type 2 diabetes (diabetes) that influence diabetes self-management behaviors for the Marshallese population in the United States (U.S.). Marshallese are a Pacific Islander population with a growing presence in the U.S. While the Pacific Islander population increased 40% in the United States between 2000–2010,¹ the U.S. Marshallese population increased 300% in the same decade.¹ The Compact of Free Association (COFA) between the Republic of the Marshall Islands (RMI) and the United States allows Marshallese migrants to enter the United States without a visa or permanent resident card to live and work.^{2,3} Arkansas is home to the largest population of Marshallese in the continental United States.¹ While the ability to freely enter the U. S. offers opportunities to the Marshallese, they face severe health inequalities. Marshallese suffer disproportionately from chronic diseases including diabetes, obesity, and cardiovascular diseases,^{4–7} as well as infectious diseases, particularly Hansen disease (leprosy), hepatitis, and tuberculosis.^{8–11}

The Marshallese suffer from diabetes at rates at least 400% higher than the general U.S. population.^{4–6,12} In the Marshall Islands, researchers have documented diabetes rates between 20% and 31% among Marshallese adults on the two most populous islands.^{4,5} In the United States, researchers in Hawaii and Arkansas found higher rates of diabetes in Marshallese adults (n=130). In 2012, the rate of Marshallese adults with diabetes or severe diabetes was 44.2% in Hawaii and 46.5% in Arkansas. In addition, 25.3% in Hawaii and 21.4% in Arkansas had pre-diabetes.⁶

What accounts for such high rates of diabetes among the Marshallese? While the answers are not completely unraveled, altered diet and lifestyle offers a partial explanation.^{13–15} Between 1946 and 1958, the United States military tested nuclear weapons in the Marshall Islands.^{16–24} Consequently, the natural food supply of fish, vegetables, and fruit was contaminated on the bombed atolls;^{16,25,26} radiation contaminated many additional islands.¹⁶ The traditional Marshall Islands lifestyle of subsistence farming and a lean, fish-based diet was destroyed by the nuclear testing.^{14,16} After the nuclear contamination, the United States provided imported foods, largely consisting of highly processed canned and packaged foods to Marshall Islanders.¹⁶ Today, these continue to be the preferred foods for Marshallese in both the Marshall Islands and in the United States.^{15,27}

This study is part of a community-based participatory research (CBPR) partnership between the University of Arkansas for Medical Sciences-Northwest Campus, the Arkansas Coalition of Marshallese, Gaps in Services to the Marshallese Taskforce and several Marshallese community members. The topic of type 2 diabetes was selected as the priority topic for exploration using a community-driven process to determine our collaborative research agenda.

Diabetes Behavior

Diabetes self-management behavior is low among Marshallese in the U.S.^{14,28} Very few Marshallese have participated in diabetes self-management education (DSME).^{14,27–29}

Healthcare providers report that very few Marshallese patients with diabetes regularly perform blood glucose checks or take medications as prescribed.³⁰ Marshallese typically do not present to healthcare providers for diabetes care until the disease reaches a crisis stage when hospitalization or amputation are often necessary.^{14,31,32} Previous attempts to implement diabetes self-management education among U.S. Marshallese communities were not successful.¹⁴ Local Marshallese refer to diabetes as the “silent killer” of their people because individuals often do not realize they have diabetes “until it strikes really bad”.²⁹ There is limited literature on Marshallese diabetes-related behaviors.^{14,33} There is currently no work published on Marshallese’s perceptions and beliefs regarding diabetes.

Health Belief Model

Achieving successful diabetes management requires understanding the beliefs that motivate or inhibit health behaviors. The Health Belief Model is a widely used conceptual framework for understanding health behavior.^{34,35} The Health Belief Model is typically utilized to explain why an individual does or does not engage in a health prevention or health maintenance action by investigating underlying beliefs.^{34,36} In addition, it has been used to develop new health behavior interventions.^{37,38} The primary constructs of the Health Belief Model include 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, 4) perceived barriers, 5) cues to action and 6) self-efficacy.^{34–36}

Research Design and Methodology

Research Design

Utilizing the Health Belief Model as a guiding theoretical framework for this exploratory research, the primary research question is: for Marshallese in Arkansas, what beliefs and perceptions related to diabetes influence diabetes self-management behaviors? The CBPR partnership seeks to better understand what underlying beliefs motivate or impede diabetes self-management behaviors for Marshallese. The researchers chose an exploratory, qualitative design using focus groups and individual interviews to gain an in-depth understanding of Marshallese beliefs and perceptions regarding diabetes. The qualitative design allows participants the freedom to use their own words when describing their beliefs and experiences because they are not confined to predetermined responses.³⁹ Semi-structured interview guides were developed using the Health Belief Model. The semi-structured interview guides ensured that all focus groups and individual interviews covered the same topics. Broad questions were constructed to encourage open dialog.^{40,41} Probes were used to better understand nuances and clarify responses.⁴¹

Sample and Setting

As part of a CBPR collaborative, the research team spent 14 months meeting with Marshallese community members and used a community-driven process to discern and prioritize the community’s primary health concerns. For this study, the research team conducted two tiers of focus groups and individual interviews. The team began in November 2013 with an initial round of two focus groups with Marshallese community members asking broad questions regarding their health concerns and health access (n=15). During

these interviews, the prevalence of diabetes, complications of diabetes, and the lack of effective diabetes education emerged as top concerns.

Based on the knowledge gained from the initial focus groups, the research team conducted a second tier of focus groups centered on health beliefs related to diabetes. Researchers scheduled focus groups for December 2013; however, due to winter weather and dangerous road conditions, attendance was low (n=3 for the two focus groups, making the session with one attendee an individual interview). In March 2014, the research team held two additional focus groups to discuss health beliefs related to diabetes (n=9), as well as one individual interview with a community member who could not attend during the scheduled focus groups. There were 10 participants in March 2014 to result in 13 total participants for the second tier of data collection. All participants were Marshallese men and women living in Arkansas. Each participant had either been diagnosed with diabetes or was a caretaker of a person with diabetes.

Data Collection Procedures

Participants were recruited by phone, email, Facebook posts, and word-of-mouth through Marshallese community partners. All participants completed an informed consent process. All focus groups and interviews were conducted in a private room at a community center in Springdale, AR, the city where the vast majority of Marshallese in Arkansas reside.⁴² Interviews lasted approximately one hour, and each participant received a \$25 gift card as compensation for sharing his/her time and knowledge.

Data Analysis

The three researchers (two qualitative researchers and a Marshallese community co-investigator) coded transcripts for deductive codes based on the Health Belief Model, as well as inductive codes and emergent themes. Both deductive and inductive codes were organized in a codebook. In CBPR research, it is important to include community members at all stages of the research, including data analysis, interpretation of results, and publication.^{43,44} The Marshallese community co-investigator provided checks on the two researchers' interpretations of the data by thoroughly reviewing the codebook and providing her input; she also coded transcripts for main themes. Her intensive participation and first-hand perspective was invaluable in validating the researchers' interpretations and ensuring that the results accurately represent Marshallese beliefs regarding diabetes. Researchers reviewed and coded transcripts individually, met several times to compare codes and themes, and discussed and resolved any discrepancies.⁴⁵

Developing Recommendations

After the interviews were coded and main themes identified, the research team began to develop recommendations to guide programs and policy. These recommendations were discussed with Marshallese stakeholders and refined based on the broader community's input. The resulting recommendations in Tables 1 and 2 are the product of multiple collaborative discussions between the researchers, Marshallese co-investigator, and Marshallese community stakeholders.

Results

Three main areas of findings are discussed: the use of a collective voice that reflects a collectivist worldview, perceived barriers, and areas of opportunity.

While the interview guide provided equal attention to each of the six areas of the Health Belief Model, participants focused on perceived barriers. Following the participants' emphasis, this article focuses on perceived structural and nonstructural barriers to diabetes management. The authors will discuss additional findings regarding Marshallese health beliefs related to diabetes in a separate article.

Collective Voice

Participants often used a collective voice and spoke about the broader community, using the terms “they” and “we,” rather than their individual beliefs and perceptions. Even when pressed for their own individual beliefs and experiences, often responses were inclusive of both their first-hand experiences and their understanding of the broader Marshallese community. The researchers asked participants and the Marshallese co-investigator about this phenomenon. They explained that in Marshallese culture, personal beliefs and perceptions are only meaningful within the larger family or community context. The use of collective voice that reflects a collective consciousness is common in non-European cultures. A collectivist culture has been documented in the Marshallese and other Pacific Islander groups.^{16,46} As such, in addition to discussing their own beliefs, participants served as key informants for the broader Marshallese community.

Perceived Barriers

As outlined in the Health Belief Model, perceived barriers include the negative aspects of a health action and the impediments to undertaking a behavior.³⁶ Participants discussed several perceived barriers that impeded their community from addressing diabetes, engaging in self-management behaviors and seeking DSME. These barriers include eating differently than the rest of the family, social stigma of diabetes, transportation, cost, lack of healthcare, time, cultural differences, trust, and language.

Eating differently than rest of family—An individual changing eating habits on his/her own is one of the most challenging aspects of diabetes self-management behavior for Marshallese. Families eat together from one pot; it is impractical and even shameful to refuse food from the family meal or eat differently from the rest of the family. When visiting a home in the Marshallese community, it is expected that the host will offer food and that the guest will eat it. For a person with diabetes to refuse food offered or eat differently is not just difficult; some respondents suggested it was nearly impossible. “I could never say no to my family and friends who give me food to eat; and you eat it all, not just some. They give me food to honor me, and to say no would be shame. I won’t do it.” Even when participants were committed to eating a different diet, they found it difficult. “It’s tempting when we have my family, food is prepared there, and I’m the only one that’s diabetic in the household.”

Social Stigma: Pride, Embarrassment, Shame and Denial—Participants describe significant social stigma associated with having diabetes within the Marshallese community. Marshallese perceive it as shameful to openly admit they have diabetes. “For Marshallese, to admit to having diabetes is to admit you cannot control yourself. It is an issue of pride, and many do not want to know or admit, even privately to themselves, that they have diabetes.” Consequently, there is widespread denial of diabetes diagnoses by the Marshallese. “A lot of Marshallese are just afraid of knowing that they have diabetes.” When asked if they have diabetes, participants report that many in the community would say: “No I don’t. Who told you? I am healthy.”

The social stigma of diabetes in the community is a significant barrier to screening, treatment, and self-management education. Participants describe, “They are ashamed, they are ashamed if other people find out they have diabetes.” “They’re afraid that they might go in the [DSME] class and people might see that they are there ...So that’s why they don’t want to.” “People know there are classes, but they won’t come, because pride, shame, embarrassed.” “They think that if they are diabetes, they hide it from people. They don’t want people to know [they] have diabetes. So they are mostly in denial.” The social stigma and shame associated with openly having diabetes has been found to be a major perceived barrier to diabetes management for other Asian and Pacific Islander groups as well.^{47,48}

Transportation—There is a lack of both personal and public transportation available to the Marshallese community in Arkansas, and this was consistently brought up as a barrier to accessing DSME and other health services. Many Marshallese do not have a personal vehicle, and public transportation is very limited. Marshallese often share one vehicle among several family members. “They don’t have any ride, but they will not tell you that [they don’t have a ride].” A younger Marshallese participant expressed concerned that the elders cannot access diabetes education and other health services because they do not have transportation. “But the elders really want to come. They want to come, but they don’t have any ride.” “I think that there should be a shuttle for the eldest, the Marshallese ‘elderlys’.”

Cost, Lack of Insurance, Time—Poverty is high among the Marshallese. Ninety eight (98) percent of Marshallese students in the Springdale, Arkansas schools participate in the free school lunch program.⁴⁹ Cost is a barrier for many Marshallese in all aspects of life. In terms of healthcare, the financial barrier is exacerbated by a high rate of uninsured and the Marshallese’s exclusion from Medicaid eligibility.⁵⁰ “Not just the knowledge of diabetes, but financial, because we have struggled through finances here in the States.” “We want to go to the doctor, but we cannot, because we don’t have insurance.” The poultry industry is the primary employer of Marshallese in Arkansas, offering mainly low-wage employment.⁴² A local study found that most Marshallese make little more than minimum wage.⁴²

A large part of diabetes education is nutrition education, and many Marshallese report that they cannot afford to eat the healthy foods required for successful diabetes self-management. Instead, their diet consists mainly of rice and inexpensive processed meats. “So not understanding what is good to eat and what not good to eat is a major part of getting diabetes. And then when they are educated, some of them will try to change what they eat, but the problem too is the cost of vegetables.” Another community member adds, “I

think the other factors too is that, you know, most Marshallese, they make little more than minimum wage and if you are going to buy Splenda™ compared to, like, regular sugar, the regular sugar is cheaper.”

Time to focus on personal health is scarce. Struggling to keep up with daily responsibilities leaves little time to attend DSME or think about proper nutrition and exercise. “Work comes first” for the Marshallese, and often there is one worker in a household supporting several children and elderly. “What the community is trying to do is keep up with bills, water, electric, car, and home, is like the number one priority.” One community member explains that the main barrier to diabetes self-management is: “Time. They have to work. And in our community, work is the number one thing that they have to do. Because the whole family is depending on the people that work.”

Cultural, Trust, and Language—The researchers do not view culture as a ‘problem’ or ‘barrier’. However, there are differences in the Marshallese and American cultures that can make it difficult for Marshallese to access services and manage their diabetes. Additionally, there is a lack of trust and some resistance, especially by Marshallese elders, to following American norms. Participants reported that this is due, in large part, to resentment regarding the nuclear history between the Marshallese and the U.S. “It’s really hard for the Marshallese to change what they are eating. Like, they came here, they said, ‘We will not [change]. Our culture is our culture. And American culture is American culture.’ And they said, ‘Why do we believe the U.S.?’ If they destroyed our island and are not giving us Medicaid, or medical attention, now. Why do we believe them now?”

Regarding language, participants report that most Marshallese in Arkansas communicate primarily in Marshallese and speak limited English; this is a barrier in all facets of life in the U.S., including accessing diabetes education and care. “You know, when you don’t speak English that well, you really cannot go out yourself and seek help because of the limitations, when the language is limited.”

Areas of Opportunity

Consistent with a CBPR approach, researchers sought input from participants related to opportunities for addressing diabetes beliefs and self-management behaviors within the community. Based on the qualitative interviews, themes emerged that the research team termed “areas of opportunity” for improving diabetes self-management behavior among the Marshallese. These include 1) family and peer reinforcement to encourage proper diabetes self-management and 2) a growing desire among the community to lift the stigma of diabetes.

Family and peer reinforcement to encourage proper diabetes self-management—A recurring theme was the common practice of family and peer reinforcement to encourage proper diabetes self-management behaviors. The research team interprets this practice as family and peer *reinforcement* rather than *support* because it is not a practice of rewarding good behavior with encouragement, but rather reminding family and community members about proper behaviors. A well-respected *madame pastor* (pastor’s wife) explains, “Even at our church, I would sometimes talk to these people that I know.

Have you been seeking medical help? Are you on medication?” She goes on to say, “I have a nephew who’s the same way. You have to say, ‘Did you get your refills?’ I mean, he has insurance. He works. And he gets them really cheap at Wal-Mart. I think four dollars. But he’ll say, ‘Oh, I forgot.’” A young male community advocate playfully describes his experience of reinforcement with his aunt, “My aunt...she’s been crazy about soda. You go to her house, she’s got like a lot of soda...And every time I explained, ‘You don’t need to eat that; it’s not really healthy.’ And she’s like, ‘No, I’m not diabetes.’ And when she was diabetes, I was really mad. I was like, ‘If you are diabetes, I’m going to kill you. (Laughs) Because I told you not to do this and that.’ And then, boom! She was diabetes and she looked at me and said, ‘Are you going to kill me?’ I said, ‘Yeah, I’m going to kill you.’”

Growing desire in community to lift the stigma of diabetes—While the community members consistently explained the embarrassment and shame associated with openly having diabetes, respondents also spoke to a growing interest among the community to lift the stigma of a diabetes diagnosis. One woman, who translates for DSME classes, would like to see more people reject the stigma of diabetes, “This is one of the things that we want our people to know, that diabetes is not something to be embarrassed of. If you have diabetes, you should say ‘Yes, I do. I have it. And so what? I’m taking care of it.’ Not a lot of Marshallese have this kind of mentality, that would stand up for them and say...I mean there’s a few of us that can do that, but not 98 or 97 percent of our people can address diabetes as something that can go public.” A respected Marshallese male elder shared his idea for addressing the diabetes stigma, stating, “Like, we could find one day in a year that we call ‘Diabetes Day’, so we can take posters and stand and rally.”

Discussion

The incidence rate of diabetes is extraordinarily high in the Marshallese community,^{6,51,52} and self-management practices so far have not proven effective.^{53,54} The CBPR collaborative with the Marshallese community in Arkansas prioritized addressing diabetes, and the Health Belief Model provided an appropriate theoretical framework to explore the beliefs and perceptions of the Marshallese community related to diabetes. While the researchers explored all areas of the Health Belief Model (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy^{34–36}) during the interviews, participants focused primarily on the numerous barriers they face to diabetes self-management. This study elucidated the structural barriers (e.g. lack of health insurance) and non-structural barriers (e.g. difficulty of eating differently than rest of family) to engaging in diabetes self-management behaviors. The barriers discussed in this article are also intertwined with the complexities of historical trauma, nuclear history, migrant status, and economic hardship experienced by the Marshallese community. While there are significant barriers, there are emerging areas of opportunity for improving diabetes self-management for the Marshallese, including family and peer reinforcement to encourage proper diabetes self-management and a growing desire in the community to lift the stigma of diabetes.

Strengths and Limitations of Study

This is the first study to investigate beliefs and perceptions related to diabetes among the Marshallese. This is an important contribution given the extremely high rates of diabetes in the Marshallese community, and the efficacy of the Health Belief Model to understanding health behavior and planning health behavior interventions.^{34,37,38} In addition, this study is based on the top health concern identified by CBPR stakeholders, making it relevant to programmatic and translational research efforts within the community.

Two Caucasian researchers facilitated the focus groups and interviews and this may have resulted in some response bias. While the Marshallese co-investigator on this study confirmed that the interpretations of the data were accurate, she explained that some of the responses were moderated by a desire to be polite and “not complain” to the non-Marshallese researchers. In future research, the CBPR team plans to have a Marshallese co-investigator facilitate the focus groups in the Marshallese language to avoid this response bias.

Most of the respondents were acculturated to U.S. culture, spoke English well, and had experience working in organizations with American culture norms. In future research, with the aid of Marshallese bilingual community co-investigators, the research team plans to gain the perspective of less acculturated residents who speak primarily Marshallese.

Implications and Recommendation for Policy and Practice

This research was community-based and oriented toward action. The Marshallese CBPR stakeholders and larger Marshallese community voiced their concern that they do not want to feel like research “guinea pigs” and instead desire action-oriented projects that serve their community. Therefore, the research findings guided our CBPR stakeholders in developing programmatic and policy recommendations to overcome the barriers to diabetes self-management that were identified. These recommendations include: Findings to Guide Culturally Appropriate DSME (Table 1) and Implications for Health Education and Policy (Table 2).

Conclusion

Diabetes self-management education has been shown effective in reducing complications of diabetes, improving health outcomes, and reducing overall costs of care; however, Marshallese are far less likely to receive diabetes self-management education.^{51,52} Furthermore, previous attempts to implement diabetes self-management education among Marshallese communities have not been successful.^{14,28} This study’s findings provide insight into the barriers that may be impeding successful diabetes self-management within the Marshallese community, and can help guide the adoption of diabetes self-management interventions that are more culturally appropriate. In addition, the findings may guide local and national level policies and programs to address structural barriers. While the challenges and complexities involved in addressing the diabetes epidemic are great, the Marshallese community is ready to take action. Our CBPR partnership will utilize findings from this

study to improve diabetes self-management education and develop culturally-appropriate health behavior interventions.

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Table 1**Findings to Guide Culturally Appropriate DSME**

- Family and community comes first. An individual is unlikely to change eating habits on his/her own. Diet and lifestyle changes should focus on family and community level changes.
- Marshallese do not want to lose connection to traditional culture and homeland. Education should integrate cultural traditions and values.
- Time and financial resources are limited and education should be provided at homes, worksites, churches, or other community venues that reduce the burden for participants.
- Peer, family, and community reinforcement is important and may encourage proper diabetes self-management. Community health workers, peer educators, and community-based/church-based interventions have been shown effective in other minority communities and may be effective with the Marshallese.
- There is significant stigma attached to having diabetes in Marshallese culture. Marshallese find it difficult to disclose that they have diabetes. Personal outreach and education in the family or church may strategically overcome this barrier. At the same time, broad community education and action is needed to reduce the stigma of diabetes.
- Language is a significant barrier for education because many Marshallese do not speak English. Diabetes education should be provided in Marshallese as well as English.

Table 2

Implications for Health Education and Policy

<u>Beliefs and Perceptions</u>	<u>Implications for health education and policy</u>
Collectivist Culture-Strong Influence of Peers	Community-Level and Family-Level DSME
Family, Elders, and Community	Interventions rather than Individual DSME
Shame and Stigma of Diabetes	Foster growing desire to lift stigma of diabetes
Resistance to Adopting American Culture	Culturally-appropriate DSME that is consistent with traditions and values
Distrust of U.S. Healthcare	Cultural competency training for healthcare providers
<u>Structural Barriers</u>	
Transportation	Social service providers, charities and churches work collaboratively to increase transportation options
Lack of Health Insurance	Restore Medicaid eligibility
Cost of Healthy Foods, Medications, Etc.	Social service providers, charities and churches work collaboratively to provide financial assistance to help meet needs, e.g., prescription payment assistance, healthy foods offered by food pantries
Language	Hire more bilingual Marshallese/English staff at healthcare and social service providers and offer diabetes education in Marshallese
Time	Provide classes in homes, worksites, and/or community locations to integrate with their day