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Cultural Adaptation of Diabetes Self-Management Education for Marshallese Residing in the United States: Lessons Learned in Curriculum Development

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Abstract

Background—Type 2 diabetes is a significant public health problem, with U.S. Pacific Islander communities bearing a disproportionate burden. The Marshallese are a Pacific Islander community that has significant inequities in diabetes, yet few evidence-based diabetes interventions have been developed to address this inequity.

Objectives—We used a community-based participatory research (CBPR) approach to adapt an evidence-based diabetes self-management education (DSME) intervention for the Marshallese.

Methods—Our team used the Cultural Adaptation Process Model, in addition to an iterative process consisting of formative data and previous literature review, and engagement with community and academic experts.

Lessons Learned—Specific cultural considerations were identified in adapting DSME components, including the dichotomous versus gradient conceptualization of ideas, the importance of engaging the entire family, the use of nature analogies, and the role of spirituality.

Conclusions—We identified key cultural considerations to incorporate into a diabetes self-management program for the Marshallese. The insights gained can inform others' work with Pacific Islanders.

Keywords

Community-based participatory research; community-engaged research; health disparities; health equity; minority health; Marshallese; Pacific Islanders; diabetes

Type 2 diabetes is a significant public health problem, with 44.3 million Americans diagnosed[1] and causing an economic cost of $245 billion.[2] The prevalence of type 2 diabetes is expected to increase, with an estimated 60.5 million in the United States and 642 million globally by 2040.[1] Unfortunately, there are gross racial/ethnic inequities in diabetes prevalence, with Pacific Islander communities in the United States and U.S.-Affiliated Pacific Islanders bearing a disproportionate burden of diabetes, with estimated rates of 15% to 50% compared with 8% of the general U.S. population (McElfish P. Unpublished Health Screening Data from August 2012 to November 2013. Springdale and Fayetteville:

University of Arkansas for Medical Sciences Northwest; 2012–2013).[1,3–10] The focus of this paper is on one Pacific Islander community: U.S.-residing Marshallese Islanders.

To evaluate strategies for reducing type 2 diabetes inequities, it is important to understand historical relationship between the Republic of Marshall Islands (RMI) and the United States. The RMI is a group of small islands that were used for the U.S. Nuclear Testing Program from 1946 to 1958 to test a payload equivalent to 7,200 Hiroshima-sized bombs.[11–14] Consequently, the RMI has one of the highest levels of nuclear contamination in the world.[12] People who inhabited the islands that were bombed were relocated, but the people living on near by islands were not relocated. After the bombings, U.S. scientists set up Project 4.1 to study the effects of nuclear radiation on humans.[15–18] Marshallese who were exposed to the nuclear radiation were interned on an island to be studied. The studies were conducted without the informed consent of and without translation of the information into the Marshallese native language.[11] Literature documents the effects of nuclear testing on the Marshallese community as expressed in songs, art, and stories; in the creation of new words; and in Marshallese health beliefs and behaviors.[11,19,20] Similar to other cultures marked by historical trauma, the Marshallese exhibit distrust of health researchers.[13,15–19]

The RMI was a U.S. Trust Territory from 1947 until 1986. In 1986, the RMI signed a Compact of Free Association (COFA) agreement with the United States that recognized the RMI as an independent nation.[1] The COFA allows Marshallese to move to the United States to live, work, and study without a visa or permanent resident card[1,2]; however, COFA migrants are not eligible for Medicaid.[1] The Marshallese began moving to Arkansas after the COFA for employment,[4] and approximately 12,000 residents live in northwest Arkansas, the home of the largest population of Marshallese in the continental United States.[5] Among the Marshallese residing in Arkansas, rates of diabetes have been documented at approximately 32% (McElfish P. Unpublished Health Screening Data from August 2012 to November 2013. Springdale and Fayetteville: University of Arkansas for Medical Sciences Northwest; 2012–2013).[21]

Despite the health inequities experienced by the Marshallese, research with Marshallese has been limited because of data aggregation and historical trauma.[11,22] Most research aggregates data on Marshallese and other Pacific Islander groups with Asian Americans.[22–28] Aggregating these heterogeneous racial and ethnic groups has resulted in Marshallese and other Pacific Islanders groups becoming an invisible population.[22,27] Thus, there is a weak body of evidence to guide service planning and decision making in health services.[22] The few evidence-based diabetes management interventions for the Marshallese that have been conducted reported limited success due to high attrition (McElfish P. Unpublished Health Screening Data from August 2012 to November 2013. Springdale and Fayetteville: University of Arkansas for Medical Sciences Northwest; 2012–2013) and low compliance with intervention protocols involving blood glucose checks and medication adherence (McElfish P. Unpublished Health Screening Data from August 2012 to November 2013. Springdale and Fayetteville: University of Arkansas for Medical Sciences Northwest; 2012–2013).[7] Clearly, an evidence-based intervention that is culturally appropriate and builds on the strengths of Marshallese communities is needed to address the diabetes inequities present within this unique population.[29,30] In this paper, we describe how our team used a

CBPR approach to develop a culturally appropriate, evidence-based diabetes self-management intervention for U.S.-residing Marshallese. Our process was informed broadly by the three phases of the Cultural Adaptation Process Model.[31] In the first phase, we developed a community–academic partnership committed to balancing the desire to reduce health inequities and maintain scientific integrity of the evidence-based intervention. Then, the CBPR team sought to understand the Marshallese culture. Finally, the collaborative team adapted the intervention in partnership with the Marshallese community, balancing cultural needs with fidelity to the evidence-based intervention. We list and discuss how specific cultural beliefs, attitudes, and behaviors informed our intervention. Key cultural considerations were incorporated into each component of a diabetes self-management program for the Marshallese.

Community–Academic Partnership

Our partnership began in 2012 when the University of Arkansas for Medical Sciences Northwest began working with the Marshallese community using a participatory process to understand community assets and needs. After 2 years of engagement, which included a broad-based mixed methods study and multiple focus groups to document the community's top priorities, the community chose diabetes as their top health concern and recommended a family approach to address diabetes.[32] Over the past 3 years, our partnership has conducted several pilot studies related to diabetes beliefs and behaviors.[20,33,34] The current paper describes our development of a family model of DSME.[35]

From our community–academic partnership, we created a Curriculum Adaptation Team (CAT) that included academic researchers (expertise in nutrition, health behavior, and education), community members (local community members with expertise as lay health educators and the Arkansas Coalition of Marshallese), and clinical experts (certified diabetes educator, endocrinologist). In addition, an Advisory Board provided ongoing input in the adaptation of the curriculum and the subsequent study. The Advisory Board consisted of academic researchers (expertise in anthropology), community members (Marshallese faith-based organizations advocacy organizations, patients, and family stakeholders) and clinical experts (certified diabetes educator, Marshallese family practice physician). In total, 14 Marshallese community partners were involved in the adaptation. These Marshallese community members included members with experience in health care, education, nonprofit management, faith-based organizations, and the Marshallese consulate. A total of nine academic partners were involved in the adaptation and provided expertise in diabetes management, anthropology, health behavior, intervention science, nutrition, and endocrinology.

Intervention Adaptation Process

Academic partners introduced the DSME to the community partners as a promising intervention to adapt for Marshallese Islanders. DSME is an evidence-based intervention designed to support individuals with type 2 diabetes to maintain blood glucose levels in a healthy range. DSME has improved biochemical (e.g., hemoglobin A1c) and psychosocial (diabetes self-efficacy) diabetes-related outcomes in the general population as well as in

minority populations.[36–44] Family models have shown some promise in improving diabetes-related outcomes in Hispanic and American Indian populations,[45,46] but a family model of DSME had not yet been adapted for Marshallese or other Pacific Islanders. Our team's family model of the DSME intervention consists of seven components: 1) healthy eating (complex carbohydrates, vegetables, fiber, protein, limited heart-healthy fats), 2) being active (30 minutes a day, 5 days a week), 3) monitoring blood glucose levels, 4) taking medication appropriately on a regular basis, 5) problem solving to maintain blood sugar levels in the targeted range, 6) reducing risks for diabetes-related complications (heart attack, stroke, kidney and nerve damage, vision loss), and 7) healthy coping with stress. These components are consistent with the DSME standards as described by the 2014 National Standards for DSME and outlined in the 2016 American Diabetes Association Standards of Medical Care in Diabetes.[36,47,48]

Curriculum adaptation was achieved through weekly meetings and 3 half-day planning sessions that took place over 7 months. All sessions included a certified diabetes educator, endocrinologist, and 3 to 12 Marshallese community members. A summary of the adaptation process is described herein.

The CAT began the DSME curriculum adaptation by reviewing the results of previously conducted focus groups and pilot studies regarding Arkansas Marshallese's diabetes beliefs and behaviors (n = 41).[20,34,35] The academic members of the CAT then conducted a broad literature review of previous health behavior interventions conducted with Marshallese groups, and a review of the published literature on Marshallese cultural beliefs, attitudes, and practices regarding health behaviors.[49] Information from the focus groups, pilot studies, and literature review was used to create a curriculum outline. The first author created the curriculum outline, which was later fine tuned by other CAT members. The outline included eight lessons that covered all recommended DSME components, with each lesson including an educational module, a personal testimony about the topic from a community member, and goal setting.

The CAT worked with the first author to fine tune the curriculum outline to define exactly how the educational modules should be presented (e.g., provide a physical model of the human body and its components to illustrate diabetes etiology, demonstrate healthy eating through facilitating a family meal), suggest who in the community could give testimonies on certain topics, and give feedback on how to facilitate goal setting (e.g., provide diagrams and photos to illustrate high and low sugar foods). After a draft of the curriculum outline was complete, the first author then drafted the first three lessons of the curriculum content, and underwent an iterative process of review and feedback with community and academic partners to refine the lessons. The team also reviewed elements outlined by the American Diabetes Association and discussed how to ensure all required elements were maintained while incorporating cultural beliefs and preferences.

The curriculum outline and first three lessons were presented during a meeting with the Advisory Board. Advisory Board members gave specific feedback for each lesson of the curriculum that included both cultural and general aspects to consider. For example, Marshallese community members on the Advisory Board explained that Marshallese

households include multiple generations, whereby households include aunts, uncles, and cousins. They also suggested culturally salient physical activities for inclusion in the curriculum. Academic members of the Advisory Board drew from their prior experience treating diabetes patients and recommended addressing the erroneous belief that taking insulin meant the patient's diabetes was worse than a patient who was on a non-insulin medication. The first author then revised the first three lessons and drafted the remaining lessons based on the outline and input from the Advisory Board.

The CAT revised the entire curriculum through an iterative process whereby the first author incorporated changes decided by the CAT over the course of several meetings. Community partners from the CAT then mock delivered the intervention to each other, provided additional input and feedback for refinement, and made final edits before curriculum launch.

Lessons Learned And Specific Cultural Adaptations Of The Intervention

The CAT and Advisory Board provided several key recommendations to incorporate into the adapted DSME curriculum. These cultural considerations were our lessons learned in creating an evidence-based diabetes self- management intervention designed for Marshallese residing in the United States, and are presented in Table 1. Specific cultural components were recommended for adaptation of the seven key components (healthy eating, being active, monitoring blood glucose, medicine, problem solving, reduce complication, and coping with stress) of the DSME curriculum.

Common to many participatory partnerships, disagreements arose during the adaptation process. The team used two guiding principles to resolve disagreements. Academics agreed to trust the broad representation of Marshallese community members regarding cultural ideas, even when it was counterintuitive to academic training, and Marshallese community members agreed that the adapted DSME would include all requirements of the American Diabetes Association's standards. Through much discussion and debate, the CBPR team was able to join the wisdom of the community with the medical knowledge of the health care providers and researchers. The result was a culturally adapted curriculum that maintains scientific integrity of the DSME evidence-based intervention. Particular strengths of the typical Marshallese diet were identified to emphasize in the healthy eating component (i.e., grilled and steamed seafood). In addition, aspects of the diet that may serve to deter healthy eating efforts were also identified (i.e., high salt and sugar intake, high refined carbohydrate intake). To mitigate the typically high intake of simple carbohydrates, community partners and experts recommended that the cultural perception of carbohydrates as filling be modified through emphasizing the intake of complex carbohydrates, and education about fiber and non-starchy vegetable intake as foods to bring satiety. According to our community experts from the CAT and Advisory Board, Marshallese in the United States typically do not eat fruit because the fruits available in the United States are different from the fruits eaten on their home islands; thus, Marshallese in the United States are reluctant to eat fruit they are unfamiliar with. Revisions to the curriculum included the gradual incorporation of fruit as snacks in the daily diet. Marshallese community members on the CAT and Advisory Board discussed the Marshallese's tendency to view some concepts dichotomously instead of in gradations, and made further recommendations that this be taken into account when

illustrating healthy food patterns (healthy foods vs. unhealthy foods instead of variations of nutritional value). The Marshallese's tendency to view some concepts dichotomously (e.g., healthy vs. unhealthy) is separate from the process of behavior change, whereby slow introduction to new behaviors, including consuming more fruits and vegetables, was recommended by community experts. Marshallese community partners also advised respecting the Marshallese's spiritual beliefs through incorporating their ideas of God giving strength to make healthy choices, including substitutions of healthy foods (e.g., brown rice instead of white rice), slowly introducing new healthy foods (e.g., vegetables), and consuming reasonable portion sizes.

Regarding the DSME component of being active, Marshallese community members on the CAT and Advisory Board explained that executing physical activity without a purpose was considered foreign in the Marshallese community. Many Marshallese people considered the physical activity they performed while at work or working at home as sufficient. Engaging in physical activity for physical activity's sake or for positive health benefits was not consistent with the community's cultural physical activity norms. Thus, Marshallese community partners recommended physical activities that would be consistent with Marshallese's cultural beliefs and practices, including playing sports such as softball, volleyball, and basketball, and cleaning or yard work. The type of physical activity conducted was typically dependent on the age of the person; thus, specific suggestions for physical activity were made for two broad age groups (< 40 and ≥40). Recommendations included suggesting grandparents take their grandchildren to the parks and play with them instead of watching them play (e.g., the grandparent can help the grandchild climb up the ladder to the slides and then walk to the other side to retrieve the grandchild). Another recommendation was having grandparents walk their grandchildren to the bus stop for school. Consistent with spiritual beliefs surrounding healthy eating, spiritual beliefs of God providing strength for physical activity was a common component in Marshallese culture, and therefore incorporated into the curriculum.

Monitoring glucose levels regularly is an essential component of diabetes self-management, and Marshallese community members on the CAT and Advisory Board recommended integrating glucose monitoring strategies within a collectivistic family framework. This strategy ensured that the whole family was involved in helping the person(s) with diabetes monitor glucose levels. Grandchildren in conjunction with an adult family member were identified as influential family members to help remind grandparents with diabetes to perform glucose monitoring. To explain the importance of keeping blood glucose levels within a certain range, Marshallese community members on the CAT and Advisory Board recommended using analogies involving natural elements from the Marshall Islands, such as the sea tide. In our curriculum, optimum blood glucose levels are described through a fishing and tide analogy, whereby fishing is best when the tide is at the right level. If the tide is too low, it is hard to get the boat out. If the tide is too high, it is too dangerous to take the boat. Thus, the tide needs to be at a certain level for fishing to be best, just as blood glucose levels need to be within a certain range for the body's optimum health.

Marshallese community members on the CAT and Advisory Board described a differentiation between ‘Pacific natural’ and ‘Western’ medicine within Marshallese's

concept of medicine. ‘Pacific natural’ medicine, or medicine directly from plants, is preferred over ‘Western’ medicine. Thus, an emphasis of how Western medicine is derived from plants was recommended in discussing diabetes medications. For example, both Marshallese community and academic partners suggested that metformin, a common type 2 diabetes medication, be presented specifically as a medicine derived from the French Lilac plant with a picture of the plant for participants to see.[50] Marshallese community partners also explained that many Marshallese take ‘traditional’ medicine in the form of herbs or tonics, and encouraged intervention deliverers to acknowledge and respect the participants' use of traditional medicine, while at the same time encouraging the regular and appropriate intake of Western medicine. Academic partners incorporated education about how Western medicine works, particularly expectations concerning side effects and appearance. Marshallese community partners stated that often, when Marshallese take Western medicine and experience negative side effects, they assume that the medicine is not helping them and stop taking the medicine; thus, academic and community partners recommended that education regarding Western medicine emphasize that mild side effects are expected, and is the body's way of adjusting to the medication.

Marshallese community members on the CAT and Advisory Board also advised including education regarding the importance of refilling medications. Often, many Marshallese believe that taking all of medicine in one bottle will cure their diabetes. Thus, community partners emphasized the importance of education regarding the need to continue medication. In addition, community partners recommended education about Western medicine's packaging. Sometimes, Marshallese will receive medication refills in a different package and thus not take the medication because the pill is a different color or shape than the previous medicine. The CAT also suggested addressing the erroneous idea of associating insulin with poorer diabetes management or more advanced diabetes, because many Marshallese community members felt that taking insulin constituted a personal failure to manage their diabetes. Marshallese community members on the CAT and Advisory Board recommended emphasizing that God made each person unique and with different bodily needs. As a result, one person may need insulin, not because they had failed to manage their diabetes, but because their body responds best to insulin rather than other oral forms of medication.

Marshallese community members on the CAT and Advisory Board explained that, owing to the collectivistic nature of the Marshallese culture, many persons with diabetes do not like to share their symptoms with other family members for fear of burdening their family. They also described the fatalistic beliefs of some Marshallese community members that they have diabetes because it is God's will or punishment. To counter these beliefs, Marshallese community partners recommended emphasizing the importance of persons with diabetes to be open with their family about their symptoms for the long-term well-being of their entire family. If symptoms are identified and treated early on, bigger problems and subsequent stressors can be avoided for the family in the long term. Engagement of the entire family to facilitate successful diabetes management was also emphasized. The spiritual belief of God providing knowledge and desiring good health for all was also recommended to counter fatalistic spiritual beliefs.

Spiritual beliefs regarding God providing knowledge and strength to change behaviors were emphasized as a way to encourage regular self-care among Marshallese with diabetes to reduce complications. Consistent with the recommendation regarding the other components of the DSME, community CAT and Advisory Board members advised engaging the entire family to help the person(s) with diabetes practice self-care, with different family members playing distinct roles in supporting and enabling the person with diabetes to practice behaviors to reduce complications. For example, a child could be responsible for reminding their grandparent with diabetes to check their feet, a spouse could be responsible for scheduling a check-up with the eye doctor, and a cousin could be responsible for reminding the persons with diabetes to floss regularly.

Marshallese community members on the CAT and Advisory Board described the emotionally reticent nature of Marshallese, particularly among those outside of their family and community. Thus, community members recommended that the DSME intervention encourage emotional expressiveness and trust-building activities (e.g., initiating genuine conversations with families, showing a willingness to help) to facilitate conversations about stress and coping. Including God's encouragement for people to support one another was also recommended, in addition to using prayer as a coping mechanism.

In addition to identifying specific culturally appropriate components to each DSME element, community partners described other aspects of Marshallese culture to consider, including the Marshallese matriarchal culture with distinct gender roles. For example, women are the head of the household and the men are typically the breadwinners. Marshallese community members on the CAT and Advisory Board also emphasized the importance of oral over written communication, and stressed that the curriculum should be used as a tool for the interventionist to dialogue with Marshallese families. Consistent with this recommendation, community partners suggested that handouts be used at a minimum, allotting a maximum of one or two pages per session.

Conclusion

Our partnership identified several key considerations to recognize in adapting the DSME for U.S. residing Marshallese with type 2 diabetes, including the role of collectivism, importance of family engagement, spirituality, education about Western medicine, perspectives on physical activity, and specific dietary habits. These elements were used to develop a family model of DSME, which is currently being tested in a randomized, controlled trial.

Using a CBPR approach was crucial to adapting our curriculum, given the historical trauma of the Marshallese and their subsequent mistrust in researchers. By using a transparent process, we were able to honestly communicate with each other to develop a curriculum that resonated with our target population. Although there was much discussion and debate, and the adaptation took a significant number of meetings, the desire to address the diabetes inequities within the Marshallese community motivated the team.

The adapted DSME curriculum is currently being tested in a comparative effectiveness randomized control trial with 240 participants, and preliminary results are promising. DSME is a well-documented, evidence-based intervention that improves type 2 diabetes management.[42,51–56] Culturally appropriate implementations of DSME have improved diabetes management for some minority groups, including African Americans and Hispanics.[36,55] However, no one has successfully implemented DSME within the Marshallese population (McElfish P. Unpublished Health Screening Data from August 2012 to November 2013. Springdale and Fayetteville: University of Arkansas for Medical Sciences Northwest; 2012–2013).[7] Given the substantial burden of type 2 diabetes among Marshallese, we hope our work will inform researchers, practitioners, and clinicians who desire to improve the health of Marshallese and other Pacific Islanders in a culturally appropriate way.

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Table 1

Diabetes Self-Management Education

Component	Cultural Considerations
Healthy eating	Nutrition strengths in the food culture: Steamed and grilled fish, chicken, seafood, seaweed. Targets for nutritional change in the food culture: Salt, a lot of rice, sweet breads, sugary drinks, fast food. Nutrition beliefs: Carbohydrates seen as filling them up/satiety. Introduce Western fruit and vegetables as snacks to increase fruit intake. Concept are viewed dichotomously—yes versus no, versus in gradations, thus present examples of health foods versus non-healthy foods instead of in variation of healthiness God has given us strength to eat healthy through making small changes and additions to the usual diet, and through consuming appropriate portions sizes.
Being active	Physical activity needs to have a purpose—Walking to a neighbor's house to visit versus walking around a track or just walking to walk. God has given us strength to be physically active. Younger generation (age <40 years) physical activity suggestions: Sports, organized events. Older generation (ages ≥40) physical activity suggestions: Gardening, cleaning, play with children and grandchildren.
Monitoring blood glucose levels	Collectivistic (vs. individualistic) orientation, for example, the whole family needs to be involved and work together to be healthier versus just the person with diabetes. Set family-oriented goals where each member of the family has a role. Grandchildren have the power to change their grandparents' behaviors. Use analogies from nature in the Marshall Islands to describe difficult or new concepts (sea tide), such as why blood glucose needs to be in a certain range.
Medicine	Value of ‘pacific natural’ medicine from plants, from nature so emphasize how Western medicine comes from plants (e.g., metformin is derived from the French Lilac). Acknowledge and respect traditional Pacific treatments for diabetes. Education on Western medicine is needed: Even if a pill looks different it is the same medication; expect mild side effects and communicate any side effects with the provider—feeling worse does not mean the medicine is not working; taking generic is not a problem; make sure to get refills before you run out of medicine. God has made us unique so being on insulin does not mean that one's diabetes is worse than someone who is not taking oral medication.
Problem solving	Tendency to want to hide symptoms from family members so not to worry them. Engage the entire family to problem solve for the individual with diabetes. Need counter narratives to some spiritual beliefs that it is God's will or punishment that one has diabetes.
Reduce complications	God has given us knowledge to be healthy and that knowledge includes practicing self-care to reduce complications. Set family-oriented goals where each member of the family has a role.
Coping with stress	God encourages us to support one another; power of prayer to cope with stress. There will likely be a limited expression of emotion, so encourage expression of emotion (fear, overwhelmed, anxiety) through trust-building activities.