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# A Community-Based Participatory Approach to Understanding Health Beliefs, Policies, Barriers, and Solutions Related to the Health Disparities of Marshallese COFA Migrants in Arkansas.

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A Community-Based Participatory Approach to Understanding Health Beliefs, Policies, Barriers,  
and Solutions Related to the Health Disparities of Marshallese COFA Migrants in Arkansas.

This dissertation is submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in Public Policy

By

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## Abstract

Public policies have different effects on different populations groups and can perpetuate health disparities among some populations. My research utilizes community-based participatory approach to research in the examination of one unique population: the Marshallese. This dissertation research presents three papers that are part of a cohesive research agenda predicated on community-based participatory research (CBPR) to facilitate policy-oriented learning. My research can be used to inform health policy, health care services, and health education. Chapter Two presents the article titled: *Health Beliefs of US Marshallese Regarding Type 2 Diabetes*. This article explores the research question: what health beliefs related to diabetes influence diabetes self-management behaviors? Chapter Three presents the article titled: *Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act*. This article explores the research questions: for Marshallese living in the United States, 1) what is their understanding of and experience with the ACA and related health policies; 2) what effect do the ACA and related health policies have on participants' and the community's health? Chapter Four presents the article titled: *Family Model of Diabetes Education with a Pacific Islander Community*, and this article explores the feasibility of a family model of diabetes education was conducted in participants' homes with extended family members. This research, and my broader research agenda, seeks to improve health equality and decrease health disparities for the Marshallese community. The Marshallese community experiences many health disparities and constraints because to actions and policies of the US federal government, many of which must be addressed through changes in public policy. This dissertation research converges into a cohesive research agenda that is built on the principals of CBPR and is designed to fuel policy and programmatic action.

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## **Dedication**

To Shannon- My forever love

To Lee and Lance- My educational support

To Kelly and Lucas- My greatest joy

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## **Chapter One**

### **Introduction**

Public policy can be described as whatever “governments choose to do or not to do,”<sup>1(p2)</sup> and is further defined as “a relatively stable, purposive course of action followed by an actor or set of actors in dealing with a problem or matter of concern.”<sup>1(p2)</sup> Public policies have different effects on different populations groups. Health policy includes the “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society.”<sup>2</sup> As referenced throughout this dissertation, there are three separate and seemingly unrelated public policies that converge to affect the health of the Marshallese community. These three policies are: Patient Protection and Affordable Care Act (ACA); the Compact of Free Association (COFA); and the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA). My research will utilize community-based participatory research (CBPR) as a means of understanding these policies’ effect, addressing the disparities created by the policies, and fueling policy advocacy through policy-oriented learning. Within Chapter One, I will: 1) provide background information about the target population and policies affecting the target population; 2) provide an overview of the dissertation’s organization, including an outline of the three articles, corresponding research questions, and target journals; 3) discuss the research approach and how the three papers fit together; and 4) discuss the significance of the research.

### **Background**

Pacific Islanders are the second fastest growing population group in the United States.<sup>3</sup> The Pacific Islander population grew by 140% from 1990 to 2000<sup>3</sup> and 40% from 2000 to 2010.<sup>4</sup> The growth in the Pacific Islander population is due to increased migration from the US Affiliated Pacific Islands (USAPI) because of natural disasters and limited health care and



education infrastructure.<sup>5-7</sup> The highest rate of Pacific Islander population growth is occurring in the southern part of the United States, including Arkansas, which experienced a 250% increase in the number of Pacific Islander residents between 2000 and 2010.<sup>3</sup>

### ***Public policies governing the USAPI***

Many USAPI migrants are from Micronesia. The USAPI consist of six jurisdictions within Micronesia including three US territories (American Samoa, the Commonwealth of the Northern Mariana Islands, and Guam), and three sovereign states (Federated States of Micronesia, Republic of the Marshall Islands, and Republic of Palau). The three sovereign nations are Freely Associated States. The United States gained control of the region (the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau) in 1947 as United Nations Trust Territories of the Pacific Islands (TPPI). Later, the United States signed the Compacts of Free Association (COFA) for the Republic of the Marshall Islands (1986), the Federated States of Micronesia (1986), and the Republic of Palau (1994).<sup>8-19</sup> The COFA provides the United States with exclusive military use and control of the region. In exchange, the United States provides COFA nations with funds for infrastructure development and the right to freely migrate to the US.<sup>20-22</sup> Citizens from the compact nations are known as COFA migrants, distinguishing them from immigrants subject to US Citizenship and Immigration Services.

### ***History between the United States and Marshall Islands***

To understand the policy and health care context of my research with the Marshallese community, it is important to understand the history between the United States and the Republic of the Marshall Islands. The Republic of the Marshall Islands consists of 1,156 individual islands and atolls in Micronesia. Between 1946 and 1958, the US Military tested nuclear weapons on

several of the Marshall Islands.<sup>23-25</sup> These tests were equivalent to 7,200 Hiroshima-sized bombs. The largest test, carried out in March 1954, had a yield of 15 megatons (over 1,000 times the strength of the bomb dropped on Hiroshima) and exposed Marshall Islanders to significant levels of nuclear radiation.<sup>23-35</sup> People who inhabited the bombed islands and atolls were relocated; however, Marshallese living on nearby atolls were not relocated and suffered immediate and long-term injuries and illnesses from exposure to nuclear fallout.<sup>23-60</sup> The Atomic Energy Commission lists the Republic of the Marshall Islands as one of the most contaminated places in the world,<sup>23</sup> and several studies demonstrate ongoing health effects from the nuclear testing.<sup>24,25,27-31,36-38,41,49-55,57,61,62</sup>

### ***Marshallese migration to Arkansas***

The Marshallese began migrating to Arkansas in 1986 after the COFA was signed. The relatively strong economy and low cost of living in Arkansas continues to attract the Marshallese community.<sup>63</sup> A local study conducted in Arkansas showed that half of the Arkansas Marshallese community rates the quality of the job market in Northwest Arkansas as “good.” The largest employer of the Marshallese in Arkansas is the poultry industry; 76% of employed Marshallese individuals work for Tyson Foods, Georges, and Butterball.<sup>63</sup> Although most came for work opportunities, 12% came to Arkansas for educational purposes.<sup>63</sup> Some have entered college at the University of Arkansas and Northwest Arkansas Community College. The Marshallese student population in Northwest Arkansas schools has grown steadily over the past several years. Currently, there are over 2,000 Marshallese students enrolled in the Springdale school district. Ninety-three percent (93%) of these students report speaking Marshallese at home.

While most Marshallese are employed, poverty is high among the Marshallese population in Arkansas.<sup>63</sup> Over one-third (34%) of the Marshallese in Arkansas live in poverty. In 2010,

29.7% of Other Pacific Islanders (which includes the Marshallese population) in the United States lived in poverty, compared to 9.9% of non-Hispanic whites, 23% of Hispanics, and 25.8% of African Americans.<sup>64</sup> In Arkansas, 41.8% of Native Hawaiians and Other Pacific Islanders live in poverty. This is higher than the Arkansas poverty rate for non-Hispanic whites (9.9%), African Americans (27.4%), Hispanics (31%), American Indians and Alaskan Natives (25%), and Asian Americans (12.6%).<sup>64</sup> Low-wage employment in the poultry and manufacturing industries, low levels of education, lack of health insurance, and lack of English proficiency characterize the Marshallese in Arkansas as an immigrant community struggling to move up the socio-economic ladder, encountering language, cultural, financial, and health barriers.<sup>63</sup>

### ***Public Policies most relevant to the Marshallese community***

As COFA migrants, Marshallese are legally considered “nonimmigrants without visas.”<sup>63</sup> The vast majority of COFA migrants live in the United States as noncitizens and cannot vote. COFA migrant status limits their access to many health and public benefits, as well as their ability to influence the policy process.<sup>65-67</sup> Prior to the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), commonly referred to as welfare reform, COFA migrants were eligible for federally-funded health care programs including Medicaid and the Children’s Health Insurance Program.<sup>66,68</sup> However, under the PRWORA, COFA migrants were excluded from the category of “qualified immigrants” for purposes of eligibility for federal public benefits including Medicaid.<sup>66,69,70</sup> Medicaid is a federal program that provides health insurance to low-income populations in the United States.<sup>71</sup> Over the past decade, benefits have been restored for other groups of legal immigrants; however, benefits for COFA migrants have not been restored. Experts believe that they have become an invisible population.<sup>65-67</sup>

### ***Health care reform policy***

The Patient Protection and Affordable Care Act (ACA) became law in March 2010. The ACA was later upheld by the Supreme Court in June 2015.<sup>72</sup> The law provides health insurance options for many citizens and legal residents of the United States<sup>73</sup> and creates marketplaces where people can purchase subsidized health plans. The law also requires legal residents to gain and maintain health insurance coverage.<sup>74</sup> The ACA offers states the option to expand Medicaid to more low-income (133% of poverty level) residents. Arkansas chose to expand Medicaid<sup>75</sup> through a unique model that creates the Health Care Independence Program, which is referred to as the Private Option. The Private Option provides premium assistance to low-income (133% of poverty level) residents who purchase private coverage in Marketplace Qualified Health Plans.<sup>75,76</sup> These programs have reduced the uninsured rate. Nationally, the uninsured rate has dropped by 3.5%, from 17.3% to 13.8%. In Arkansas, the uninsured rate has been reduced by half from 22.5% to 11.4%.<sup>77</sup> Marshallese living in Arkansas are eligible for the broad premium assistance provided under the Affordable Care Act based on income, but they remain ineligible for Medicaid, Children's Health Insurance Program or the premium assistance provided under Arkansas' Private Option- Medicaid Expansion.<sup>68,78,79</sup>

### ***Health disparities***

The Marshallese population suffers from a significant and disproportionate burden of type 2 diabetes. The prevalence of type 2 diabetes in the Marshallese is among the highest of any population group in the world.<sup>80-86</sup> My thorough review of local, national, and international data found estimates of diabetes in the Marshallese population (both populations living in the US and the Marshall Islands) ranging from 20% to 50% compared to 8.3% for the US population and 4% worldwide.<sup>83-86</sup> In 2012, University of Hawaii and University of Arkansas for Medical Sciences

independently documented diabetes in 130 US Marshallese (56 in AR and 74 in HI).<sup>87</sup> The percentage of Marshallese with severely uncontrolled diabetes (HbA1c levels  $\geq 9\%$ ) was  $\sim 29\%$  at both sites. When pre-diabetes (HbA1c 5.7–6.4%) through severely uncontrolled diabetes (HbA1c  $\geq 9\%$ ) are included as disease, prevalence rates in the two groups were 68% and 69.5%, respectively.<sup>87</sup>

In addition, the Marshallese suffer disproportionately from Hepatitis B, tuberculosis, and Hansen's disease.<sup>88-96</sup> Little prevalence data is available on Marshallese because much of the data that is available is aggregated in a broad group of Asian and Pacific Islander; however, those studies that are available estimate that 10–16% of the Marshallese population is infected with chronic HBV (positive for hepatitis B surface antigen or HBsAg).<sup>91,95,96</sup> One study in Arkansas shows the prevalence of chronic HBV in pregnant Marshallese women in Arkansas at 10.4%, in stark contrast with a prevalence of 1% in the general population.<sup>95</sup> While Hansen's disease has been eradicated in much of the world ( $<1$  per 10,000), Marshallese have the highest rates of Hansen's disease in the world ( $\sim 11$  per 10,000), and Arkansas has the most cases of Marshallese with Hansen's Disease in the United States, with 46 cases among a population of  $\sim 10,000$ .<sup>95</sup> Marshallese mothers in the US also have high rates of low birth weight babies (8.4%) and preterm birth (18.8%).<sup>97</sup> Further exacerbating these disparities, Marshallese often do not seek health care services until their disease or condition reaches a crisis stage.<sup>98,99</sup>

### ***Diabetes self-management education***

Diabetes self-management education (DSME) is an evidence-based program that has been shown effective in reducing diabetes complications. Prior cost/benefit analyses of DSME programs have shown positive net benefits.<sup>100-103</sup> Klonoff and Schwartz documented that for every \$1 spent on DSME, there was a net savings of up to \$9.<sup>104</sup> Duncan et al found that

commercially insured members who use DSME reduced cost to their insurers by 5.7% compared to those members who do not participate in diabetes education.<sup>101,102</sup> Medicare members had a significantly higher cost benefit and showed a 14% cost reduction.<sup>101,102</sup> A systematic review conducted by Boren et al. showed that DSME reduced costs and produced net savings.<sup>103</sup> This review also documented that for the privately insured population there was even greater savings.<sup>103</sup> In this study, the group that did not participate in DSME had 12% higher costs than the group who received DSME.<sup>103</sup> Finding a cost-effective strategy to address diabetes is of considerable importance to the disparate Marshallese population, as well as public and private insurers.

Previous pilot studies suggest that culturally targeted diabetes interventions that include family members can have positive effects on a range of diabetes outcomes for both patients and their family members.<sup>105,106</sup> Hu Wallace et al's (2013) study of a family-based diabetes intervention for Hispanic patients demonstrated positive outcomes including reduced HbA1c, increased diabetes self-efficacy, increased family support for patients, increased diabetes knowledge, and lower BMI for family members.<sup>106</sup> Mendenhall et al (2011) showed improved health outcomes for urban American Indian patients with diabetes who participated in the six-month Family Education Diabetes Series (FEDS).<sup>105</sup>

An exploratory study of Hispanic patients with diabetes and their family members found two main themes emerged from family members: "we can provide support," but "we lack knowledge" on how to provide that support.<sup>106,107</sup> A study of perceived support among African American women with type 2 diabetes revealed that the women perceived their families as caring, but not as understanding of their support needs.<sup>108</sup> The authors recommend family education on diabetes to address discordance between the patient and her family.<sup>108</sup> Notably,

when asked if the entire family needed to change eating habits in order for the patient to change her diet, the majority of participants answered emphatically “yes”.<sup>108</sup>

While there is no existing literature on the efficacy of family-based diabetes interventions for Pacific Islanders or Marshallese specifically, the Marshallese culture is strongly family-centered, and patient and community stakeholders believe a family model of diabetes education has a high potential for improving diabetes outcomes in this population. Marshallese community members I have interviewed emphasized that “family comes first.” Family networks are the main source of support and guidance in Marshallese culture.<sup>107</sup> Marshallese community members state that in order to be effective, changes in diet and lifestyle activities to improve diabetes outcomes must be *family changes*.<sup>107</sup> Integrating family members into diabetes interventions can provide support to patients, develop healthy family behaviors, and promote diabetes self-management for patients.

### ***Health Belief Model***

To improve diabetes self-management behavior among a group with a unique culture and history, it is necessary to understand the beliefs and perceptions underlying behavior. There is limited literature on Marshallese diabetes-related behaviors.<sup>109,110</sup> The Health Belief Model is an empirically supported conceptual framework for understanding health behavior,<sup>111,112</sup> and is a particularly effective tool when researchers seek to understand a population’s cultural beliefs prior to adapting health behavior interventions.<sup>113-116</sup> The six dimensions of the Health Belief Model are: 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, 4) perceived barriers, 5) cues to action and 6) self-efficacy.<sup>111,112,114</sup>

The construct of perceived susceptibility describes a person’s perception of the probability of getting a disease or health condition. The construct of severity refers to the perceived

seriousness of a disease. These two constructs make up perceived threat. In addition to perceived threat, behavior change is influenced by a person's perceptions of the benefits of taking the prescribed actions. The construct of barriers describes the perceived and structural barriers to taking the prescribed action. Perceived benefits and barriers involve beliefs about the positive and negative consequences of taking a particular health action, and together, create an internal cost vs. benefit analysis.

The Health Belief Model also describes cues to action as a construct. Cues to action serve as instigators to the prescribed action. Cues to action can be internal (i.e. a pain) or external (i.e. a doctor recommendation). Self-efficacy is a more recent addition to the Health Belief Model.<sup>111</sup> and takes into account that a person must feel capable of overcoming perceived barriers in order to take a health action.

### **Organization of the dissertation, research questions, and rationale for the articles**

This dissertation research is presented in five chapters with three journal articles comprising Chapters Two, Three, and Four. Collectively, the research uses a community-based participatory approach to help fill a gap in the current literature related to the health beliefs, policies, and diabetes care for Marshallese COFA Migrants in Arkansas.



**Table 1: Articles, research questions and target journals**

Title	Research questions	Target journal
<i>Health Beliefs of US Marshallese Regarding Type 2 Diabetes</i>	What health beliefs related to diabetes influence diabetes self-management behaviors?	<i>Health Education</i> Impact factor: 2.508
<i>Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act</i>	For Marshallese living in the United States, 1) what are their understandings of, and experiences with, the ACA and related health policies; 2) what effect does the ACA and related health policies have on participants' and the community's health?	<i>Journal of Health Care for the Poor and Underserved</i> Impact factor: 1.526
<i>Family Model of Diabetes Education with a Pacific Islander Community</i>	What is the feasibility of a family model of diabetes education conducted in participants' homes with extended family members?	<i>Diabetes Care;</i> Impact factor: of 8.1

The article in Chapter Two is titled: *Health Beliefs of US Marshallese Regarding Type 2 Diabetes*. The research question is: what health beliefs related to diabetes influence diabetes self-management behaviors? The Health Belief Model is a well-documented theoretical framework for understanding why people do or do not engage in recommended health behaviors.<sup>113,114</sup> The Health Belief Model is often used as a first step in understanding a current set of behaviors prior to developing health education interventions.<sup>113,114</sup> This article builds upon the research conducted with the Health Belief Model in other populations and fills a gap in the current literature related to Marshallese beliefs related to type 2 diabetes.<sup>113-117</sup>

The article in Chapter Three is titled: *Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act*. Policies often have different effects on different groups of people, and the Marshallese population is uniquely affected by the ACA. The research questions are: for Marshallese living in the United States, 1) what are their understandings of, and experiences with, the ACA and related health policies; 2) what effect does the ACA and related

health policies have on participants' and the community's health? While other articles have documented the legal aspects of the ACA, they are all essays that do not include perspectives of the Marshallese. Yanow (2000) argues that in addition to asking "what are the costs of a policy," policy analysis can and should include a question of "what are the meanings of a policy?"<sup>118</sup> Yanow suggests an interpretive approach to sense-making in policy analysis, which includes qualitative processes of engaging a broad range of stakeholders to understand the values, beliefs, and feelings about a policy.<sup>118</sup> This paper builds upon the interpretative policy approach, and documents a gap in the literature related to Marshallese COFA migrant's understanding and experience of the ACA and related health policies, as well as the effect of the ACA and related health policies on the Marshallese community.

The article in Chapter Four is titled: *Family Model of Diabetes Education with a Pacific Islander Community*. The research question for Chapter Four is: what is the feasibility of a family model of diabetes education conducted in participants' homes with extended family members? Diabetes self-management education (DSME) is an evidence-based program that has been shown effective in reducing diabetes complications. Cost/benefit analyses of DSME programs have shown positive net benefits.<sup>101,102,104,119</sup> Previous pilot studies suggest that culturally targeted diabetes interventions that include family members can have positive effects on a range of diabetes outcomes for both patients and their family members.<sup>105,106</sup> However, there is no existing literature on the efficacy of family-based diabetes interventions for the Pacific Islanders community, and this study builds upon the existing literature related to DSME and family models of diabetes education and fills an important gap in the literature for Pacific Islanders with significant health disparities.

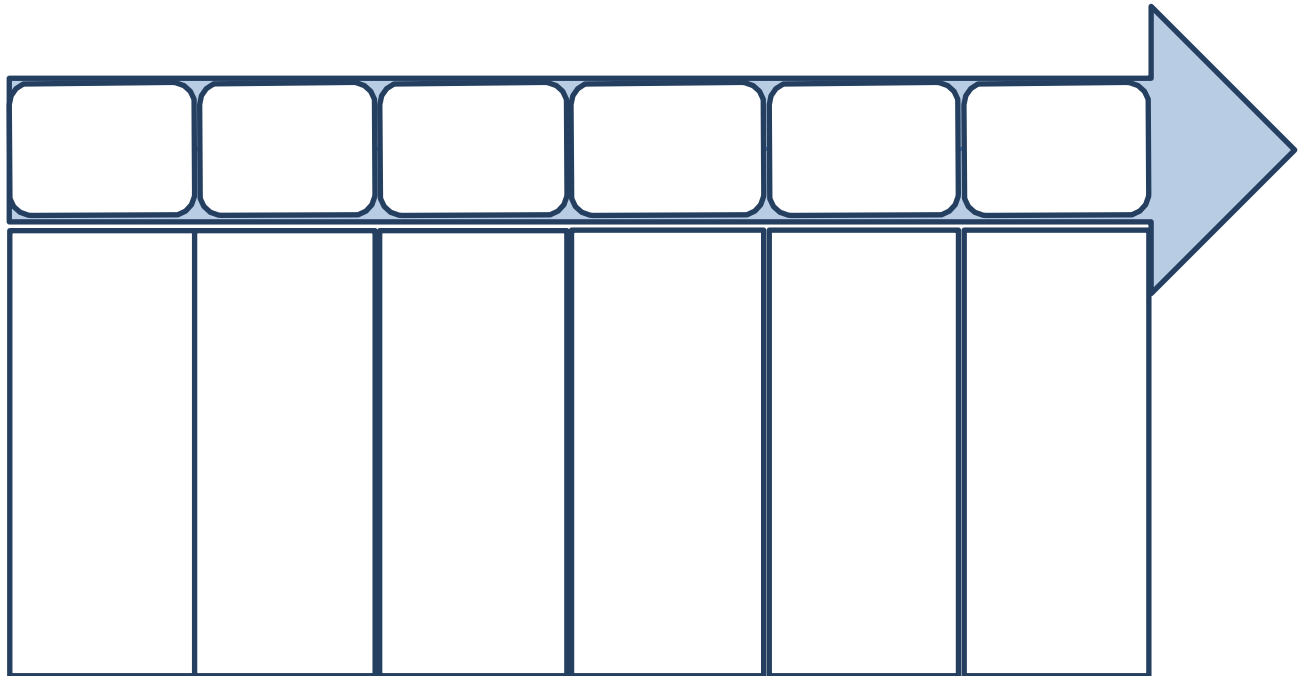
## **Research approach and how the three papers fit together**

### ***Community-based participatory approach***

This dissertation research utilizes a community-based participatory research (CBPR) approach. CBPR, also referred to as community-engaged research, action research, participatory action research, community-based action research, patient centered participatory research, as well as other terms,<sup>120-126</sup> is promoted as a way of addressing health disparities and promoting health equity in disenfranchised communities.<sup>120-122,124,126-129</sup> CBPR uses participatory approaches to research that engage nontraditional partners (patients, nonprofits, disenfranchised communities) in the research process. CBPR honors the unique contributions that these stakeholders bring to problem/research question identification, research design, research conduct, data analysis, interpretation, and dissemination.<sup>121,122</sup>

As Gaventa describes, CBPR has turned the traditional research paradigm upside down.<sup>130</sup> Traditionally, a principal investigator within an academic institution determines the research questions, tools, methods, and interventions, as well as the outcomes that are valued, documented, and disseminated; CBPR shares the power and responsibility for these decisions and processes with community stakeholders.<sup>120-122,126,131</sup> While pure CBPR is often community driven and involves community stakeholders in all aspects of the research process,<sup>120-122</sup> CBPR can be conceived on a continuum (see Figure 1) that on one end includes community involvement in a limited manner and at the other end involves full community engagement in all aspects of research.

**Figure 1: Community engagement continuum.** Adapted from Collman, GW. Community-based approaches to environmental health research around the globe. *Reviews on Environmental Health* 29(2) 125-128. March 2014, and *Principles of Community Engagement – Second Edition*. ATSDR. <http://www.atsdr.cdc.gov/communityengagement>



CBPR is not a research method and utilizes quantitative, qualitative, and mixed methods. CBPR is an approach to research.<sup>121,122</sup> As outlined by Israel et al.,<sup>122</sup> the core principles of CBPR are: 1) it is participatory; 2) it is cooperative, engaging community members and researchers in a joint process in which both contribute equally; 3) it is a co-learning process; 4) it involves systems development and local capacity building; 5) it is an empowerment process through which participants can increase control over their lives; and 6) it achieves a balance between research and action. Stringer (2007) outlines similar principles, stating that community-based action research is democratic, equitable, liberating and life enhancing.<sup>123</sup> CBPR uses many

community development techniques to facilitate an inclusive process predicated on identification of both community assets and needs.<sup>120-126,130-136</sup>

The three articles fit together into a cohesive research project that is predicated on the principals of CBPR and a research agenda that fuels policy, clinical, and programmatic action.<sup>121,122</sup> There is a growing body of literature that shows that CBPR can be effective in facilitating policy change.<sup>137-152</sup> While public policy is relatively stable,<sup>153-158</sup> research conducted using CBPR can help in this policy-oriented learning process. In addition, the community organizing nature of CBPR has also been shown to help communities convene for political action.<sup>120,129</sup> The overall goal of the research is to improve health equality and decrease health disparities for the Marshallese. Collectively, the three articles will advance: 1) awareness of the health beliefs (including discussion of policy barriers), 2) understanding of the policy effects on Marshallese COFA migrants, and 3) knowledge of the feasibility of a program to address type 2 diabetes in the Marshallese Community.

The Advocacy Coalition Frame (ACF) provides significant insight on how my CBPR research can be used to advance the policy agenda of the Marshallese. The ACF describes how political participants align themselves with others who have similar policy core beliefs to form advocacy coalitions.<sup>155-157</sup> These advocacy coalitions can include a broad number of actors, including legislators, agency officials, interest groups, content experts, and individuals. The ACF conceptualizes policy making as a complex, iterative process which includes multiple actors who must specialize in order to focus their efforts and achieve results. The ACF posits that, in order for people to have influence in the policy process, they must join with others who have similar interests. According to the ACF, interest groups are organized around a policy domain. For issues to be brought forward and change to happen, advocacy collations (multiple advocacy

groups) converge around a policy issue. It is important to note that some of the groups may hold the issue being advocated for as a primary (core) belief, while others may hold it as a secondary belief. Additionally, groups may have different motivations for their advocacy of an issue. However, despite these differences, the groups come together around a coalescing issue to form an advocacy collation.<sup>155-157</sup> The ACF conceives the political system as being influenced by relatively stable parameters and external system events, with two critical paths to policy change. The first path is policy-oriented learning, and the second path is external shocks. Policy-oriented learning can be facilitated through CBPR that provides information to advocacy groups.<sup>155-157</sup>

Through the act of CBPR, local Marshallese are connected to larger advocacy coalition and my research can be utilized to define and document the problem and develop key messages, as well as to provide research results that can give a voice to the problem and facilitate policy-oriented learning to advocate for incremental policy changes. Below, I provide additional detail on how my CBPR work and these three papers specifically are connected through an effort to inform policy change.

### ***Helping connect local Marshallese to larger advocacy coalitions***

It is important to connect our CBPR efforts to larger advocacy organizations whose policy “core beliefs”<sup>155-157</sup> are consonant with our local efforts. By working together, we can have more power to effect change.<sup>155-157</sup> To do this, I have connected with other Arkansas advocacy groups: the Arkansas Minority Health Council and Arkansas Advocates for Children and Families. I anticipate that my research will be used by the Arkansas Minority Health Commission and Arkansas Advocates for Children and Families. We have already worked together to advocate for restoration of the Children’s Health Insurance Program (ARKids) and will continue to advocate for Medicaid. Specifically, the research helps document the health

disparities, reasons for the disparities and a possible solution for addressing type 2 diabetes health disparities. Nationally, I have connected our CBPR efforts to Asian Pacific Islander Health Forum, the White House Initiative on Asian and Pacific Islanders, and I have established relationships with the University of Hawaii. These national relationships have helped provide key messages (see below) for local and state level advocacy efforts. My research will help reinforce and provide key messages for local efforts as well as larger, national efforts.

### ***Research can be used to develop key messaging***

As Rocheford and Cobb<sup>159</sup> discuss, the policy problem as well as the policy solution need to be thoughtfully defined in order for a policy to be successful. In defining the problem and solutions, my research can be used to develop key messages.<sup>159</sup> The messages must also be broad enough to allow for multiple audiences.<sup>154,155,159,160</sup> The CBPR methods that I use combine both qualitative and quantitative methods which can be used to draft key messages. Specifically, in Chapter Three, I use interpretative policy analysis to illuminate the effect of current health policies on the lived experience of the Marshallese. As outlined in the ACF, policy-oriented learning involves advocacy coalitions educating policy makers to influence their position on a policy issue.<sup>155,156</sup> As a researcher committed to a community-based participatory approach, my research is conducted with a disenfranchised community to provide them with the information needed to educate policy actors.

### ***Additional public policy literature and CBPR approach***

In each of the three articles, the research can be used to help give “voice” to the health disparities and barriers faced by the Marshallese. Public policy theorists outline the importance of problem definition in agenda setting.<sup>154,155,158-161</sup> Rocheford and Cobb (1994)<sup>159</sup> posit that in order for a policy problem to reach the formal policy agenda it must be perceived as significant

and meaningful. In addition, for problems to make it to the public agenda, the issue should be seen as urgent.<sup>155,159,160</sup> To date, the problem of health access for Marshallese has not been well defined, and my research can help document the concerns of the Marshallese Community. There are many public policy theories that provide insight into why the issue has not gained a significant voice or presence on the national agenda. In the most simplistic view, Putnam's (1976) and Walker's (1966) elitist theories would posit that the average Marshallese citizen is too busy focusing on their more immediate lives and the things they conceive as important: jobs and food for their families, leaving little time for political action.<sup>162-164</sup> Bachrach & Baratz (1962), Gaventa (1982), and Cobb & Ross, (1997) put forth theories that offer a different explanation.<sup>160,161,165</sup> These theorists contend that the lack of attention to the concerns of Marshallese has created a power cycle that perpetually excludes this population from information and power needed to advocate (and perhaps even understand the COFA).<sup>160,161,165</sup> Not unlike initial images of the Appalachian region outlined in Gaventa's (1982) *Power and Powerlessness*, Marshallese suffer from a dual characterization that often perpetuates their exclusion.<sup>161</sup> Social Construction Theory outlined by Ingram, Schneider, and deLeon states "the allocation of benefits and burdens to target groups in public policy depends upon their extent of political power and their positive or negative social construction on the deserving or undeserving axis."<sup>155</sup> The three most common socially constructed views of the Marshallese populations are 1) happy, carefree and nice, 2) ignorance and laziness, and 3) morally perverse.<sup>166-168</sup> While one image may be positive and the two others negative, all the images construct Marshallese populations as having less power and influence, and two of the images present the Marshallese as being less deserving. As discussed in Chapter Four, the Marshallese cultural values and concepts of advocacy may also limit their voice.



By using CBPR to document the health concerns, I can help give voice to the health disparities of the Marshallese. These health disparities are caused in large part by the social determinates of health, including access to health care, which can be addressed by public policy. Through policy-oriented learning, my research can serve as a means to assist in policy change. Because of the community-based participatory approaches used to conduct the research, the community is better organized to advocate for itself.

### **Significance**

This research is important to health care providers and policy makers because it fills a current gap in published literature. The Marshallese in Arkansas are part of the rapidly growing population of Pacific Islanders in the United States.<sup>3</sup> Marshallese and other Pacific Islanders face significant health disparities and are underrepresented in health research.<sup>169-171</sup> Specific health information on Pacific Islanders is often obscured in aggregated data on Asian Americans and Pacific Islanders.<sup>169,170</sup> The Health and Human Services Action Plan to Reduce Racial and Ethnic Health Disparities recognizes the need for better health information on Pacific Islanders and recommends the development of research to address the needs of low-density populations including Native Americans, Asian Americans and Pacific Islanders.<sup>172</sup> There is little data on Pacific Islanders living in the United States and even less health information available on Marshallese specifically. While most Pacific Islanders in the United States live in Hawaii and California, many Pacific Islander subpopulations, including Marshallese, are dispersed across the United States to smaller southern and mid-western communities.<sup>3</sup> The populations in smaller southern and mid-western communities continue to grow at a rapid rate.<sup>3</sup>

The three papers make a significant contribution to the literature. There are a few articles published on the impact of the PRWORA and the Affordable Care Act on COFA migrants

(including Marshallese); however, these articles are essays and commentaries.<sup>68,173</sup> There is currently no published research on COFA migrants and the ACA using qualitative policy analysis approach. There is only one study on Marshallese's health beliefs related to diabetes, and it focuses solely on barriers, rather than the full Health Belief Model. There is a limited body of work on family models of diabetes management and no literature on family models in Pacific Islander communities.<sup>127,174-177</sup> In short, my research agenda and three-paper dissertation fills a gap in the literature. My research seeks to improve health equality and decrease health disparities for the Marshallese community by providing information that can be used for policy-oriented learning. The research can be used to inform health policy, health care services, and health education.

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## Chapter Two

### Health Beliefs of Marshallese Regarding Type 2 Diabetes

#### INTRODUCTION

This study identifies the underlying beliefs and perceptions that affect diabetes self-management behavior among the US Marshallese population. The Marshallese are a Pacific Islander group with a growing population in the United States. From 1946 through 1958, the US military tested nuclear weapons in the Marshall Islands. Cumulatively, these tests were equivalent to 7,200 Hiroshima-sized bombs.<sup>1-4</sup> The Atomic Energy Commission lists the Marshall Islands as one of the most contaminated places in the world.<sup>1</sup> In 1986, the Republic of the Marshall Islands signed a Compact of Free Association (COFA) agreement with the United States that permits Marshallese migrants to come to the United States without a visa or permanent resident card to live and work.<sup>5,6</sup> The COFA also provides the US government with a strategic location for ongoing military activity, which includes the Ronald Reagan Ballistic Missile Defense Test Site located on Kwajalein Atoll. This site is the central location of US missile defense and missile testing programs.<sup>2</sup> First drawn by employment in the poultry processing industry in the early 1990s, there is a growing community of Marshallese in northwest Arkansas.<sup>7</sup> Currently, the largest population of Marshallese living in the continental United States resides in Arkansas with ~10,000 residents.<sup>8</sup> Marshallese COFA migrants face many health inequalities as well as social, economic, and political disadvantages. Chronic diseases, particularly diabetes, are extremely high among the Marshallese.<sup>9-11</sup> Infectious diseases, including Hansen's disease (leprosy), hepatitis, and tuberculosis, have been documented at 10 times higher than the general population.<sup>12-15</sup> The rate of low birth weight babies and preterm birth babies born to Marshallese mothers is also significantly higher than other racial/ethnic groups in the United States.<sup>16</sup>

Furthermore, Marshallese in the United States are predominantly low-income, noncitizens with limited English proficiency facing a host of health care access problems and cultural barriers.<sup>17-19</sup> As COFA migrants, the Marshallese cannot vote, nor can they access many health safety net programs such as Medicaid.<sup>20</sup>

### **High rates of type 2 diabetes**

The Marshallese population suffers from disproportionate rates of type 2 diabetes. The Marshallese suffer from diabetes at a rate 400% higher than the general US population.<sup>9,10,21</sup> In the Marshall Islands, diabetes rates between 20% and 31% have been found among Marshallese adults on the two most populous islands.<sup>9,10</sup> A health assessment of Marshallese adults in the United States found 44.2% in Hawaii and 46.5% in Arkansas had diabetes. An additional 25.3% in Hawaii and 21.4% in Arkansas had pre-diabetes.<sup>22,23</sup>

### **The diabetes epidemic**

The US nuclear testing program in the Marshall Islands,<sup>2,24-31</sup> resulted in radiation contamination of the fish, vegetable, and fruit supply on the bombed atolls<sup>2-4</sup> and additional islands exposed to the nuclear fallout.<sup>2</sup> After the nuclear contamination, the United States provided food aid to Marshall Islanders, which consisted mainly of highly processed canned and packaged foods.<sup>2</sup> The majority of the food consumed in the Marshall Islands today is imported processed food, such as canned meats and rice. These foods continue to make up the preferred diet of the Marshallese in the United States.<sup>17,32</sup> The nutritional and health consequences of the nuclear testing, combined with a lack of health education, and health care access barriers, have contributed to a diabetes epidemic among the Marshallese population.<sup>17-20</sup>

## **Diabetes self-management behavior**

Diabetes self-management and prevention behavior is low among Marshallese in the United States.<sup>33,34</sup> Health care providers report that it is rare for Marshallese patients with diabetes to regularly perform blood glucose checks and take medications as prescribed.<sup>35</sup> Due to a lack of health insurance, information, and opportunity, few Marshallese have participated in diabetes self-management education (DSME).<sup>33,34,36,37</sup> Previous attempts to implement DSME among Marshallese in the United States have not been successful.<sup>33</sup> There is no known documentation of Marshallese participating in diabetes prevention programs.

## **Health Belief Model**

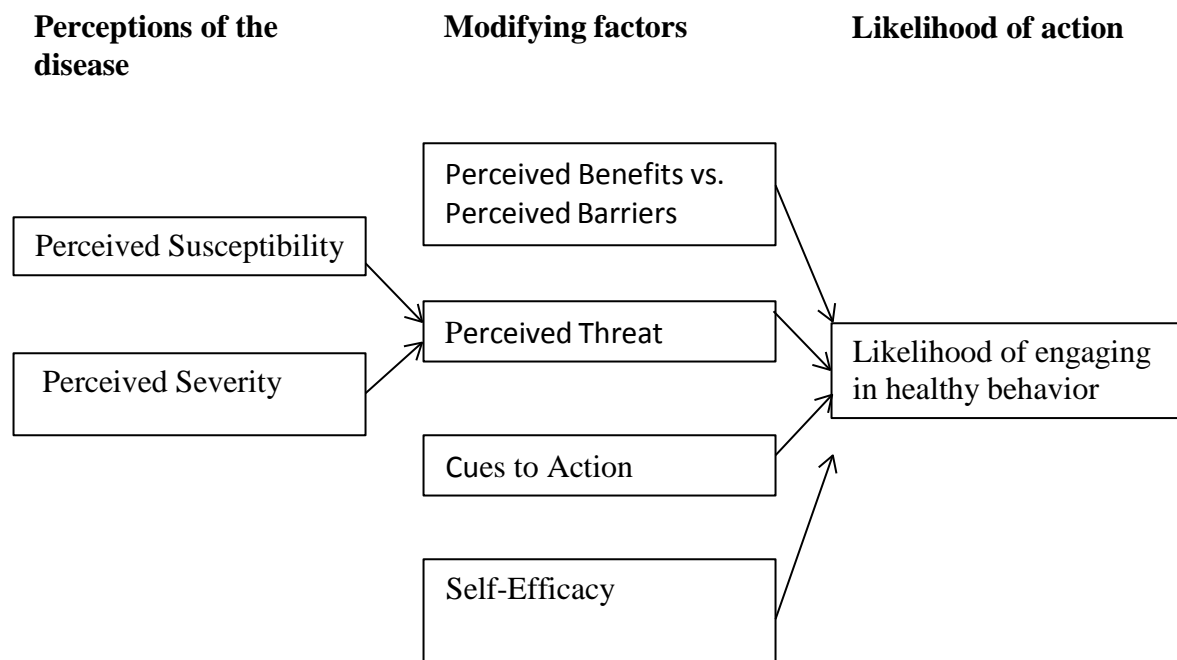
Diabetes self-management is most effective when aspects of culture and history are taken into account. It is necessary to understand the beliefs and perceptions underlying the group's behavior. There is limited literature on Marshallese behaviors related to diabetes.<sup>33,38,17</sup> The Health Belief Model is an empirically supported conceptual framework for understanding health behavior.<sup>39,40</sup> The six dimensions of the Health Belief Model are 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, 4) perceived barriers, 5) cues to action, and 6) self-efficacy.<sup>39-41</sup> The Health Belief Model is used to better understand why a person does or does not undertake health prevention or health management action.<sup>39,41</sup> The model can be useful for developing health behavior interventions.<sup>42,43</sup> The Health Belief Model can be particularly effective with ethnic and racial minority groups, because it assesses a person's cultural beliefs, perceptions, and values and provides valuable information that can be used to inform culturally appropriate interventions.

Perceived susceptibility refers to one's perception of the likelihood of getting a disease or health condition. Perceived severity refers to the perceived seriousness of a disease. Together,

perceived susceptibility and perceived severity are referred to as *perceived threat*. However, perceived threat alone does not lead to behavior change. Behavior change is influenced by a person's beliefs regarding the benefits of actions to reduce the threat of the disease, and by the perceived and structural barriers to action. A person's perceptions of the benefits and barriers create an intrinsic cost benefit analysis regarding the positive and negative consequences of taking a particular health action.

In addition, cues to action can serve as instigators to action. Cues to action can be internal (i.e. a cough) or external (i.e. a media campaign) and wide-ranging. Self-efficacy is a more recent addition to the Health Belief Model.<sup>39</sup> While the original five constructs explain changes in health behavior, particularly taking preventive health action,<sup>41</sup> the model is predicated on the concept that people must feel capable of overcoming perceived barriers in order to take a health action, and, therefore, self-efficacy has been added to the model.<sup>39</sup>

**Figure 1: Health Belief Model<sup>40,44</sup> Adapted from Glanz, Rimer, and Lewis 2002 and Rimer and Glanz, 2005**



## METHODS

An exploratory study design utilizing the qualitative method of focus groups was used to examine the research question: *What health beliefs related to diabetes influence diabetes self-management behaviors?* The focus group methodology allowed the research team to explore the topic with participants and observe rich discussion between participants.<sup>45-49</sup>

To recruit participants, the research team worked in collaboration with Marshallese community groups including: Arkansas Coalition of Marshallese, Gaps in Services to Marshallese Task Force, Marshallese pastors, and the local Republic of the Marshall Islands Consulate. Recruitment was also advertised on Facebook. Marshallese community members are high users of Facebook, and it is an efficient way to spread information to a large segment of the Marshallese community. Our community partners provided us with contact information for potential participants and they encouraged potential participants to contact members of the research team about the study. Participants were provided the opportunity to consent. Inclusion criteria included those who self-reported Marshallese and were 18 years or older.

Qualitative data was collected from a total of 41 participants using focus groups.<sup>46</sup> Two waves of focus groups were conducted using a sequential exploratory design in which the first wave of focus groups informed the next wave of focus groups. Each focus group was run by a lead researcher and a research associate. At least one of the bilingual Marshallese community co-investigators was present. The Marshallese community co-investigator provided translation, as appropriate. Each focus group had between four and nine people. The focus groups used a semi-structured interview guide with open-ended questions to allow participants to speak in-depth, yet ensure that all focus groups covered the same topics. The semi-structured guides were

constructed by the CBPR team, which included two Marshallese community co-investigators, and piloted with Marshallese CBPR stakeholders.

In the initial wave, two focus groups were conducted with a total of 15 Marshallese participants. The interview guide included broad questions concerning community health concerns and health access. In this first wave of focus groups, participants discussed the high rate of diabetes, health beliefs concerning diabetes, health care access barriers to diabetes care, and the lack of diabetes education, which they felt were the top health concerns of the community. These focus groups informed the second wave of focus groups. After on the first wave of focus groups and input from CBPR stakeholders, the CBPR team developed a semi-structured interview guide based on the Health Belief Model for the second wave of focus groups. This interview guide was designed in order to better understand which of the US Marshallese’s beliefs and perceptions of diabetes promoted or impeded diabetes self-management behaviors.

In the second wave, four additional focus groups were conducted with a total of 26 participants who either had diabetes or had a family member with diabetes. The guiding research question for the second wave of focus groups was: *For US Marshallese, what health beliefs related to diabetes influence diabetes self-management behaviors?*

## Figure 2: Study waves



- Total of 15 participants in two focus groups
- Self-reported Marshallese over age 18
- Semi-structured interview guide, questions related to overall health beliefs and health access (not disease specific)

- Total of 26 participants in four focus groups
- Self-reported Marshallese over age 18 who had diabetes or a family member with diabetes
- 
- Semi-structured interview guide, based on health belief model and barriers to diabetes self- management

The research team conducted all focus groups in private meeting rooms in Springdale, the city that is home to the largest population of Marshallese in Arkansas.<sup>50</sup> Focus groups ranged from four to nine participants per group. The duration of each focus group was about one hour. Each participant received a \$25 gift card as compensation for sharing their knowledge and experiences with the researchers.

### **Data analysis**

The data from each wave of focus groups were transcribed verbatim. The CBPR team coded transcripts for priori codes based on the constructs of the Health Belief Model and for emergent themes within those constructs. Codes were discussed, grouped, and then organized in a codebook<sup>51</sup> that described the priori and emergent codes. The CBPR team met five times to ensure coder agreement.<sup>52</sup> After the data had its final consensus codes, the CBPR team compared the coded data to see if there were significant differences between the six focus groups, and found that the themes were consistent between the two waves and six focus groups. The codes are presented in table 1:

<b>Table 1: Final codes</b>	
Priori codes based on Health Belief Model constructs	Emergent themes within priori constructs
Perceived susceptibility to diabetes	a) Inevitability
Perceived severity of diabetes	a) Death sentence b) Limits lifestyle c) Medical challenges d) Social stigma
Perceived benefits of diabetes self-management behavior	a) Generally positive b) Limited knowledge of benefits
Perceived barriers to diabetes self-management behavior	a) Limited health care access a. Medicaid b. Providers who see those without insurance b) Social stigma c) Lack of transportation d) Cost of healthy foods e) Cultural food practices
Cues to action	a) Diagnosis
Self-efficacy	a) Outside their control 1) Genetic 2) Nuclear testing b) Within their control 1) Nutrition 2) Exercise 3) Medication adherence c) Difficulty in adhering to recommendations d) Need for role model

Most importantly, the Marshallese community co-investigators provided feedback on the interpretations of codes to ensure the nuanced meaning of participants' responses were understood. The Marshallese community co-investigators' input was particularly crucial to ensuring that the findings and discussion presented accurately reflected Marshallese beliefs and perceptions about diabetes. To develop recommendations, the lead researcher shared findings with a broader group of 14 Marshallese CBPR stakeholders. Through a shared interpretation process, CBPR stakeholders explored what the findings meant to the community, how the



findings could best guide programs and practices to address diabetes, and assisted in the development of recommendations (see discussion and table 2).

## **RESULTS**

Findings are organized based on each construct of the Health Belief Model: 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, 4) perceived barriers, 5) cues to action, and 6) self-efficacy. Emergent themes are provided within these constructs.<sup>39,41,53</sup>

### **Perceived susceptibility**

Perceived susceptibility relates to one's perception of the likelihood of getting a disease.<sup>40,41</sup> The Marshallese perceive a high level of susceptibility to diabetes within the community. Marshallese people discuss diabetes as an inevitable condition for many in their community, rather than a preventable disease. Participants describe diabetes as "our community's curse." "Most of my family has diabetes. I know I will get it too." "If you are Marshallese, you have it [diabetes] or you get it [diabetes] someday."

### **Perceived severity**

Perceived severity refers to feelings about the seriousness of a disease, and includes both medical and social consequences.<sup>41</sup> Marshallese participants generally perceive diabetes to be a deadly disease. "I would say it's the most killer disease in our community." In the Marshallese community, a diabetes diagnosis is viewed as a death sentence, rather than a manageable condition. When describing the typical response of a community member to a diabetes diagnosis, one participant stated, "You are dying. You are dead. I mean, you are going to die in a few years." Another participant shared, "When I first found out that I might have diabetes...First thing [that] came to my mind, I am going to die." When asked what Marshallese people think

when a community member has diabetes, one person stated simply, “Just that you will eventually die.”

Participants also discussed restrictions on their daily lives and ability to work. Diabetes “limited everything for us.” Other participants noted that diabetes “limited their abilities to do things.” “When a person with diabetes [tries to] go to work, their abilities are limited.” Family members discussed the difficult medical consequences of diabetes.

Diabetes is a big issue for us Marshallese . . . . For example, I have four aunts I am taking care of at this moment and they are all diabetes. One of them is lose her vision because of diabetes . . . One of them is about to lose their kidney, because of diabetes.

Another participant discussed: “it’s very hard because, as for my mom, she’s a diabetic, diabetes [type] 2. She goes into dialysis three times per week.” An additional participant described her family member’s experience: “its heart wrenching to see her suffer from it. There was a time that her sugar was really low, and she had a stroke, and I had to witness it. We thought we were gonna lose her then.” Another participant recounted: “I did have a cousin, but he died five-something years ago. But before he died they had to cut off his legs.” Some participants described the severe physical and emotional toll that diabetes has on a person’s body: “he was a really handsome man when he was younger, and then the having diabetes. I could see changes in people’s appearances when they have diabetes. They look more sickly and I know that they try to . . . sometimes I, like see suicidal in their face.”

The social consequences of diabetes are also perceived as severe. The stigma of a diabetes diagnosis is very high among the community and precludes many individuals from openly admitting they have diabetes and seeking care. One participant explained, “They are ashamed, they are ashamed if other people find out they have diabetes.” Another added, “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." These social consequences seem to be exacerbating the medical consequences of diabetes because it keeps many Marshallese from seeking diabetes education and care at an earlier stage.

### **Perceived benefits**

A perceived benefit refers to a person's belief in the effectiveness of a recommended health behavior to help them reduce risk or impact of the disease. Participants seemed to understand what many of the self-management behaviors were. "Exercise, lose weight, more vegetables, reduce fat." "A healthy diets, perfect, if we can exercise." Participants generally felt positive about the potential benefits of diabetes self-management behavior; however, they did not articulate the benefits of those behaviors. Of all the dimensions of the Health Belief Model, perceived benefits was the most difficult to capture. Participants unanimously stated that diabetes self-management behavior and DSME would help their community, but they were not able to articulate how they would benefit. Many participants simply stated, "I don't know." Other participants quickly shifted to stating that they wanted DSME for themselves or their family, or began discussing barriers to DSME. Overall, when questions of benefit were asked, participants were far less verbose than when discussing any other aspect of health beliefs and perceptions. One of the reasons for the limited discussion on the benefits of diabetes self-management behavior may be a lack of understanding about self-management behaviors and the lack of the lack of DSME available to the Marshallese.

### **Perceived barriers**

Perceived barriers refer to the negative aspects of a health action and the obstacles to undertaking a health behavior.<sup>41</sup> Participants identified numerous barriers that impede the

Marshallese from practicing diabetes self-management behaviors. Participants discussed both structural and nonstructural barriers including: limited health care access, lack of transportation, cost of healthy foods, cultural food practices, and social stigma. These barriers are explored in-depth in a separate article devoted solely to the barriers faced by the Marshallese community.<sup>17</sup>

Participants identified their primary barrier to self-management as lack of access to health care services and medication because they are not eligible for Medicaid. “To be honest, I think that is going to continue to be a challenge [because] Marshallese [are] not able to access Medicaid.” Those without insurance have very few options to access health care services and medication. “So a lot of our elders passing away the past year have diabetes. They have no access to their insulin or their medicine, because they don’t have any insurance.” Transportation to attend doctor appointments and to attend DSME was also a significant barrier. Participants described how families often share only one car between many members, and public transportation is very limited in the area. As one participant summarized: “No insurance. No money to see a doctor. No ride to the doctor.”

Participants discussed several barriers to eating healthy, including the cost of food and the role that food plays in the community. “We have to feed a lot of people, and healthy food like vegetables and meat cost a lot of money. Rice and noodles don’t cost too much.” Food is central to the Marshallese culture and changing eating patterns is difficult when eating communal meals. “Food and family means there’s happiness; they’re social, you get to know people, I mean it’s a big part of our custom. That’s one thing that you cannot take from us. And because we’re from a very far country into this place that we barely know, how do we adapt to their culture?” “Because everyone knows diabetes is bad, but to manage is really hard in our community because of the food we eat. We eat together every Saturday in our family. Birthday parties are a

really important thing for our community. So if you come to one of our birthday parties, we go home with a plate of food. And people cannot blame us because it's our culture." Participants said that meals are eaten together and eating separately from the group or eating a different diet is not acceptable. Another participant stated, "Eating well, which I haven't done in a while because like I said, you go to these parties and then I go to my cousins house, and I cannot have my own meal because that is offensive to her." In addition to these external barriers, participants discussed social stigma and a sense of shame. "To say you have diabetes is to say you are no longer strong, and maybe you cannot support your family. So sometimes people don't want to go to [DSME] classes or even check their blood to see if they have diabetes, because if they do [have diabetes], they feel bad."

### **Cues to action**

Cues to action are the factors that activate likelihood to take action. The primary theme for cues to action, identified by focus group participants, was the diabetes diagnosis itself. Respondents explained that once a Marshallese person is officially diagnosed with diabetes, it often stimulates behavior change or at least the consideration of behavioral change. A Marshallese man stated, "After my aunt knows that she's diabetes, she doesn't drink any more soda. And she controls eating her rice because she (ate) the regular rice from the oriental store. But now she's eating . . . the long rice. And my sister, she always (ate) candy and soda, and after she was diagnosed, she drinks only water and not eating any candy. Because her doctor told her that." A Marshallese woman who translates at DSME classes explained, "The persons that . . . just found out recently that they have diabetes, they're pretty much good; they're controlling themselves. But I know a lot, a high percentage of our community that are still in denial. They don't do check-ups, they don't go; they don't do anything until it comes to a point where it's

really extreme, that they get admitted [to the hospital].” While a diabetes diagnosis is the primary cue to action, the shame associated with diabetes keeps many Marshallese from having their blood sugar tested to determine if they have diabetes.

### **Self-efficacy**

Self-efficacy refers to confidence in one’s ability to perform an action.<sup>40,53</sup> While participants’ responses regarding other constructs were quite homogenous, the responses for self-efficacy varied widely. This variation was present within each of the focus groups, rather than between focus groups. Confidence in one’s ability to successfully preform self-management behavior is complicated by many participants’ beliefs that the nuclear testing and their genetics are the primary factors that influence diabetes, making diabetes outside their control. “They know they’re gonna get diabetes.” “ It was caused by the bomb . . . . Before the bomb testing and the war there were no diabetes. It was after that we started getting more cases of diabetes. Then we started [having] people feet getting amputated because of diabetes.” Others questioned, “Do you know if it was caused by the bomb? Is it because of genetic inheritance or from what we eat?” Among many in the Marshallese community, there is the belief that the nuclear testing caused, at least in part, the epidemic of diabetes.

“I’ll die, but most people also believe that it [diabetes and then death] will happen to them. A lot of people say it has to do with the radiation that happened, at home [in the Republic of the Marshall Islands], although we have no solid proof, we’re just suspecting. Because you know all the time . . . people get sick with this [diabetes]. And people are suspecting that it could be related to back in the 50s [when nuclear testing occurred] . . . . It [diabetes] is prevalent. Most people grow up and end up being diabetic like myself. I once was very healthy and active. As I grow, I’m getting the sickness . . . . It is not good, it is not healthy for us to be in this way. So if you get the sickness, . . . as far as why, well like I said, people are suspecting it might be something else [other than lifestyle] that is causing this problem. So people when they get the sickness, and then management failure is due to our diet, the way we eat.

Regardless of the cause, some participants felt like self-management behavior was outside their control. “Because it is something that they cannot control. It comes, it comes . . . even though sometimes they take their medications, they still cannot control it. Their body cannot control it.” This lack of self-efficacy was cited as a reason why they did not practice self-management behaviors. “And there’s nothing you can do . . . at least let her enjoy it [preferred foods].”

However, others voiced that self-management was possible and expressed high self-efficacy and their belief that their behavior determined outcomes. “And so for people to know that [have] diabetes, some will try to help themselves. With enough knowledge, they can try to control.” Other participants expressed confidence in their self-efficacy. “If you follow all the directions given to you, do what the doctor instruct you and drink your medications. Exercise and do what is necessary for a diabetic person.” Even among those who believed that self-management was possible, self-efficacy was mitigated somewhat by the frustration that diabetes self-management is difficult. While some respondents expressed that they could perform diabetes self-management behaviors, they explained that daily maintenance of diabetes is frustrating and laborious.

You know, I get up in the morning, when I eat the right kind of food and, you know, I check my blood sugar is 90 or is 100, hey, I can do this. Even though I have to take the ice cream away, take all the rice away. At first, I miss having all my Marshallese, delicious food...but once you get used to it .... Sometimes I slack, I am not perfect at this, but I try.

Another man discussed the difficulty he sees those close to him dealing with every day. “It’s really hard to deal with people that have diabetes because there is a lot of complicated things you have to do. First, you have to see what you are eating. Second, exercise. Third is taking your insulin. If you don’t take care of the insulin and the food you eat and exercise, it

would be not good.” In addition, participants discussed the numerous structural barriers to diabetes care and prevention that reduce feelings of self-efficacy. As discussed above, the celebratory role of food is viewed by some participants as limiting their self-efficacy. “I mean, how can you lose weight when you’re invited every weekend to go to birthday parties, or funerals, all serving food and the food there is not [healthy] nutrition wise.”

When participants were asked what might improve self-efficacy, they stated that real-life examples and role models from within the Marshallese community were needed to increase their self-efficacy. “Yeah, you can educate these people but there has to be an example . . . there has to be that one person that can say, yes, I did it. We haven’t had that one person say yes, I was a diabetic and now [I can manage my diabetes]. Other participants agreed stating, “There’s that one first example. Because . . . we don’t like to listen and then we do it. We want to see it. We want to see action. We want to see a real result and then we’re gonna do it.” “That example would help people believe or have confidence that they could do it too.”

## **DISCUSSION**

Marshallese suffer from extremely high rates of type 2 diabetes.<sup>9,10,22,23,54</sup> Prior studies evaluating DSME have failed to show glycemic control among participants.<sup>33,34</sup> Cultural adaption of DSME has been shown to be more effective in other minority population.<sup>55,56</sup> The Health Belief Model has been used and a tool to understand a population groups cultural beliefs which serve as a foundation for developing or adapting health behavior interventions.<sup>41,57-59</sup> This is the first article using all of the constructs of the health belief model to examine the beliefs and perceptions of the Marshallese related to diabetes self-management behavior, and provides an important foundation for interventions with the Marshallese community.<sup>17</sup>



## **Perceived threat**

Perceived susceptibility and perceived severity together are conceptualized as *perceived threat*. Findings indicate that the perceived threat of diabetes is very high for the Marshallese. Marshallese perceive diabetes as a deadly disease that most members of their community will develop. However, it appears as though many Marshallese regard diabetes as a "death sentence" specifically for their community. This suggests that the Marshallese perceive themselves to be uniquely susceptible, due to genetics or nuclear exposure, which makes diabetes an especially deadly disease for their community. Based upon the high level of perceived threat, educators can clarify the etiology of diabetes to decrease the perception of inevitability. Educators can also help personalize risk based on a person's behavior, and focus on areas of consequences and risk that are most important to the population. However, it is important to balance the effort to personalize risk in a way that does not exacerbate the stigma and shame associated with diabetes in the community and does not blame patients.

## **Benefits vs. barriers ratio**

Positive health behavior is more likely when there are higher perceived benefits and lower perceived barriers, which provides a positive benefits-to-barriers ratio. Currently, the benefits of diabetes self-management are not well understood and the barriers are numerous. These barriers are both internal and external and prevent the Marshallese from achieving effective self-management of diabetes. It is important to note that many of these barriers, including limited health care access, lack of transportation, cost of healthy foods, and lack of culturally appropriate health education, are beyond the control of the person with diabetes and the Marshallese community. In order to address the current benefits-to-barriers ratio, educators will need to clarify the anticipated positive outcomes of self-management behavior and DSME

for individuals, families, and the broader Marshallese community. In addition, policy and programmatic action are needed to address the barriers identified by the Marshallese community, many of which are outside of their control. Educators will need to partner with others in policy and health care to work on efforts to: restore Medicaid benefits for COFA migrants, increase the number of providers who see those without insurance, increase public transportation, and improve access to healthy food choices. In addition, programs are needed to address aspects of the cultural norms including the social stigma of diabetes and making positive changes in the food that is served in cultural celebrations.

### **Cues to action and self-efficacy**

It is very concerning that the primary cue to action is the diabetes diagnosis. Because of limited access to health care and social stigma, this cue is often identified after diabetes has become quite severe. If Marshallese expect to get diabetes, it may be difficult to encourage them to take action with preventive health behaviors before diabetes develops. It is also important to cultivate earlier cues to action, perhaps through community programs that focus on diabetes prevention.

Self-efficacy was one area with significant variation in responses. Some participants were convinced that while their behaviors might have a small influence in their diabetes management, genetics and nuclear contamination are the primary cause of diabetes, and, therefore, there was little they could do to change or manage the progression of diabetes. To expand cues to action, educators can provide culturally appropriate information and examples to promote awareness of actions that can be taken to prevent diabetes and to manage diabetes earlier. Additionally, educators can promote diabetes screenings to allow for quicker diagnosis prior to the onset of more severe symptoms. To increase self-efficacy, educators can provide

culturally tailored DSME to address misconceptions and encourage self-efficacy in performing recommended diabetes self-management actions. Educators can also promote successful role models to build confidence in the individual's abilities to successfully manage diabetes.

### **Limitations and strengths**

The convenience sample of Marshallese adults living in Springdale, Arkansas is a limitation of the study and reduces the generalizability of the results. The qualitative design is appropriate for this exploratory study and allows the research team to explore the health beliefs of a Pacific Islander population who suffer from significant health disparities in the rate of diabetes. The qualitative design provides participants with the opportunity to share their beliefs, perceptions, and lived experiences in their own words. This study contributes to an area where there is currently a dearth of literature on Pacific Islanders populations and subgroups of Pacific Islanders populations, such as the Marshallese. The findings can be used to ground future research and practice of diabetes education within the Marshallese community. The use of a CBPR design and the involvement of two community co-investigators helps increase the validity of the results by ensuring that they accurately represent the nuances of the Marshallese culture.

This CBPR study is action-oriented. From the start of preliminary fieldwork, Marshallese community members told the CBPR team that they do not want to be "guinea pigs" and only want research done in their community that has tangible benefits. This speaks to the ethical imperative inherent in CBPR to *contribute to*, rather than *take from*, health disparate communities when conducting research.<sup>60-62</sup> Given that the long-term goal of our CBPR partnership is to improve the health of the Marshallese community, discussion focuses on how findings can inform culturally appropriate health care practices, diabetes education, and other

health promotion efforts. Based on CBPR stakeholders' recommendations, we offer recommendations for practices and programs in Table 2.

## **CONCLUSION**

The Marshallese community suffers from rates of type 2 diabetes that are 400-500% higher than the general population. There are few studies or programmatic efforts to address these disparities. The research grounded in the Health Belief Model provides important information that can help advance diabetes self-management efforts within the Pacific Islander communities. The CBPR team is developing and testing a family model of diabetes self-management education based upon this exploratory research. In addition, the CBPR team is working to address the policy, environmental, and systems barriers that prevent self-management behavior.

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**Table 2: Recommendations for health educators & health care providers**

<p>Perceived susceptibility: One's perception of their chances of getting a condition</p>	<p>High perceived susceptibility. Participants see diabetes as inevitable.</p>	<ul style="list-style-type: none"> <li>• Personalize risk based on a person's behavior.</li> <li>• Clarify the etiology of diabetes as based on personal lifestyle rather than fate.</li> <li>• Take care not to perpetuate the stigma and shame.</li> </ul>
<p>Perceived benefits: One's belief in the efficacy of the advised action to reduce risk or seriousness of impact</p>	<p>Generally positive, but uncertain and uninformed about benefits of diabetes self-management. While participants generally felt that self-management behavior was good, they did not discuss specific benefits.</p>	<ul style="list-style-type: none"> <li>• Clarify the positive outcomes of self-management behavior and DSME for individuals, families, and the broader Marshallese Community.</li> </ul>
<p>Cues to action: Activate "readiness" to take action</p>	<p>The primary cue to action is a diagnosis of diabetes. This cue is often avoided because Marshallese frequently do not want to know if they have diabetes due to the stigma within the community. In addition, lack of health care access (barrier) often prevents the cue from emerging until the disease progresses to a more severe state.</p>	<ul style="list-style-type: none"> <li>• Provide culturally appropriate information about early risk factor to increase preventive actions.</li> <li>• Promotion of diabetes screenings to allow for quicker diagnosis.</li> </ul>
<p>Self-efficacy: Confidence in one's ability to take action and overcome barriers</p>	<p>There is variation in self-efficacy because of the participants' perceived inability to perform self-management behaviors. All participants discussed difficulty in performing self-management behaviors.</p>	<ul style="list-style-type: none"> <li>• Promote successful role model cases to build confidence in individuals' abilities to successfully manage diabetes.</li> <li>• Provide culturally tailored DSME to address misconceptions and encourage self-efficacy.</li> </ul>

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## Chapter Three

### Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act

#### INTRODUCTION

The United States controlled the Republic of the Marshall Islands as part of the Trust Territory of the Pacific Islands (TTPI) from 1947 to 1986. The Republic of the Marshall Islands was the principal site of the United States' nuclear testing program from 1946 to 1958.<sup>1,2</sup> Upon the signing of the Compact of Free Association (COFA) between the Republic of the Marshall Islands and the United States in 1986, the Republic of the Marshall Islands became a sovereign nation. The COFA allows Marshallese citizens to enter the United States, and lawfully to reside, work, and study without a visa or permanent resident card.<sup>3</sup> COFA migrants are legally defined as "nonimmigrants without visas".<sup>4</sup> As part of the COFA agreement and other federal grants to the Republic of the Marshall Islands, the United States funds the majority of the health care system in Republic of the Marshall Islands.<sup>5-8</sup> The United States also maintains the Ronald Reagan Ballistic Missile Defense Test Site on Kwajalein atoll in the Republic of the Marshall Islands, and occupies 11 of the 97 islands of that atoll for military activity. The COFA allows the United States to maintain control of approximately two million square miles of strategic Pacific territory for defense purposes. Native Hawaiians and other Pacific Islanders, like the Marshallese, join and serve in the US military at higher per capita rates than US citizens.<sup>9</sup>

The Patient Protection and Affordable Care Act (ACA) is a public policy that has reduced the uninsured rate, providing insurance for many previously uninsured citizens and legal residents of the United States. However, this public policy has not benefited all. Marshallese migrants living in the United States have limited access to federal and state benefits programs under the ACA.<sup>4,10-13</sup> While a few essays have described the lack of insurance coverage for

COFA migrants,<sup>3,13-15</sup> no previous research presents the COFA migrants' understanding of and experience with the ACA or related health policies. Nor do other articles describe the lived experience of COFA migrants and the law's effect on COFA migrants' health in their own words. The lead researcher has been working with the Marshallese community on community-based participatory research (CBPR) since January 2013 to address type 2 diabetes.<sup>16</sup> While the CBPR stakeholders worked to address type 2 diabetes, participants continually brought up the topic of the ACA (participants often referred to it as "Obama Care") and Medicaid Expansion at each stakeholder meeting. This article is structured to allow the voice of Marshallese COFA migrants to be heard and to provide an opportunity for them to explain their understanding and interpretation of the ACA and related policies on their health in their own words. In addition, we offer policy recommendations to address participant concerns.

### **Marshallese in the United States and Arkansas**

The Marshallese population is rapidly expanding in the United States. Between 2000 and 2010, the Marshallese migrant population in the United States more than tripled from an estimated 6,700 to 22,434.<sup>17</sup> While 22,434 is the official 2010 Census count, the Marshallese Consulate suggests the Marshallese population in the United States may currently be as high as 40,000.<sup>18</sup> The exact number of Marshallese living in United States is difficult to capture because their status allows them to move freely between the Republic of the Marshall Islands and the United States without a visa. Compared to the general US population, Marshallese migrants are typically younger, have lower educational attainment, and higher rates of poverty.<sup>19</sup>

Based upon local health department and school records, an estimated 10,000 Marshallese people currently reside in Arkansas, which is the largest population of Marshallese living in the continental United States.<sup>18</sup> Springdale, a city in northwest Arkansas, is the center of this

burgeoning Marshallese community. Beginning with only a few Marshallese migrants arriving in the late 1980s to work in the poultry industry, the Marshallese community has grown steadily over the past three decades.<sup>20</sup> Marshallese migrants continue to settle in northwest Arkansas where they have children, study at local schools and colleges, and work in local industries.<sup>4</sup>

Between 1946 and 1958, the US military tested nuclear weapons in the Marshall Islands. The load of these nuclear tests were equivalent to more than 7,000 Hiroshima-sized bombs, and the Marshall Islands is now considered to have the highest level of nuclear contamination anywhere in the world.<sup>2</sup> The nuclear tests destroyed entire atolls in the island chain and contaminated the plant and sea life of many other islands.<sup>2,21-23</sup> The nuclear explosions, subsequent contamination of the Marshall Islands, and the relocation of Marshall Islanders permanently altered the traditional subsistence farming lifestyle and lean, fish-based diet of the Marshallese.<sup>2,24</sup> In the aftermath of US nuclear testing, the food accessible to Marshall Islanders changed to primarily packaged and canned food, imported from the United States as food aid. These types of foods, especially white rice and canned meats, continue to be the favorite foods of Marshallese both in the Marshall Islands and the United States.<sup>25,26</sup> The resulting change in the Marshallese's diet has serious health effects. The Marshallese population living in the United States has significant health disparities. Rates of diabetes are documented at five times the national average.<sup>27,28</sup> Infectious diseases, particularly hepatitis B, tuberculosis (TB), and Hansen's disease (leprosy) are also found at higher rates among the Marshallese.<sup>29-36</sup> In addition, Marshallese mothers in the United States give birth to low birth weight babies at higher rates.<sup>37</sup>

### **Health care reform policy**

The Patient Protection and Affordable Care Act (ACA) was signed into law by President Obama in March 2010 and later upheld by the Supreme Court in June 2015.<sup>38</sup> The ACA

expanded health insurance options for citizens and legal residents of the United States.<sup>39</sup> The law creates marketplaces where consumers can purchase subsidized health plans and it also requires legal residents obtain health insurance.<sup>40</sup> Medicaid is a federal program that provides health care coverage to millions of low-income residents in the United States.<sup>41</sup> The ACA offers states the option to expand Medicaid to more low-income (133% of poverty level) residents. Arkansas is one of 27 states that expanded Medicaid to low-income adults.<sup>42</sup> The Arkansas state government chose a unique model of Medicaid expansion, which created the Health Care Independence Program and is popularly known as the "Private Option." The Private Option offers Medicaid expansion funds as premium assistance to those purchasing private coverage in Marketplace Qualified Health Plans.<sup>42,43</sup> Nationally, these programs reduced the uninsured rate by 3.5%, from 17.3% to 13.8%, and in Arkansas, the uninsured rate declined from 22.5% to 11.4% from 2013 to 2014.<sup>44</sup>

Marshallese COFA migrants are uniquely affected by the ACA. As lawfully present migrants, they are required to purchase health insurance. COFA migrants are eligible for advanced premium tax credit subsidies and are subject to the standard penalties if they do not enroll in a health plan.<sup>45</sup> COFA migrants, however, are not eligible for Medicaid or Medicaid Expansion. When the COFA was signed in 1986, Marshallese migrants were eligible for Medicaid and other federal safety net programs. However, in 1996, COFA migrants living in the United States were rendered ineligible for Medicaid with the implementation of the federal Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA). COFA migrants were excluded from the category of "qualified immigrants" eligible for Medicaid and the Children's Health Insurance Program (CHIP) with the passage of PRWORA.<sup>11,46,47</sup> While PRWORA disqualified COFA migrants from eligibility for these federally-funded benefits

programs, state governments have the discretion to continue Medicaid coverage exclusively with state funds.<sup>12</sup> In 2009, the Health Insurance Program Reauthorization Act allowed states to extend CHIP benefits, with federal matching funds, to lawfully residing children if the states develop and submit an amendment. Arkansas has not yet done so and COFA children remain without coverage. Since Arkansas has not funded Medicaid or CHIP coverage, COFA migrants residing in Arkansas do not have access to any publicly-funded health care programs, including Medicaid, CHIP, and Medicaid Expansion under the ACA.<sup>10,11,13</sup>

To implement the ACA, the state of Arkansas utilized navigators and in-person assistors (IPAs) to help consumers understand “insurance options, determine eligibility, and facilitate enrolment.”<sup>48</sup> In northwest Arkansas, three bilingual Marshallese IPAs and navigators were hired and worked with the Arkansas Department of Health and the local legal aid office. However, only one navigator was located within the community where most Marshallese live, and the two IPAs were located in an adjacent town. IPAs were not allowed to process applications offsite. Thousands of Marshallese attempted to sign up for health insurance with each new application taking approximately two hours; and many applications required additional follow-up.

The lead researcher began working with the Marshallese community in early 2013 to address type 2 diabetes.<sup>16</sup> However, in every community stakeholder meeting, more than 30 meetings in total, the ACA and Medicaid Expansion were brought up as major concerns. As Anderson (2003) describes, public policy is understood as whatever “governments choose to do or not to do,”<sup>49(p2)</sup> and is further defined as “a relatively stable, purposive course of action followed by an actor or set of actors in dealing with a problem or matter of concern.”<sup>49(p2)</sup> It is important to understand the lived experiences and the meanings of a public policy among different sectors of a community.<sup>50</sup> Honoring our commitment to ensure the community is driving our research

agenda, we chose to conduct interpretative policy analysis research to document Marshallese COFA migrants' understanding and experiences regarding the ACA and related health policies. To do this, we use an interpretive approach to sense-making in policy analysis, which includes engaging stakeholders to learn about their understanding and experiences regarding a policy.<sup>50</sup>

## **METHODS**

### **CBPR approach and the role of the community co-investigators**

The research team is fully committed to using a pure CBPR approach<sup>51,52</sup> and we document this throughout the paper. The idea for this research came from a broad group of Marshallese stakeholders. A subset of those stakeholders also served as community co-investigators. Community co-investigators were present at the interviews, transcribed and reviewed transcripts, participated in coding, data interpretation, and are co-authors of this paper.

### **Design**

A qualitative design was utilized as an exploratory method to understand better how the Marshallese interpret the ACA and related health policies, as well as how the Marshallese describe the effect of these policies on their lives. Qualitative, exploratory methods are appropriate when little is known about the experiences of a specific population, because it allows us to understand better the extent of the policy impact on a unique population.<sup>53</sup> The guiding research questions are: for Marshallese living in the United States: 1) what are their understanding of and experiences with the ACA and related health policies; and 2) what effect does the ACA and related health policies have on the community's health? A semi-structured interview guide was created with open-ended questions to allow participants to speak freely and give in-depth responses about their understanding and experiences, yet it also ensured all focus



groups and individual interviews covered the same topics.<sup>54</sup> The interview guide was developed with input from CBPR stakeholders.

Participants were recruited through our CBPR partnership with the local Marshallese community. Participants were 18 years of age or older who self-reported as Marshallese. Community members who met the participation criteria were invited to take part in the study via e-mail, church groups, and Facebook. Participants were given the opportunity to provide verbal consent. After verbal consent, participants completed a brief survey that captured demographic information, insurance status, and whether or not the participant had a primary care provider. Five focus groups were conducted at a local community center.<sup>55-59</sup> Three individual interviews were conducted with people who were unable to attend the focus groups, in a location of the person's choice.<sup>58</sup> Bilingual research staff helped conduct each focus group and individual interview. Qualitative data was collected from 48 participants. Participants were given a \$20 gift card as remuneration for their contribution. The Institutional Review Boards (IRB) at the University of Arkansas for Medical Sciences and the University of Arkansas at Fayetteville reviewed and approved the study procedures.

Focus groups and individual interviews were recorded and transcribed verbatim. Data collected in Marshallese was first transcribed in Marshallese and then translated into English. The transcript was confirmed by a second Marshallese translator prior to coding. Content analysis was then performed. The researchers coded the data for *priori* themes (from the interview guide) as well as emergent themes. Both *priori* and emergent themes were organized into a codebook, which two qualitative researchers used to code the transcripts. A summary of themes was presented and discussed with the CBPR team, including seven Marshallese community co-investigators. The Marshallese co-investigators participated throughout the

research and writing process to ensure that cultural context and nuances in meaning were accurately captured and presented. In analyzing our transcripts, we reached saturation with thematic codes after the first two focus group interviews. The remaining interviews continued to provide the same themes, but with additional richness. Themes were consistent across both the focus groups and the individual interviews. Working with the Marshallese community co-investigators, we selected quotes that most represented the participants' collective experiences. The quotes selected were obtained from 21 separate participants participating in the five focus groups and three individual interviews.

## **RESULTS**

### **Participant demographics**

Table 1 presents the information related to participants' age, income, and health insurance coverage; and percentages reported below are based upon the number of participants who responded to each item. The majority of participants (89.2%) reported income at or less than \$30,000. Twenty-five (25) participants (54.3%) reported having health insurance and 21 participants (45.7%) reported having a primary doctor to meet their family's health care needs. Interestingly, of the 25 people with insurance, only 15 of them have a primary care physician; and of the 21 people with a primary care physician, 15 have insurance coverage.

**Table 1.** Participants: age, income, and health insurance coverage.

<b>Response Category</b>	<b>(N = 48)</b>	<b>Percent of sample<sup>a</sup></b>
<b>Age</b>		
18-24 years of age	3	6.5
25-30 years of age	4	8.7
31-40 years of age	9	19.6
41-50 years of age	17	37.0
51-60 years of age	9	19.6
61-70 years of age	4	8.7
71 years of age and above	0	0.0
<b>Annual Income</b>		
Below \$10,000	17	37.0
\$10,000-\$20,000	10	21.7
\$20,000-\$30,000	14	30.4
\$30,000-\$40,000	3	6.5
\$40,000-\$50,000	2	4.3
<b>Do you have health insurance?</b>		
Yes	25	54.3
No	21	45.7
<b>Do you have a primary doctor for your family's health needs?</b>		
Yes	21	45.7
No	25	54.3

a. Percentages are based on the number of responses for each item.

### **Participant quotes**

Within the results section, the research team intentionally provides extensive quotes. While this approach is cautioned by some qualitative researchers, others note the power of longer quotes to provide a better representation of participant voices.<sup>53,60</sup> This approach was encouraged by both CBPR stakeholders and the community co-investigators. The decision to use longer quotes is also based upon the richness of the quotes and the participants' ability to articulate clearly their lived experiences.

### **Themes and sub-themes**

The content analysis revealed six primary themes (three *priori* and three emergent). These themes and sub-themes are outlined in **Table 2**. Results are organized within these themes.

**Table 2: Themes and sub-themes.**

1) <b>Understanding.</b> Participants’ understanding of the ACA and related policies	<i>In-depth understanding</i> <i>Lack of understanding</i> <i>Lack of understanding because of poor follow up</i> <i>Lack of understanding about insurance premiums, co-pays, and who accepts their insurance</i> <i>Lack of understanding and frustration about tax penalties</i>
3) <b>Effect.</b> Participants’ description of how the ACA and related policies’ effect participants/community health	<i>Health status</i> <i>Treatment differences</i>
4) <b>Relational/historical lenses.</b> Participants’ view of the policies in relation to the Compact of Free Association, US nuclear testing, use of their land, and the current relationship with the US military	<i>Friendship agreement</i> <i>Nuclear testing</i> <i>Value of land</i> <i>Military Service</i>
6) <b>Plea.</b> Participants’ discuss their desire to have their voices and experiences heard and their culture’s method of advocacy	<i>Hear our voices</i> <i>Culture and advocacy</i> <i>Good friends</i>

**Understanding**

*In-depth understanding.* Many participants had an in-depth understanding of the ACA and were able to describe the program in great detail. “It [ACA] will help those who have no health insurance. It’ll help them get health treatment.” “From my understanding, we know that we all need to have insurance. The way I see it is, there will be a penalty if you don’t [have insurance].” Another participant stated “as for my understanding, it can provide me with my own

primary physician, so knowing that made me apply for the Obama Care insurances.” Several participants articulated an in-depth understanding, which the following quote illustrates.

The reason this law was created by Obama, was so that every one of us who are beneath the poverty level and little bit higher can enroll in it ... That's what I know from what I've heard. [ACA] is to make those who are under the poverty level in America, as well as those who cannot afford it, to be able to afford to purchase health insurance, to be able [to] prevent all the diseases they encounter in the United States. Also, to make it affordable for those who were going through hardships and that when they get sick, they weren't able to get [any] insurance due to some sort of pre-existing conditions or diseases that [they] had been diagnosed with.

*Lack of understanding.* While many participants were quite knowledgeable about the ACA, others still reported significant confusion: “One of the main things ... I see that there are many Marshallese who are still confused ... they're still confused.” Other participants stated that they did not fully understanding the ACA. “[The] people who help us apply sometimes explain to us what the Obama Care is all about, but they don't fully explain, so sometimes we are still lost.” In addition to the confusion of what the ACA is, some participants are also confused about their eligibility for the ACA. “Some mentioned that it is free- totally free according to their understanding. But some don't understand how they can get help from this thing. Some applied and some were denied. True. And now it is even more confusing to the Marshallese, especially the older generation.”

Participants repeatedly stated they wanted to understand and actively sought out information. “Because you know as a Marshallese, I would like to know if you can get resources. Sometime we would hear such thing like we can help get the same privilege . . . but really, we just want to fully understand.” Although many tried to inquire about the ACA and how it affected them personally, they received conflicting information regarding their eligibility for insurance through the ACA and the penalties they faced if they did not obtain insurance

coverage. Participants recounted being told different things by various people. Participants also recalled being told that they were not eligible due to their COFA migrant status. “When I went to DHS they told us that we are not [US] citizen.”

Whenever we ask [the federally qualified health center located at the local public school] if we can apply [for insurance] or if there is any assistance, they tell us to call the DHS [Department of Human Services]. When we call and check with them they say we’re not eligible. But what is this that we’re hearing about the Obama Care?

Several participants did not understand why they were left out of Medicaid expansion and inquired, “Is there anyone that can explain to me why am I am not qualified for Medicaid?”

There were only three Marshallese IPAs and Navigators hired to assist with applications; and only one of the three was located in the Marshallese community. As a result, many participants tried to use the phone assistance center or non-Marshallese staff to assist them with their application. Participants reported they observed a broad lack of understanding among the non-Marshallese staff about their COFA migrant status and eligibility for the ACA and Medicaid. Participants reported frustration because ACA staff did not understand their COFA status or even where the Marshall Islands are located: “you drop your bombs on our land and you don’t even know where the Marshall Islands are?” This lack of understanding among ACA staff meant those trying to sign up were often referred to someone else without being helped. Participants described being referred five or six times before finding someone who could help them, and many gave up before completing their applications.

*Lack of understanding because of poor follow-up.* The participants also explained they had reduced understanding and frustration because of the lack of follow-up after applying for the ACA. “I have two applications for the Market Place. They told me to call Little Rock and when I do, they don’t answer at all. Until this day I still have not received anything at all.” Participants

reported filling out forms multiple times and calling the information line two or three times per week for a year without a resolution of their application. Participants stated that after “a hundred calls, and no one can help you, you just give up.” The following quotes are from different focus groups showing a common experience and frustration with the application process. “That’s what they say, they tell us to fill out the forms. And then what? It’s DHS job to look over it? Because I already filled out my form and I already sent it.

I filled out one. [An IPA- name removed] came to the church and we all filled out our forms but we have not heard back from them. So what? Do we reapply or what? So now that that they aren’t giving us any information [regarding whether they got accepted or denied for insurance] and let us know. [I have been waiting for] one year now.

The way I see it it’s [ACA] good, and they [the IPAs] are helpful in many ways, but for me, I lose interest in doing anything about it. In another word, it was a waste of my time and effort. I filled out applications and go here and there and trying to do what I can to be insured. Today, I still don’t have insurance and so doesn’t my family. [IPAs] come and work with me and my family and it’s also a waste of your time. I gave you all my information and still I haven’t heard from any one and I still don’t know my status. Today, I still don’t know my application status and still uninsured.

Now they told me to apply for the Obama Care. I did and when [DHS] looked over it, they saw that I’ve apply two times so when I call the people for Medicaid, they told us to call back, and when we do, they don’t answer. I don’t know, maybe they lied to me.

***Lack of understanding about insurance premiums, co-pays, enrollment periods, and who accepts their insurance.*** The US health care system with its insurance premiums, open enrollment periods, co-pays, and primary care providers is very different than the health care system in the Republic of the Marshall Islands and is new and often confusing to Marshallese migrants. “There are those who don’t understand [the US health care system]. From point one and all the way through and still don’t understand. They don’t, they don’t understand.”

Participants noted a significant lack of understanding and widespread confusion about the cost of insurance premiums and co-pays.

Some say that if you have the Obama Care, if you have one [insurance card] you will not have to pay for your hospital bills. This is something I've heard. Some other people also say that if you have Obama Care your hospital visits will be free.

[They] pay for those thing – the premium for those health insurance plan- for the health insurance but they really don't know what they're for, paying for . . . we don't understand what we're enrolling in - we're paying for.

Well, just from what I know, it was for everyone who weren't able to afford it before. That those with low income can be qualify for it [ACA] and then they don't have to pay for the medical costs. Like they won't owe anything, just like it is free. But nowadays, what I am hearing is, those that were enrolled in this program still owe money or they still have medical bills. So, this is how much I know.

Participants also noted pervasive confusion about open enrolment. “The first one says one-time deal. It's a one-time deal. But now, we heard that they reopened the door for another open enrollment for the Affordable Care Act.” Another noted, “One day, I was watching TV and I heard the news was saying that enrollment period was over... it was the deadline and no more enrollment. I haven't heard anything else since then.” Some participants were also confused about the level of coverage that is provided and if all health care providers accepted the insurance obtained through the ACA: “I hear people say that Obama Care is accepted at some hospitals and not [at] other hospitals.” Another stated, “They said some hospitals accepts, and some they don't. It's not good at all.”

***Lack of understanding and frustration about the tax penalty.*** Participants discussed at length their confusion and frustration related to the tax penalty for not having insurance. “Yeah, you will still be penalized. Penalizing is the thing they talk about the most.” For this



impoverished population, the tax penalty is of tremendous concern because it will greatly affect their household finances. “If you didn’t have insurance all last year, you will be penalized with \$1000.” “They take it out of your tax refund.”

One of the scariest thing ... now they’re saying that if you don’t... don’t make payment, they will charge you thousands. And they’re talking about the income tax. File income tax, but they said they will charge you \$1,000. And so for us Marshallese, and I don’t know where this came from, they said if you didn’t get any insurance, if you didn’t apply for insurance and you don’t have any insurance and if you have money in your bank account, they will garnish it. I don’t know where this is coming from, but these are the rumors that have most of these people confused. And these are some of the issues we need to address.

Well, they already said that those who doesn’t have insurance will be penalized. Like they have already penalized some people in the year. The ones that already filed their taxes for income-tax and they don’t have an insurance the year that just passed, they took \$400 . . . they said that this coming year, if they don’t have insurance, or we still don’t have insurance, they will take even more out of your income tax [refund].

## **Experiences**

*Some get approved and some do not.* Participants were the most vocal about their confusion and frustration with the lack of consistent experiences regarding who is and is not approved for the ACA’s Medicaid expansion. As one participant explained, “When we apply for [coverage] some get in and some don’t.” The experiences differed widely: “I was told to wait to receive my eligibility letter, which I have never received.” Another participant recounted, “Our older siblings, we took them, and helped them get insurance, but no luck. Some people get approved and some they don’t get approved.” Even among those who had received coverage there were inconsistent messages. “I’ve been told that I wouldn’t qualify for Medicaid. I don’t know when they told me that, but next thing I know I received my approval letter.” Another participant stated they received an insurance card, but later found that the card was not accepted.

But, when they take their insurance cards to use them when seeking medical attention, the card was not recognizable. When they visit a doctor the clinic says the cards are not acceptable, and then when ask why, they are told that it is because they are not citizens, so the question is, why were they given insurance and the cards in the first place? Why approve their status during the process and then later tell them during their visits to the doctors ‘you’re not approved’ because you’re not a citizen? What’s worse is that after they have collected all their personal information and their social security numbers, date of births they tell them they are not approved because of their status. I’ve tried many times to apply and I just gave up. I don’t want to try anymore.

The participants also discussed their attempts to try and understand why some were approved and some were not, but they could not see any pattern.

When we go with [name removed] we don’t get in Obama Care, but some people do. Like I already said, we filled out forms with [name removed] and also at the church, but we didn’t get anything. All the people that filled out forms said that they didn’t get anything either, but the preacher and his family got their [insurance]. Their kids have food stamp. See! But, they were born in the Marshall Islands.

Another participant added, “That’s what I said. Why do some get approved, and other don’t.” Interviewees described how even within one family some people were approved and others were denied. “I would like say that after I applied my family was approved, except my wife, and so I would like to know why she was denied.”

*The ACA is not affordable.* When discussing their experiences with the ACA, many voiced their concern that the tax credit alone, without access to Medicaid Expansion, meant that the ACA was not really affordable for them. Participants explained most Marshallese migrants are low-wage workers in the poultry industry and that one worker is often supporting a large household of children and elderly family members. Providing insurance coverage for all in their household is not obtainable. “You said Affordable Care Act, but I cannot afford it.” Another participant expressed concern with their family members’ ability to pay for the insurance, stating that “Even with the Premium Tax Credit, it is [too] expensive for them to afford it.” “The Obama

Care, only some people can afford to have it depending on the amount of money they make.”

Other interviewees expressed similar opinions. “My budget can no longer afford it [insurance].

For most of us, there will be only one breadwinner but we take care of everyone, even extended family members that live with us.”

I do have issues with this. They [the Marshallese elders] have no income, but they’re only eligible for the Premium Tax Credit and aren’t eligible for Medicaid. Their children only make so much; maybe let’s say \$17,000 annually for many people in the household. They don’t make that much annually, but the credit they received from federal [government] is less comparing to what they need for their health. Why enrolling these Marshallese in the Marketplace when they’re not eligible to these [Medicaid expansion] assistance?

The bottom line is . . . our particular population, which is non-immigrant, which they are under non-immigrant status as long as they are not qualified for the Medicaid or Medicare, you know they, it’s good to have [the ACA] available but you’re talking about families that only make maybe \$9.00 an hour or \$11.00 an hour for the most part so getting to a doctor, even going to those low cost clinics, you know there’s still a lot of money to pay . . . .

In addition, there was concern that even after they signed up and were approved for insurance that if they were not able to afford premiums for one month, then they would be dropped from insurance and have a lapse in coverage

***Improving the experience.*** Despite their experiences, participants were generally supportive of the ACA, but felt that the system needed improvement:

I’m a big fan. I think as one of the community leaders, I’ve seen a lot of technical issues when it comes to the actual process of the enrollment. The overall concept really make sense, but when it comes to execution, there’s a huge gap there and a big barrier.

The system needs to be user friendly. [There] is just way too much. We need to make it user friendly. I think the concept of Affordable Care Act is awesome. Execution, poor execution. We need to come up with better ways.

## Effect

*Health status.* Participants discussed how the absence of insurance coverage affected their health. Without insurance they did not seek health care services or refill their medications when needed to due to the high cost. “For me, sometime when I’m sick, I don’t go seek medical attention, because I can’t afford to go. So, I just stayed home and do nothing. And I know it’s not healthy.”

For me, it’s not good because for someone diagnosed with diabetes, sometime I don’t take my medication as I’m suppose because I can’t afford to buy [the medication]. Because I’m not working and it’s hard to stay healthy when there is little resources to get the help we need. It’s just not healthy. I would say that, not being able to have access to a Primary Physician, since I know that they are the one who map out your health in how to manage it. All because I can’t afford one . . . . Oh yes, the cost of the medication; they are very expensive.

*Treatment differences.* In addition to not being able to afford health care services, participants shared their perceptions of discrimination based on insurance status, which they believe results in less effective or different treatment from health care providers. “They don’t care about us - the patient, because we don’t have insurance.”

Well here [in the United States], there are places that if you don’t have insurance they won’t want [to] see us and help us. My understanding and my very own point of view is that they don’t care for us. Because for those that have insurance, like for example my husband, he’s telling people that his insurance was an amazing one, that it took 8 months for doctors to heal him. He had a surgery on his leg, and now he’s feeling better. After his surgery, they took him to wound care. After wound care they took him to another place . . . . Even if his bills were high, they still cared for him because he had insurance . . . . [However], after that, some old lady said, ‘I wasn’t done, and I am still feeling very sick, but they released [me]’. Why? Because she had no insurance.

There are times when those who don’t have insurance are not cared for. When we go to see the doctor, they say ‘oh, take them out’ [discharge the patient], but they’re not really feeling any better because what? They don’t have insurance? There are a lot of people who don’t have Obama Care.

Our older siblings, we helped them [apply for insurance], but they haven't gotten their insurance. But when they go visit the doctor, she had no insurance because she has not been approved. For those who don't have insurance can be in no more than two to three days in the hospital; they don't care, because they don't have an insurance.

### **Relational/historical lenses**

*Friendship agreement.* Participants interpreted the ACA and restrictions on health insurance coverage through the lenses of the COFA, prior nuclear testing, past and current use of their land, and the Republic of the Marshall Islands' current relationship with the US military. Participants clearly understood the terms of the COFA, but they interpret it as more than a legal agreement; they see it as a commitment of friendship between the Republic of the Marshall Islands and the United States.

The Compact of Free Association was passed in June of 1986. It is a law that binds the friendship between the Marshall Islands and the United States. To simplify this for better understanding, this law was enacted for security purposes for using Kwajalein Atoll. This is one of [the] purposes of the COFA as well as being able to protect the Pacific Ocean, including the Federated States of Micronesia and Palau in order to create peace. [It also] protects America from the countries that America is afraid of regarding the military and combat. [Republic of the Marshall Islands] was under the government of Micronesia up until 1979. We were able to stand up with our own feet and created our own nation and have our constitution and now we are our own country with its own government. We were able to do this because we talked about wanting to be our own government and country with the help of the United States. We wanted to be independent, and we enacted the COFA so [the] US can help the Marshall Islands in any way possible. We created the COFA so that we can help America and so that America can help us. So we let America use our lands, and in return America allow us to come to the states.

Because the United States provides most of the funding for health care in the Republic of the Marshall Islands as part of the COFA, participants believed they would have the same health care access when they came to the United States.

When I first left Marshall Islands my thoughts about visiting a doctor would be like how it's done at home [in the Marshall Islands]. Back home we have benefits that are granted to our government from the federal government of the United States through the Compact of Free Association that makes seeking medical attention easy and affordable. When I first moved to the United States, I lived in Hawaii and I thought that I was able to seek medical care under what I understood as 'equal protection under the law.' But, everything is different and harder here. What I don't understand, that is mind boggling, is that back in the Marshall Islands, health care is fully funded by the US government, but it is not the same when we are physically here in America. I thought since there was an agreement between my country and the United States, and they [the United States] used our lands for nuclear testing that they would help in some ways, but I guess that's not how they do things here.

Participants also referred to health care insurance coverage when the COFA was signed and before the welfare reform of 1996. Several participants said that the Republic of the Marshall Islands had partnered in good faith with the United States and that the United States had failed to fulfill their responsibility in the partnership. "During 1996 the welfare [reform], it kicked out those that are under COFA; us, the ones that are under the COFA. After Bill Clinton signed it, it became a law."

Back when late President Amata Kabua was our leader [of the Marshall Islands] they [the United States and Marshall Islands] seemed to be in agreements with many things. I was still a young lad, and when I grew up and learned to read, my understanding was that there was a law stating we could seek medical attention while living in America. Like I said, I thought we would have been fully funded in the health/medical system since it is easy for us to come to the United States and also because we are fully funded in the Marshall islands by the US government, but when we move here where it truly belong to the Americans, we are otherwise funded. You would think that since we moved to their country they would help, but it seemed as if they have closed their hands and turn their heads the other direction so all we can see is the back of their heads, and not help us when we are in need.

***Nuclear testing and value of land.*** A participant summarized what many others voiced about the connection between the nuclear testing and the current restrictions related to health insurance: "What I'm thinking right now is for the Americans to acknowledge that what they did

to us and our country with the testing of nuclear bombs should be recognized and take full responsible for what happened.” Other participants were much more direct in stating that the United States has a responsibility to provide health care access to Marshallese COFA migrants because of US nuclear testing. “They [the United States] used the islands to conduct their nuclear weapon tests.” “It’s like to set a bait, when it was said, I give you our lands to test your nuclear weapons on, and study them . . . we all don’t understand what was done to us.” “Marshallese people are contaminated with radiation. We are sitting here, but we have been poisoned. Yet, they don’t want to provide us with free health care? I miss my parents and my grandparents. They died from poison [from the nuclear testing].”

It’s okay to claim yourself as a COFA migrant; it’s okay to talk to politicians about lack of access to health care because of our status. It’s okay to tell them that you know our lands were used as grounds for nuclear testing and because of that, now we see a lot of people with health issues due to the testing, so it’s okay for us to tell them: You’re wrong, you know. You can’t just give me a ticket and say I’m done with you after you destroyed our lands. You know it’s going to have to be more than that. Don’t just give me a ticket and say, I’m done, you know, because the aftermath effect of the nuclear testing is pretty profound. It caused health care issues and caused also social issues as well. So, it is quite okay to talk about it and tell your politicians that you know we’re not here because we want to be here.

I think the main thing I want is for them [Americans] to acknowledge us, know what they did to us and stop turning a blind eye, pretending that it didn’t happen, because the reason these things arises [health issues] and the reason people die young are due to diseases that occurred/resulting from the explosion [nuclear testing] that were tested on the islands. They [Marshallese people] didn’t just get sick and die. They died from being poisoned. Not just one [nuclear test] but fifty-eight or fifty-six, I couldn’t be too sure with the numbers . . . . I know these bombs were very powerful and affected the whole Marshall Islands.

Participants explained the cultural importance of their land as “priceless, most important thing, and as core to our identity, core being, legacy, and inheritance for future generations.”

Participants described that they saw the lack of coverage from the ACA’s Medicaid Expansion as

a betrayal of their relationship with the United States. “We gave our best gift to the United States and you won’t even give us health care, which is a small gift in return.”

*Military service.* In addition to nuclear testing, participants brought up the fact that Marshallese serve in the US military at a greater per capita rate than US citizens do; and that they die during military service at higher rates than other US citizens. Those Marshallese interviewed also highlighted the current presence of the Ronald Reagan Missile Defense Base on Kwajalein Atoll in the Republic of the Marshall Islands and its use for strategic US military defense.

It is way more deeper than just the COFA agreement. You know we have a military base in the Marshall Islands that is positioned there, and this military base is Kwajalein Missile Range, Reagan Missile Range, and basically, this was put there as a shield to the US. Our lands are used as security shield [for] security purpose, you know, more than just a COFA, so it is okay for COFA citizen to tell them that.

We Marshallese are serving [in the military]. Notice that our children serve in the military. We allow them to serve and they can easily die in combat, and because of so many things, they [United States] should consider... and, our relationship with them [United States]. You know, maybe sometimes they [United States] don’t understand. They [United States] should consider their government’s relationship with ours, because they freely come in and out of the Marshall Islands. They can come recruit Marshallese to join the military, and sometimes it’s hard for us to let go of our children, but we still do and we lose our lives this way.

I want you to know how my country collaborates with your country. As for us Marshallese nowadays, we serve this country [United States] as we’re qualified to serve in the arm forces. It’s like we’re giving our own to the war zones, and they die. They [United States] need to really look into how our country collaborate with their country [United States]- our relationship with them [United States]. And maybe sometimes, they [United States] don’t comprehend it. So they [United States] can’t understand our relationships as a nation to another nation. Because for them, they have so much freedom to come to the Marshall Islands. They [United States] can come to our islands and recruit soldiers for them [US military] and sometimes these things are hard for us to do but we give our lives for them [United States].

So you guys [United States] should look out for us. The reason America is strong is us. Yes, why do you think America is strong in combat? Because



you and me. We allowed them [United States] to test their nuclear weapon in the Marshall Islands. You allowed them to and still allow them to release missiles from one place to another. And, to poison Bikini Islands, not just Bikini Islands, but all of Marshall Islands.

### **Taxes and contributions to the national and local economy**

Many of the participants were frustrated they are paying state and federal taxes, including Medicaid tax, but are excluded from Medicaid and other federal benefits. “You work here in America, you have to pay taxes to them.” “We pay taxes and pay into the Medicaid and Medicare system and yet, we cannot qualify for Medicaid.”

You deduct tax out of my salary for about 20 to 30 years and when I apply for Medicaid, [I am told] NO . . . . Tell me how many Marshallese are here [in the United States]. Who is suffering? Us [Marshallese] or you [United States]? Who’s benefitting? Us [Marshallese] or you [United States]?

Participants discussed their contribution to the local and national economy and were frustrated that these contributions were not recognized because of discrimination. “The reason Northwest Arkansas is growing is because of us Marshallese. We the Marshallese as a whole, we contribute a lot to tax, and our taxes are used for developing this state, but we have limited benefits.”

[Marshallese COFA migrants] generate revenue to the city, generates to the state, and to the federal, and now that you actually reside here, they make these our barriers or issues. You don’t qualify for this and that, you can’t because you are Marshallese. Well, I believe that is called being discriminated against.

### **Plea**

*Hear our voices.* The overall tone of the focus groups was one of frustration. Participants are frustrated the Marshallese have, and continue, to give their most valuable gifts of their

homelands, military service, and labor to the United States, while the United States is not reciprocating. Participants want their voices to be heard.

By recording our voices and discussions today so that Arkansas can recognize us and open these opportunities to us. That's why when people don't understand they tend not to speak up. They keep silent. Imagine how many years they've been working different places . . . and we're paying toward Medicaid. That's why we represent, as our saying goes, *Jepilpilin ke ejukaan* (interpreted as 'accomplishment through joint effort'). We're here now and we're the voice of the community. And by voicing our discussions through the recorder, it will show our issues.

***Culture and advocacy.*** Participants discussed the lack of attention from the United States on the Marshallese need for coverage. When asked about the absence of advocacy within the Marshallese community, participants explained advocacy was a foreign concept to their culture.

We don't normally just speak out because we have too much respect. It's a culture [value]. And, when I say we don't normally argue, it's because it's our culture. We usually appreciate people and say, she won't argue because she have too much respect, she won't show off her powers, she won't show off her strength, all because she grew up respecting her culture. And so, when she moves to the United States, she doesn't voice her concern because she was brought up to respect the culture and others.

***Good friends.*** When participants talked about their exclusion from Medicaid and Medicaid expansion that is part of the ACA, they did not discuss advocating for policy changes. Instead, participants continually noted they had "been good friends" to the United States and that they expected the United States to be good friends in return. Marshallese prefer a cultural system of reciprocity and trust rather than advocacy or confrontation. As one participant stated, the COFA "is a law that binds the friendship between the Marshall Islands and the United States."

At the end of one of the focus groups, a Marshallese pastor prayed with participants for their voices to be heard through their participation in the study and that unjust laws would be addressed.

Let us pray. Our heavenly Father, we praise thee and worship you. We want to thank you for a fellowship in which there were accomplishments that were needed to reveal to make it better for the Marshallese, those who are dwelling in this community. We hope that it can also work for other communities in other states- make it better, the hardships that these people are facing. Lord, we ask that you open doors. Let your favor take place. There will be laws and magistrates that will make it unbearable for us, but we put our faith in the God we know, who lives amongst us. There will be miracles that have to take place for these hardships to lift off of us. These we pray. The purpose for this fellowship, O Lord, is so you can combine all these thoughts for the betterment.

## **DISCUSSION**

As a public policy, the ACA and Medicaid Expansion provides health insurance coverage for many Americans and has drastically reduced the number of uninsured; however, Marshallese COFA migrants have not benefited equally. There are a few essays that describe the lack of access to Medicaid and insurance coverage for COFA migrants;<sup>3,13-15</sup> however, no previous research presents the COFA migrants' understanding of and experience with the ACA or related health policies. This article adds an important contribution to the literature because it presents the Marshallese's interpretation of the laws in their own words.

Marshallese COFA migrants are caught in a broken and unjust system. By law Marshallese migrants are required to have insurance and pay state and federal tax; however, they are excluded from Medicaid and Medicaid Expansion offered under the ACA. This exclusion significantly impacts the health of the lowest-income Marshallese migrants who struggle below, or near, the poverty line to support their often multi-generational households. While COFA migrants are eligible for tax credits to assist with insurance coverage, these tax credits are based on earning above 133% of the poverty limit. Most Marshallese fall below this level, and those under 133% would typically qualify for Medicaid and would be exempt from paying premiums. Because COFA migrants do not qualify for Medicaid, the cost of premiums is far more

expensive than they can afford. This means most Marshallese cannot afford to purchase insurance through the ACA. While they cannot afford insurance, they are still required by law to have insurance, or face stiff tax penalties if they do not have coverage. Those Marshallese who attempt to apply for insurance under the ACA face significant barriers navigating the application process due to language differences and a lack of understanding of the policy by ACA enrollment staff. In northwest Arkansas, only three bilingual staff were hired and two of those were not stationed in the city where most Marshallese live. Participants recounted numerous stories of unsuccessful attempts to gain insurance, yet they will be penalized if they do not comply with the law requiring them to have health insurance.

Most participants' demonstrate a high level of understanding of the ACA and clearly understand the COFA and details of their COFA migrant status. Their confusion and frustration primarily centers on the lack of understanding about their eligibility among non-Marshallese staff who are supposed to help them enroll in the ACA, coupled with frustration with the contradictory answers they receive concerning how these health care laws affect them. Our findings document that many Marshallese do receive conflicting messages regarding their eligibility for the ACA and Medicaid Expansion. Marshallese COFA migrants also experience extended wait times, as well as widely varying experiences with who is and is not approved for coverage. In addition, there is evidence that the lack of insurance and long delays in approval for insurance is affecting Marshallese access to health care services by postponing treatment and medication refills. Participants also report perceived discrimination when they try to access health care services.

Participants do not view the ACA and related health policies as discrete and separate issues, but instead have a more holistic view and interpret the ACA within the much broader

context of the ongoing relationship between the Republic of the Marshall Islands and the United States. The relationship between the Republic of the Marshall Islands and United States is outlined in the COFA. Participants explain that the COFA is much more than a legal agreement between two nations. For the Marshallese, this agreement represents a compact of friendship between the American and Marshallese people. As our Marshallese community co-investigators and CBPR stakeholders explain, within the Marshallese culture the COFA agreement is more akin to a familial relationship in which friends are revered and honored. Within this relationship, each party is committed to taking care of the other's needs. "Jem-jerā" is the Marshallese term that describes how the Marshallese understand the compact relationship. The concept of "jem-jerā" roughly translates as "blood brothers," or a lasting relationship in which non-family members are placed into a deep nexus of mutual caregiving and obligations within an adoptive family network. As community co-investigators explain, the Marshallese people see the United States as a great friend that saved them during World War II from the cruelty they endured under Japanese occupation. The Marshallese honor their friendship with the United States by giving their lands for the US military's nuclear weapons testing program and missile defense program. Community co-investigators continually stress that nothing is more important to the Marshallese than their land, and they explain that "without land you are a person of no consequence." Participants and community co-investigators feel the United States has taken the most precious gift of land from the Marshallese and then betrayed them by not providing the small gift of access to health care coverage through Medicaid Expansion.

Traditional concepts and methods of policy advocacy in the United States are antithetical to the Marshallese culture's commitment to respect, humility, and graciousness. The undertone of the interviews reveal frustration and dismay that the United States had turned their backs on

the Marshallese people and refuse to honor the friendship agreement. At the same time, participants are gracious, humble, and kind in their attempts to voice this frustration. Throughout the interviews there was an obvious struggle between participants' desire to voice their concern and frustration with the policies while still behaving respectfully and graciously. Throughout data collection and fieldwork, participants and CBPR stakeholders discussed the need for health care coverage by noting that the Marshallese are a good friend to the United States. Rather than demanding their rights, the interviewees continually recount US nuclear testing on their islands, the presence of a US military installation in the Republic of the Marshall Islands, and Marshallese service in the US military. Participants emphasize that since they have been good friends to the United States it is only logical that the United States honor their friendship by being a good friend in return. However, "jem-jerā," or "contract of the friendship," is not reciprocated by the United States.

### **Limitation and strengths**

One of the primary limitations of the study is that the qualitative data was collected from a convenience sample. As Table 1 shows, we achieved a diverse sample within the Marshallese community. Participants included a range of ages, with approximately half insured and half uninsured. Similarly, approximately half had a primary care physician and half did not. While only 50% of participants were uninsured, local studies estimate that the uninsured rate among COFA migrants in Arkansas is closer to 70%. In addition, while bilingual research staff co-facilitated interviews, all participants also spoke English. The understanding of insurance may have been increased because of their relatively high insured rate and English proficiency. We reached saturation after the first two focus group interviews, and consistent themes emerged across the remaining focus groups and individual interviews. For internal validity and credibility,

qualitative researchers are concerned with the degree to which their findings represent the lived experiences of the participants.<sup>61,62</sup> The intensive level of involvement of seven native Marshallese community co-investigators greatly increases the internal validity of the results. Community co-investigators enhanced the data analysis and offered significant cultural insights that unpacked the nuances of participant responses. While there are limits with generalizing beyond Marshallese living in Arkansas, this exploratory study provides important information on these COFA migrants. Qualitative methods allowed us to collect powerful and rich data on the lived experiences and policy interpretation from a segment of the population that is uniquely effected by the ACA and related policies. This study also provides a foundation for future research, policy change, education, and outreach programs.

### **Recommendations for policy and practice**

Several actions and policies of the US federal government (COFA, ACA, PRWORA, nuclear testing, recruitment of Marshallese into the US military, and the use of Republic of the Marshall Islands land for military purposes) create challenges for Marshallese COFA migrants living in the United States. While each of these actions and public policies are made at the federal level, states must now grapple with how to care appropriately for COFA migrants living within their borders. Consistent with our commitment to give voice to our CBPR stakeholders, we offer recommendations for policies and practices based upon the findings of this study.

At the federal level, policy action is needed to restore Medicaid for COFA migrants. COFA migrants were eligible for Medicaid when they agreed to the COFA and then later were left out when PRWORA did not include COFA migrants in the category of “qualified immigrants.”<sup>63</sup> A congressional delegation from Hawaii introduced bills in both the US House of Representatives and the US Senate in an attempt to amend title IV of the PRWORA and restore

Medicaid coverage for citizens of the Freely Associated States lawfully residing in the United States under the COFA. The House Bill (H.R. 2249) was referred to the House Committee on Commerce and Energy and the Senate Bill (S. 1301) was sent to the Senate Committee on Finance. Passage of this legislation would provide much-needed access to health care services for tens of thousands of COFA migrants.

In addition to legislative action, organizations can take steps to mitigate barriers. Local, state, and federal staff, responsible for processing applications and enrollment for ACA, need additional training on COFA migrants' eligibility for coverage. One significant way to eliminate frustration and confusion at the local level is to employ more bilingual IPAs and navigators who are located in the communities where the majority of the Marshallese live. Bilingual fact sheets, both printed copies and on-line web documents, could also be provided to COFA migrants who are scattered throughout the United States.

## **CONCLUSION**

While the ACA and Medicaid Expansion have reduced the uninsured rate nationally and in Arkansas,<sup>44</sup> not everyone has benefited from this policy. Participants in this study recount inconsistent information and long wait times, along with reduced access to health care and medications. The Marshallese interpret the ACA, its requirements and penalties, and their lack of access to Medicaid and Medicaid Expansion as part of the broader relationship between the Republic of the Marshall Islands and the United States rather than a discrete public policy. The COFA is described by the Marshallese as “jem-jerā,” a deep friendship that binds our countries together in a relationship of commitment to care and support. “We created the COFA so that we can help America and so that America can help us.” While participants discuss their frustration with the current policies, rather than engaging in policy advocacy efforts, participants recount



how the Republic of the Marshall Islands and the Marshallese people have been good friends to the United States, and they appeal to the United States to honor their commitment to friendship with the Republic of the Marshall Islands and the Marshallese people. The United States has the opportunity to honor our friendship with the Marshallese people by restoring Medicaid benefits, which would provide equal access to health care benefits.

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## **Chapter Four**

### **Family Model of Diabetes Education with a Pacific Islander Community**

#### **INTRODUCTION**

The northwest Arkansas region is home to the largest Marshallese population in the continental United States.<sup>1,2</sup> The Marshallese are a Pacific Islander community that faces many health disparities due in large part to their current and historical relationship with the United States.<sup>3-9</sup> Between 1946 and 1958, the US Pacific Nuclear Weapons testing program was responsible for detonating 76 atomic and thermonuclear weapons in the Marshall Islands, which is equal to 7,200 Hiroshima-sized bombs.<sup>3</sup> The United States later assumed trusteeship of the Marshall Islands, which required that the United States protect the Marshallese against the loss of land and resources while also promoting their health and well-being.<sup>10</sup> In 1986, the Compact of Free Association (COFA) redefined the relationship between the United States and the Marshallese, and the Republic of the Marshall Islands became an independent country. The COFA agreement allows Marshallese citizens to freely enter, lawfully reside, seek education, and work in the United States without a visa. In exchange, the Republic of the Marshall Islands agreed to the US military's continued presence in their country and permitted the US military to conduct ballistic missile testing in the Republic of the Marshall Islands.

The US military's weapons program has had a profound effect on the health of the people of the Republic of the Marshall Islands. The native Marshallese diet consisted of fresh plants and seafood and the incidence of obesity and diabetes was extremely low.<sup>10</sup> The nuclear fallout from US weapons testing resulted in long-term contamination of the native food supply, creating a reliance on imported processed foods high in refined carbohydrates and saturated fats.<sup>11</sup> The United States provided canned meats and white rice as food commodities during and after

nuclear testing; and these continue to be the preferred foods of the Marshallese after they migrate to the United States.<sup>6,11</sup> This non-native diet coupled with a more sedentary lifestyle has resulted in the Marshallese suffering from a disproportionate burden of diabetes. While there is limited health data on the Marshallese, the available literature documents significant health disparities in the prevalence of type 2 diabetes. Age-adjusted incidence of type 2 diabetes in Marshallese adults, aged thirty or older, is 27% on Ebeye in the Republic of the Marshall Islands.<sup>8</sup> Health screenings conducted by the University of Hawaii and University of Arkansas for Medical Sciences Northwest (UAMS-NW) found the incidence of type 2 diabetes to be 44.2% in Hawaii and 46.5% in Arkansas.<sup>12,13</sup> A local needs assessment in Arkansas, funded by the Centers for Disease Control and Prevention, revealed that diabetes is a top concern for the Marshallese community, with 75% of the respondents listing diabetes as a primary concern.<sup>14</sup>

In 2012, UAMS began engaging the Arkansas Marshallese in a community-based participatory research (CBPR) process to understand what health disparities the community wanted to address. The Marshallese stakeholders chose diabetes. Using a CBPR approach and exploratory qualitative research methods,<sup>1,6,15,16</sup> investigators worked with stakeholders to gain a better understanding of the burden of diabetes in the community, as well as the barriers to care, with the goal of collaboratively addressing the health disparities identified. Investigators began to understand how family and matriarchal kinship play a key role in the life of the Marshallese patient with diabetes.<sup>6</sup> The Marshallese community suggested that for the individual to change, the family must change. In the Marshallese culture, family includes extended members and many households include multiple generations. For example, the same word that is used for mother is also used for aunt and the same word that is used for sibling is also used for cousin.<sup>15,17,18</sup> Based on this information, the Marshallese leaders of the CBPR partnership proposed that diabetes



education be implemented within an extended family model so that the entire family could benefit from the education, and the patient could be supported in their efforts to make lifestyle changes.

Diabetes self-management education (DSME) is an evidenced-based practice that has been found to improve glycemic control and reduce the complications and cost of diabetes management. Though often taught in a group setting, traditional DSME focuses on individual behavior change.<sup>19-24</sup> Traditional DSME may not be as effective in collectivist cultures such as the Marshallese. Prior studies that implemented traditional group-based DSME in the Marshallese population have had limited success.<sup>25,26</sup> Reddy et al. (2005) reported 100% attrition and closed their diabetes educational sessions in Oahu early due to lack of participation.<sup>25</sup> A later study conducted by the same team with Marshallese living on Ebeye in the Republic of the Marshall Islands found a statistically significant improvement in weight loss and blood pressure. They also cited trends toward increased statin use, participation in nutritional counseling, and glucose self-monitoring, but were unable to document significant improvements in glycemic control.<sup>26</sup>

The evidence regarding the influence a patient's family has on glycemic control is evolving.<sup>27,28</sup> In a recent study targeting urban-dwelling adult American Indians and their families, a Family Education Diabetes Series was implemented, and researchers found that social and group-supporting activities are the most important elements affecting behavior change and ongoing disease management.<sup>29</sup> Similar research has been conducted with Hispanic patients where a family-based diabetes intervention showed improved diabetes self-efficacy, increased family support for patients, greater diabetes knowledge, and lower BMI for family participants.<sup>30</sup> Another family-based study focused on patients with the most poorly controlled diabetes also

reported similar positive biometric outcomes and noted improvements in psychosocial well-being and adherence to dietary and exercise recommendations.<sup>31</sup> These studies support the growing evidence that a family model may benefit both the patient with diabetes and their family members as well. Treating diabetes as a family disease influences the planning of educational interventions by including family support members in assessment, modification, and the development of new dietary routines.<sup>32</sup>

## **METHODS**

The interprofessional CBPR study team was comprised of five clinical faculty (one nurse/certified diabetes educator (CDE), two pharmacists, and two endocrinologists), two Marshallese community co-investigators (one community leader and one community health worker), and the lead investigator of the CBPR partnership. The pilot study utilized a pre-test/intervention/post-test design to measure change in hemoglobin A1C (HbA1c) as well as other biometric measures. Questionnaires were administered at the pre- and post-test events, and focus groups were held for each family once the intervention was complete. In addition, we systematically documented the feasibility of a family model of DSME using participant observations and research field reports.

### **Data collection**

Six Marshallese individuals with diabetes were identified and invited to join the study, and these participants invited their family members to become participants in the study and fully participate in all study activities. After all willing family members provided consent, a pre-intervention data collection event was conducted. Participants were asked to fast for at least eight hours prior to the event. Three questionnaires were administered to participants with diabetes and the core questionnaire was administered to all participants, regardless of diabetes

status. The core questionnaire included basic demographics and topics such as past medical history, current medications, social history, and health care and insurance access. The two diabetes-related questionnaires measured self-efficacy and self-care activities. Biometric data was collected using point of care tests for HbA1c, LDL, HDL, triglycerides, total cholesterol, and glucose. A urine collection for microalbumin/creatinine ratio was initially requested from participants; however, participants refused the collection. In addition, blood pressure, height, weight, and waist and hip circumference was measured. Each participant with diabetes was provided a glucometer (Walmart ReliOn brand), test strips (Walmart ReliOn), lancets, and a sharps disposal container. The same procedures and measurements were collected at the post-intervention data collection event.

To capture qualitative data, the lead researcher and a research assistant observed and recorded participants' reactions, behaviors, and interactions among family members, during the educational sessions. After each educational session, the CDE and Marshallese community health worker documented process notes related to feasibility and potential improvements to the DSME curriculum to make it more culturally appropriate for the Marshallese community and family model of delivery. The CBPR research team met monthly to discuss and document what was working well and what was not. Observations and meeting notes were captured as qualitative data.

## **Intervention**

Participants received a total of ten hours of diabetes education over six weekly sessions. Consistent with the American Diabetes Association recommendations, the DSME topics included: healthy eating, being active, glucose monitoring, understanding blood glucose and taking medication, problem solving, reducing risks and healthy coping, mitigating complications

of diabetes, and goal setting.<sup>33-35</sup> Educational sessions were provided in the participant's home or a location of their choice. Five families chose their home and one family chose their church. A CDE taught the educational sessions. A Marshallese community health worker collaborated with the CDE to translate words and concepts as needed and a qualitative researcher documented observations during each session. The educator allotted time at each visit to answer questions and discuss blood glucose measurements from the preceding week.

### **Analysis of quantitative data**

Descriptive statistics were conducted on biometric and survey data. Due to the small sample size and non-normal distribution of continuous outcomes, non-parametric tests were used. Exact chi-square tests for tables larger than 2x2 and Fisher's exact tests for 2x2 tables were applied to compare the differences in proportions. To test the distributional equality in continuous outcomes, correlated-samples Wilcoxon signed rank test was utilized. Analyses were performed with both SPSS and SAS statistical software packages. An alpha level of .05 was chosen as the level at which associations were considered statistically significant.

### **Analysis of qualitative data**

Research field reports, CBPR meeting summaries, and post-event focus group transcripts were coded for core themes related to glucose monitoring, physical activity, nutrition, and medication adherence, which are the cornerstones of DSME.<sup>36</sup> Emergent themes related to feasibility were also identified and coded. Themes were discussed and confirmed with the entire CBPR team (including Marshallese community co-investigators).<sup>37,38</sup>

## RESULTS

### Quantitative results

*Participant survey findings.* Twenty-seven participants, making up six families, were enrolled in the study. Table 1 outlines the participant profiles by diabetes status. Participants were predominantly female (77%), 18-44 years of age (57%), HS graduates or less (71%), and uninsured (56%). Those reporting a diagnosis of diabetes tended to be older and have a lower level of educational attainment than those without a diagnosis of diabetes.

Ratings of health and exercise frequency did not vary significantly with regard to diabetes status. For overall health status, only 15% reported “Excellent” or “Very Good” health. Those participants reporting “Excellent” or “Very Good” health did not have diabetes or pre-diabetes. Despite large numbers of respondents reporting “good,” “fair,” or “poor” health, the majority of all of respondents (73%) indicated that they exercised at least two to three times per week, for at least 30 minutes at a time. Thirty-one percent (31%) reported getting physical activity more than five times per week at half hour or more intervals.

More than half of study participants (59%) answered “no” or “don’t know” when asked if they had a primary care doctor. Those with diabetes were significantly more likely to have a primary care doctor (33%) than those without diabetes (7%),  $p < .05$ . While over half (56%) of respondents reported having had a routine checkup within the last year, 25% of those with diabetes indicated that they had never had a routine checkup and 22% of those with undiagnosed pre-diabetes or diabetes reported never having a routine checkup or having one more than five years ago. In contrast, there were no respondents without diabetes that had not had a routine checkup within the last two years. Nearly half of the participants (48%) reported forgoing health care because they could not afford to see a doctor. This number was skewed by those with

diabetes. Nearly 65% of those with diabetes stated that they needed to see a doctor, but did not because of cost, while only 31% of those without diabetes reported the same.

**Table 1. Participant Demographics and Health Factors by Diabetes Status**

	n*	Diabetes†	No Diabetes†	p-value‡
Age				
18-44	15	4 (15%)	11 (42%)	<b>.002</b>
45+	11	10 (38%)	1 (4%)	
Sex				
Male	6	5 (19%)	1 (4%)	.165
Female	21	9 (33%)	12 (44%)	
Education				
High School Graduate or Less	17	11 (46%)	6 (25%)	.182
Some College or College Graduate	7	2 (8%)	5 (21%)	
Insurance Coverage				
Yes	12	4 (15%)	8 (30%)	.128
No	15	10 (37%)	5 (19%)	
Health Status				
Excellent/Very Good	4	0	4 (15%)	<b>.041</b>
Good/Fair/Poor	23	14 (52%)	9 (33%)	
Weekly Exercise				
5 x week or less	18	8 (31%)	10 (38%)	.216
>5 x week	8	6 (23%)	2 (8%)	
Primary Care Doctor				
Yes	11	9 (33%)	2 (7%)	<b>.021</b>
No	14	4 (15%)	10 (37%)	
Don't know	2	1 (4%)	1 (4%)	
Time Since Routine Checkup				
Never/More than a year ago	10	5 (22%)	5 (22%)	.685
Within the past year	13	5 (22%)	8 (34%)	
Couldn't get care due to cost				
Yes	13	9 (33%)	4 (15%)	.174
No	12	4 (15%)	8 (30%)	
Don't know	2	1 (4%)	1 (4%)	

\*Total sample = 27; categories with less responses indicate missing values

†Diabetes status determined by HbA1c values at pre-intervention data collection; HbA1c  $\geq 6.5\%$  indicates diabetes

‡Fisher's exact test;  $p < 0.05$

**Participant retention and attrition.** Of the 27 participants who enrolled in the study and completed the pre-intervention data collection, 21 completed the post-intervention data collection, resulting in a retention rate of 78%. One (1) participant family completely dropped out of the study. This participant was unable to recruit additional family members to participate with her and cited a lack of family support as the primary reason for withdrawing from the study. The other five (5) non-completers attended some educational sessions, but did not complete the post intervention data collection event. Family members of the five who did not complete the post-event data collection stated that the participants moved out of the household. Table 2 illustrates the characteristics of those who did and did not complete the study.

**Table 2. Profile of Retention and Attrition**

	Diabetes Status*		Pre-Intervention Mean and Standard Deviation				
	Diabetes	No Diabetes	Age	Total Cholesterol (mg/dL)	HbA1c (%)	HbA1c (mmol/mol)	BMI
Completers	11	10	49.1 (12.9)	170 (42)	8.9 (3)	74 (32.8)	31.1 (5)
Non-Completers	2	4	37.9 (15.6)	149 (24)	6.4 (1.3)	46 (14.2)	35.2 (7.4)
Total Sample	13	14	45.5 (14.3)	155.7 (37.4)	7.7 (2.6)	61 (28.4)	32.1 (5.7)

\*Diabetes status determined by HbA1c values at pre-intervention data collection; HbA1c  $\geq$  6.5% indicates diabetes

**Biometric data.** The pre-intervention test results revealed that 44% of participants (12) had undiagnosed diabetes (HbA1c = 6.5% and greater) or pre-diabetes (HbA1c = 5.7-6.4%). Pre-intervention HbA1c results yielded a mean of 9.7% for participants with diabetes and 8.1% for the entire sample (Table 3). Participants' lipid profiles did not reveal any significant dyslipidemia.

Post-intervention data showed a mean HbA1c of 9.0% for participants with diabetes and 7.7% for the entire sample. Thus, over the period of the study, there was a 7% reduction in HbA1c among participants with diabetes and a 5% reduction in HbA1c among all participants.

**Table 3. Pre- and Post-Intervention Biometric Results**

	Pre-Intervention (mean and SD)	Post-Intervention (mean and SD)	t	p-value*
BMI	31.2 (5.0)	31.3 (5.6)	-0.3	.782
Total Cholesterol (mg/dL)	157.6 (40.8)	167.2 (43.7)	-1.4	.178
HDL (mg/dL)	38.4 (12.7)	41.7 (12.3)	-1.8	.087
HbA1c (%)	8.1 (2.8)	7.7 (2.4)	1.5	.142
HbA1c (mmol/mol)	65 (30.6)	61 (26.2)		

\*Includes completers only (n=21)

Variations between families were evident; some families had better outcomes than others (Table 4). Families 2, 3, and 4 had an HbA1c reduction, while Families 1 and 5 remained virtually the same. The CBPR team reviewed process notes and discussed the possible reasons for this. The research team postulates that there was notable variation in engagement levels of family groups, and this may have impacted results. Table 4 outlines changes in selected measures as well as study retention by family unit. Possible explanations for these variations are discussed in the conclusion.

**Table 4. Change in HbA1c, Total Cholesterol, HDL, and BMI by Family**

Family ID	Enrolled	Completed	Mean Change in Selected Measures				
			HbA1c (%)	HbA1c (mmol/mol)	Total Cholesterol (mg/dL)	HDL (mg/dL)	BMI
1	3	3	0.1	1.1	21.3	14.8	0.2
2	3	2	-1.85	-20.2	39.5	1.5	0.75
3	6	4	-0.53	-5.8	4.3	2.75	0.05
4	8	6	-0.43	-4.7	9.3	-1.83	0.08
5	5	4	0.1	1.1	-23.3	1.6	2.15



## **Qualitative results**

The four cornerstones of DSME are blood glucose monitoring, physical activity, nutrition, and medication adherence.<sup>36</sup> Qualitative observations will be presented according to these four categories. In addition, emergent themes relating to the feasibility of implementing DSME within an Arkansas Marshallese family group are presented. The themes that emerged from the observations included: the feasibility of data collection events, the family dynamics in a home environment, and family engagement and support.

### **DSME Cornerstones**

***Blood glucose monitoring.*** The intervention team observed that participants had little understanding of blood glucose, basic internal anatomy, or biological function of the body. The Marshallese language does not have words for many internal organs; nor are there common words to describe how internal organs function. DSME sessions often started by asking questions such as “do you know what your pancreas does?” This type of quizzing about internal anatomy was not effective, and researchers observed the participants becoming embarrassed and defensive when they were asked questions about anatomy. The lack of knowledge about basic anatomy meant additional time was needed to explain internal organs - such as the pancreas - and their function. Additional time was also needed to explain why persons with diabetes need to check their blood glucose regularly, how different foods affect blood sugar, and how the glucometers work. The CDE found it necessary to review glucose monitoring at each educational session.

***Physical activity.*** When physical activity was discussed, purposeful activities such as yard work and house cleaning were regarded as more acceptable by participants than formal exercise. Participants reported that walking around the neighborhood for exercise would be odd and is not seen as culturally appropriate within their community. While participants under forty years old reported practicing for traditional dances and playing sports such as baseball, basketball, and volleyball and discussed ways to increase these activities, older participants reported very little physical activity and found it more difficult to formulate plans to increase physical activity. Participants also reported that they show respect to elders by allowing them to sit still while younger people do daily activities. This show of respect greatly reduces the amount of daily physical activity for older Marshallese adults. In addition, all families noted that most formal exercises, sports, and dance must be done in groups of men only or women only to adhere to cultural standards of behavior.

***Nutrition.*** Standard nutritional approaches used with DSME curriculum were not well understood by participants. Marshallese families reported that they lacked knowledge regarding many foods available in the US and how these foods are prepared. In addition, serving sizes and basic measurements of food were not well understood. Additional cultural adaptation of the basic meal plans presented in the DSME was required because most of the foods on standard meal plan charts are not the foods that the Marshallese families recognized or routinely consumed. Participants also lacked a basic understanding of nutrients -carbohydrates, protein, and fat - that are the foundation of diabetes nutritional counseling. Participants reported understanding that sugar affected their diabetes, but did not understand that simple carbohydrates had a similar effect. Participants with diagnosed diabetes discussed the difficulty of eating differently than the rest of the family. Meals are very rarely eaten alone and were discussed as social events that

include extended family and friends. Participants explained that to honor or thank someone, it is culturally appropriate to offer food and that refusing food is seen as disrespectful.

***Medication adherence.*** Participants discussed numerous misconceptions about and barriers to medication adherence. Participants reported that they thought they were only supposed to take the medication until it ran out and did not understand that they were supposed to refill their medication. Educators spent significant time discussing how diabetes medication worked, the importance of taking your medication consistently, and refilling prescriptions after they ran out. Participants also reported that the cost of medication was a primary barrier. Many participants (56%) did not have insurance and 52% stated that they could not afford to purchase their medications or see the doctor to obtain updated prescriptions. Even participants with insurance reported not being able to afford the co-pay for prescriptions. Currently, Marshallese COFA migrants are excluded from Medicaid and Medicaid expansion under the Affordable Care Act.<sup>9</sup>

### **Feasibility**

***Data collection events.*** While the team successfully conducted pre- and post-event data collection in the home environment, biometric data collection among Marshallese participants had challenges. Weight and waist measurements needed to be collected in a private location, which was often difficult in a small home. We did not capture hip measurements on men due to feedback that it was culturally inappropriate for a female data collector to take that measurement. Many participants did not fast if data collection events took place after noon. Our initial protocol called for collecting urine to conduct micro albumin/creatinine ratio analysis, but the first two families refused collection. After further discussion with our CBPR advisory board and the Marshallese community health worker, this collection was dropped because the urine collection

was seen as culturally inappropriate. The participants also reported difficulty interpreting the continuum of responses on a Likert scale and preferred responses that were yes or no.

***Family dynamics and home environment.*** A home environment requires flexibility. Educators have less control over the environment and had to make changes based upon the dynamic within each family. For example, three (half) of the families had children under five who were present at each meeting. There were frequent interruptions with children and family members coming in and out of the DSME sessions. Most of the homes were small and often educators and participants sat on the floor. While homes were a more challenging environment for educators and clinicians, participants reported many benefits to receiving DSME in the home environment. Specifically, participants did not have to overcome barriers to transportation and they did not have to find childcare. Participants also reported feeling more comfortable and relaxed.

***Family engagement and support.*** There were varying levels of family-member engagement observed by the research team. Those family members with diagnosed and undiagnosed diabetes and pre-diabetes were observed as having the highest level of engagement. In all of the five families who completed the study, there was a family member who the research team identified as being a primary family caretaker and DSME “encourager.” Sometimes this person had diagnosed or undiagnosed diabetes, and sometimes they did not. This person was female in all but one family. The “encourager” typically was not the primary participant, but instead the child or spouse of the primary participant. Consistent across all families was the “encourager” role in continuously engaging family members in the education process.

## CONCLUSION

### Limitations and strengths

The study has some limitations that need to be acknowledged. The sample size of six families (27 individual participants) is small; however, the sample size was appropriate for a feasibility pilot with a population where the DSME had not previously been successful. The pilot allowed researchers to document feasibility and identify additional adaptation needed for a larger randomized control trial. The study's primary outcome measure was HbA1c; however, HbA1c levels have been shown to be influenced by race and ethnicity.<sup>39,40</sup> While HbA1c is considered the best measure of long-term glycemic control, future studies may need to consider other markers including fructosamine and glycated albumin, given the potential limitations of HbA1c.

While the pilot study sample was small, it is encouraging to see a mean HbA1c reduction of 5% across all participants and a 7% reduction among those with type 2 diabetes. The information gained from this pilot helps bridge the gap between knowledge of an evidenced based intervention – DSME - and the actual implementation of the intervention among a Pacific Islander sub-population with especially high rates of type 2 diabetes and significant health disparities. Building on the emerging literature on family models of DSME, this study shows that family models may help increase retention in hard-to-reach populations. Prior studies with Marshallese participants were not successful primarily because of poor retention.<sup>25</sup> Participant retention was reasonably high for this study; only one family dropped out of the study and 78% of all participants completed the study which indicates a high level of participant acceptability.

Varying levels of family-member engagement were observed. We did not utilize a specific engagement scale; however, the implementation team discussed family engagement at

length. Three of the six families were observed as having high levels of engagement and three families had lower levels of engagement. The three families with the highest level of engagement saw notable decreases in HbA1c. One family with lower levels of engagement dropped out, and the other two families with lower levels of engagement remained virtually the same with respect to HbA1c. Documentation of family engagement measures would allow researchers to identify and test whether the level of engagement influences outcomes.

Total cholesterol levels were lower than would be expected, given the suboptimal glycemic control seen among participants. Because the sample size is small and not all participants fasted, this a tentative, yet interesting observation. Additional data collection with fasting lipids is needed to better characterize the degree and frequency of lipid abnormalities in this population.

Based on the emerging evidence related to family models of DSME, the pilot provides insight into the feasibility of providing DSME in a home environment with family participants who do and do not have diabetes. While additional adaptations are necessary for implementation in a clinical setting, an extended family model may be a crucial factor in ensuring better outcomes for the Marshallese and other collectivist communities.

Further research is needed to reduce the health inequalities and significant disparities in type 2 diabetes care and outcomes experienced by the Marshallese. Field process notes suggest that DSME curriculum cultural adaptations are needed in each of the four cornerstone areas of DSME (glycemic control, nutrition, physical activity, and medication adherence). Based upon the results of this pilot study, the interprofessional research team is conducting a randomized control trial of a culturally adapted DSME curriculum delivered in a family model.

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## **Chapter Five**

### **Conclusion**

This dissertation presents three papers that are part of a cohesive research agenda predicated on a community-based participatory research (CBPR) approach. My research can be used to inform health policy, health care services, and health education at the organizational, community, state, and federal levels. Chapter Two presents an article titled: *Health Beliefs of US Marshallese Regarding Type 2 Diabetes*. This article explores the research question: what health beliefs related to diabetes influence diabetes self-management behaviors? Chapter Three presents an article titled: *Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act*. This article explores the research questions: for Marshallese living in the United States, 1) what is their understanding of and experience with the ACA and related health policies; 2) what effect do the ACA and related health policies have on participants' and the community's health? Chapter Four presents an article titled: *Family Model of Diabetes Education with a Pacific Islander Community*, and this article explores the feasibility of a family model of diabetes education that was conducted in participants' homes with extended family members. In this concluding chapter, I discuss the overarching goal of the research, significant findings of each article, and their contribution to the literature. I also discuss limitations and strengths of the research and provide recommendations for policy and practice. I conclude by discussing recommendations and plans for future research.

#### **Goal of the research and contributions to the literature**

My dissertation research uses a CBPR approach to build evidence that will address health disparities in the Marshallese community living in Arkansas. This research is important to health care providers and policy makers because it fills a current gap in knowledge. Marshallese are a

group of Pacific Islanders, and the Pacific Islander population is rapidly growing in the United States, having increased 40% between 2000-2010.<sup>1</sup> During that same time period, Pacific Islanders increased by more than 250% in Arkansas.<sup>1</sup> Pacific Islanders have severe health disparities, and they remain underrepresented in health research.<sup>2-4</sup> Specific health information on Pacific Islanders is often obscured and confounded when it is aggregated with Asian Americans.<sup>2-8</sup> It is well established that prevalence estimates of health-risk behaviors and health research outcomes exhibited by Asian Americans and Pacific Islanders are very different and should be reported separately. The current aggregation of data renders many subgroups of Pacific Islanders, such as Marshallese, invisible and perpetuates the health disparities of these populations.

This research is timely and significant for health policy, health care practice, and health education. In September 2011, a summit focusing on “Diabetes in Asian Americans, Native Hawaiians, and Pacific Islanders: A Call to Action” was held in Honolulu, Hawaii, by the National Council of Asian Pacific Islander Physicians, American Diabetes Association, and other member organizations of the Asian American, Native Hawaiian, and Pacific Islanders Diabetes Coalition.<sup>9</sup> Recommendations from that summit and a review of the literature following the summit cited the lack of Pacific Islander participation (including Marshallese) in diabetes prevention and treatment practices and called for increased research to understand the effectiveness of both community-based and clinical diabetes prevention, education, and treatment options.<sup>10</sup> Similarly, both the National Institutes of Health and Patient Centered Outcomes Research Institute have called for increased research in Pacific Islander populations. In October of 2009, President Obama signed an executive order that restores the White House Initiative on Asian Americans and Pacific Islanders. The initiative is dedicated to addressing concerns of the

Asian American and Pacific Islander community and calls for increased research to address health disparities within subpopulations of Pacific Islanders. My work aims to respond to these calls for action and addresses the gaps in the literature related to Pacific Islanders health disparities. My research can be used to improve health care services, health education, and policy action.

### ***Chapter Two contributions***

Chapter Two presents the article titled: *Health Beliefs of US Marshallese Regarding Type 2 Diabetes*. In this article, I use qualitative methods to explore the diabetes health beliefs of Marshallese in Arkansas. The Health Belief Model is an established theoretical framework for understanding why people do or do not engage in recommended health behaviors such as diabetes self-management. The model is often used as a first step in understanding the reasons underlying behaviors prior to developing health education interventions. The results show that Marshallese participants believe that diabetes is a significant threat and describe it as a deadly disease, and they see the threat as unique to their community. They also see the threat and their susceptibility linked to genetics or nuclear exposure rather than behavior. There is little understanding of the benefits of diabetes self-management behavior and significant barriers to achieving the recommended behaviors. The research demonstrates that many of the barriers are environmental and outside the control of the patient and broader Marshallese community. These barriers include: limited health care access, lack of transportation, cost of healthy foods, and lack of culturally appropriate health education. The primary cue to action among participants was the diagnosis of diabetes. Participants demonstrate varying levels of self-efficacy and recommended real-life examples of people within their community who have been successful in achieving self-management behaviors as the best way to increase self-efficacy.

This research is significant because Marshallese suffer from extremely high rates of type 2 diabetes, and <sup>11-15</sup> prior research evaluating interventions address diabetes in the Marshallese population failed to show glycemic control, the primary clinical outcome for diabetes, among participants.<sup>16,17</sup> Cultural adaption is often needed for health interventions to be effective in minority populations.<sup>18,19</sup> The Health Belief Model, is an evidence-based model that is used to examine cultural beliefs, and the model can serve as a foundation for developing or adapting health behavior interventions to focus on the beliefs of a population.<sup>20-23</sup> This article is significant because it is the first article that uses all of the constructs of the health belief model to examine the beliefs of the Marshallese related to Diabetes.<sup>24</sup> The article will be an important foundation for diabetes interventions with the Marshallese community. The research can be used to inform health educators and to develop health interventions to improve diabetes self-management behavior. The findings may also be informative to diabetes prevention efforts with the Marshallese. In addition to the person level barriers, this article identifies systems, environmental, and policy barriers that must be addressed through public policy in order to facilitate self-management behavior among the Marshallese in Arkansas. See Chapter Two and pages 124-127 of this chapter for additional details on specific recommendations for addressing those policy barriers.

### ***Chapter Three contributions***

Chapter Three contains the article titled: *Interpretive Policy Analysis: Marshallese COFA Migrants and the Affordable Care Act*. In this article, I use an exploratory, qualitative method predicated upon Yanow's (2000) approach of policy interpretation that seeks to understand the meaning of a policy for a particular audience.<sup>25</sup> Yanow recommends that policy analysts take an interpretive approach and use qualitative methods to engage stakeholders to understand their

values, beliefs, and feelings about a policy.<sup>25</sup> The paper seeks to understand: 1) what are the Marshallese's understandings of and experiences with the ACA and related health policies; and 2) what effect do the ACA and related health policies have on participants and the community's health?

This article provides evidence that most participants have a high level of understanding of the ACA; however, participants reported their observations that many non-Marshallese staff who are responsible for ACA do not understand how the ACA is uniquely applicable to COFA migrants. Participants reported significant frustration with their experiences trying to apply for the ACA and reported that their lack of eligibility for Medicaid expansion and difficulty enrolling in the ACA has affected their access to health care and their health status.

Participants do not describe the ACA as discrete and separate policy outside their overarching relationships with the United States. Participants interpret the ACA as an integral part of the relationship between the Republic of the Marshall Islands and the United States. The COFA details the relationship between the Republic of the Marshall Islands and United States, and participants conceptualize the COFA as much more than a legal agreement. Participants describe the COFA as a compact of friendship. In the Marshallese language the term “Jem-jerā” is used when referencing the COFA. A “Jem-jerā” is a deep relationship where each party is committed to taking care of the other party's needs. Participants describe the many ways in which they had fulfilled their responsibilities in the relationship, but expressed frustration that they did not think that the United States is fulfilling its part of the relationship. The implementation of the ACA and lack of Medicaid access was described as evidence that the United States was not fulfilling its obligations. This article also provided insight into the Marshallese's perceptions related to traditional methods of policy advocacy in the United States.



These methods are antithetical to the Marshallese's strong belief in the importance of respect, humility, and graciousness.

While the ACA and Medicaid Expansion provide health insurance coverage for many Americans, and these policies have reduced the number of uninsured, Marshallese COFA migrants have not benefited in the same way as other populations. This paper fills a gap in literature related to Marshallese COFA migrants' understanding and experience with the ACA and related health policies. While there are a few essays that describe the lack of access to insurance coverage for COFA migrants,<sup>26-29</sup> this research is the first to amplify the voices of the Marshallese community. This article presents the Marshallese's interpretation of the laws in their own words and can be used to implement systems interventions at the organizational and community levels. In addition, the research can be used to advocate for policy change to improve health equity. See Chapter Three and pages 124-127 of this chapter for additional details on specific policy recommendations.

#### ***Chapter Four contributions***

Chapter Four presents the article titled: *Family Model of Diabetes Education with a Pacific Islander Community*. This research tests the feasibility of a family model of diabetes education that is conducted in participants' homes with extended family members. The Marshallese are a Pacific Islander community with extremely high rates of diabetes. While diabetes self-management education has been shown to be effective in reducing diabetes complications and cost,<sup>30-33</sup> there is no literature that documents a successful implementation of diabetes self-management education in the Marshallese population. There is a growing body of literature that suggests that culturally-targeted diabetes interventions that include family

members can improve outcomes for both patients and their family members;<sup>34,35</sup> however, these methods had not been tested in the Pacific Islanders community.

This article demonstrates initial feasibility of a family model of DSME in the Marshallese community. Specifically, prior studies with Marshallese participants were not successful retaining participants through the 10 hours of intervention.<sup>17</sup> This article documents comparatively high retention rates, with 78% of all participants completing the study. In addition, the mean reduction in HbA1c of 5% across all participants and a 7% reduction among those with type 2 diabetes is quite encouraging and provides a possible solution to the diabetes related health disparities.

The article is a significant bridge in the gap between an evidenced based intervention and the actual implementation of the intervention among a Pacific Islander sub-population with especially high rates of type 2 diabetes. The evidence has the potential to help address the drastic health disparities in type 2 diabetes in the Marshallese community. This article builds on the emerging literature on family models of diabetes management.<sup>36-41</sup> This pilot data will be used to inform a larger, randomized control trial using a comparative effectiveness design to test the ability of the family model of diabetes self-management education to improve glycemic control (HbA1c).

Collectively, my work is significant and fills a gap in the literature related to the COFA migrants, how they are affected by the ACA and related health policies, and how the COFA, ACA, and PRWORA are perpetuating health disparities. A thorough review of articles published on Marshallese health shows a limited number of studies on the health of Marshallese living in the United States. The vast majority of previous studies were conducted in the Marshall Islands and focused on cancer and other health effects resulting from radiation

exposure.<sup>11,12,16,17,42-95</sup> There is a small body of literature that addresses type 2 diabetes among the Marshallese, and nearly all studies fail to document the prevalence and severity of diabetes or cultural and structural influences related to the diabetes epidemic.<sup>11,12,16,17,42,49,60</sup> There is only one article that documents the health beliefs of Marshallese migrants related to diabetes. This article focuses solely on barriers to self-management and does not use the full health belief model.<sup>24</sup> The two studies that documented diabetes education interventions with the Marshallese included one conducted in the Republic of the Marshall Islands and one conducted in Hawaii. Both of these studies failed to show improvement in glycemic control, which is the primary clinical goal for diabetes education.<sup>16,17</sup> There are two articles regarding COFA migrants and Medicaid access, but both are essays rather than qualitative policy analyses.<sup>26,27</sup> My research builds upon these published studies, and significantly expands the knowledge related to the way health policies affect the Marshallese, diabetes disparities among the Marshallese, and possible solutions to address those disparities. .

### **Limitations and strengths**

There are limitations to the research presented in this dissertation. For each of the articles, the primary limitation is the convenience sample of Marshallese adults living in Arkansas. While each study was successful in recruiting a diverse sample of Marshallese participants, the studies were focused solely on one population group in one geographic location. The convenience sample limits the study's generalizability to other populations and Marshallese living outside Arkansas. Furthermore, the studies did not have a comparison group to determine how the responses and results compared to the results of other populations groups.

The sample size is also a limitation to the study. The sample size of each study was appropriate for exploratory nature of the studies; however, they were relative small.<sup>96,97</sup> The

sample size is most important in the pilot study designed to determine the feasibility of a family model of diabetes self-management education presented in Chapter Four. The sample size was only six families, with 27 participants. The small sample size does not allow confounding factors to be controlled for during the statistical analysis. While small, the sample size is appropriate for a feasibility pilot with a population where the diabetes education had not been successfully implemented.<sup>98</sup> The pilot was successful in documenting feasibility, and it allowed me to identify additional adaptations needed before implementing a larger, randomized control trial.<sup>98</sup> While the retention rate of 78% is consistent with most clinical trials,<sup>99</sup> and the retention rate is much higher than previous trials with the Marshallese population,<sup>17</sup> the loss of six participants further weakens the results of the trial.

Even with these limitations, the design of each of the studies is appropriate to answer the research questions. For Chapters Two and Four, the qualitative design is appropriate for this exploratory study and allows me to explore the beliefs and perceptions of a Pacific Islander population who face significant health disparities and who are uniquely affected by health policies. The qualitative design in Chapters Two and Four provides participants with the opportunity to share their beliefs, perceptions, and their lived experiences in their own words. To increase the value of the feasibility pilot presented in Chapter Three, I chose a mixed-methods design and utilized educators' clinical notes and research associates' field notes to systemically document elements of feasibility beyond quantitative data (recruitment, retention, and biometric data).

Most importantly, the use of a CBPR approach and community co-investigators help increase the internal validity of the studies. For the two qualitative studies, internal validity is determined by how well the results and discussion represent the authentic lived experiences of the

participants, rather than the sometimes inaccurate interpretations of the researcher.<sup>100-107</sup> The community co-investigators helped unpack the nuances of meaning and greatly increased the internal validity of the article. In addition, I analyzed themes across focus groups and interviews to determine if there were differences among groups, as well as to understand when I reached thematic saturation. For both qualitative studies, there was consistency across groups and saturation was reached early in the study. The additional participant data collected after saturation served to provide richness and confirm accuracy of the data.

### **Recommendations for policy and practice**

From the start of my engagement with the Marshallese, community members stated that they did not want to participate in research where they are "guinea pigs." Instead they want to partner in research that will result in action and tangible benefits for their community. CBPR goes beyond just documenting problems by engaging in research that *contributes to*, rather than *takes from*, a community by providing addressing topics deem important by the community.<sup>108-110</sup> Most importantly, CBPR can fuel policy action by providing information for policy-oriented learning and by connecting CBPR partners to larger coalitions. Below, I discuss the recommendations for policy and practice at the federal, state, community, and provider levels.

#### ***Federal***

Based upon the finding of Chapters Two and Three, it is evident that a lack of access to Medicaid and Medicaid Expansion through the ACA is a significant barrier to for the Marshallese. Therefore, it is recommended that Medicaid to be restored for COFA migrants. This must be addressed at the Federal level. Marshallese were eligible for Medicaid when they agreed to the COFA, but ten years after the agreement was signed, they were left out when PRWORA's definition of qualified immigrants did not include COFA migrants.<sup>111</sup> Delegates from Hawaii

have introduced bills in the US House of Representatives and the US Senate in an attempt to restore Medicaid coverage for citizens of the Freely Associated States lawfully residing in the United States under the COFA by amending title IV of the PRWORA. H.R. 2249 was referred to the House Committee on Commerce and Energy. S. 1301 was referred to the Senate Committee on Finance. Approval of the legislation would restore Medicaid and provide health insurance to tens of thousands of COFA migrants.

### *State*

Based upon the findings in Chapter Three, staff processing ACA enrolment applications need additional training on COFA migrants' eligibility for coverage under the ACA. Areas with high numbers of COFA migrants need to hire more bilingual, in-person assisters (IPAs) and navigators who are located in the towns where the Marshallese reside. The state should also consider producing bilingual information and providing that information in print and on-line.

### *Community*

In addition to action at the federal and state levels, there are policy changes and actions that need to take place at the community infrastructure level. The primary recommendation is to expand and promote access to health care services for the uninsured. In Chapters Two and Three, Marshallese participants discussed the difficulties of finding a health care provider to care for them when they do not have insurance. While there are safety net clinics in the area, the Marshallese participants did not report accessing them very often. This could be due to organizational barriers, or could be a lack of knowledge about the safety net clinics and how to access the clinics. A community needs-assessment needs to be conducted to understand and mitigate barriers to accessing care at safety net clinics.

A second community-level barrier identified in Chapter Two is a lack of access to healthy foods. Preventing and managing diabetes requires adhering to nutritional guidelines for a diet high in vegetables and lean proteins. These foods cost more than the highly processed carbohydrates and fatty, processed meats that participants reported eating. Participants discussed the cost of food as a primary barrier to following a healthy diet. Food pantries and community meal programs should implement healthy food policies and programs that promote health food distribution, which would increase access to healthy foods among low-income community members, including Marshallese. Chapter Two also identified a lack of public transportation as a barrier to getting the medical treatment required to care for diabetes. Transportation also limits work and food options. It is important for Northwest Arkansas to consider how to expand public transportation options.

### ***Health care providers and health educators***

The research also informs recommendations for health care providers and health educators working with the Marshallese community. Chapters Two and Four provide insight into Marshallese beliefs about and experiences with diabetes that can be used to understand why interventions may or may not be effective within the Marshallese Community. The research in Chapters Two and Four indicates that cultural adaptations will be needed for diabetes education and the promotion of effective self-management behaviors. It appears that a more collectivist, family approach to diabetes education should be developed, refined, and tested using a randomized control trial design.

Based upon the Marshallese participants' belief that diabetes is largely outside their control, health educators can take care to relate diabetes to a person's behavior, and clarify the etiology of diabetes as a disease based on personal lifestyle rather than fate. Care should be

taken to do this without heightening the stigma and shame associated with diabetes. The Marshallese are a collectivist culture, and as noted above, education efforts should involve family and community members, rather than focusing solely on individuals. Educators can also focus on the positive outcomes of self-management behavior for individuals, families, and the broader Marshallese community. Health care providers and health educators can promote diabetes screenings to allow for quicker diagnosis. Marshallese participants discuss learning by example, and educators can promote successful role-model cases to increase Marshallese patients' confidence in their abilities to successfully manage diabetes. Education should take into consideration language barriers, provide written information in Marshallese, and consider using Marshallese translators and community health workers to mitigate barriers.

### **Future research**

Marshallese and other Pacific Islanders face significant health disparities. Health information and clinical trials data is often aggregated with Asian Americans.<sup>2-4</sup> Several organizations, including US Department of Health and Human Services, National Institutes of Health and Patient Centered Outcomes Research Institute recognize the need for more research on Pacific Islanders. Given the limited amount of research with Pacific Islanders, and Marshallese specifically, there is much important and exciting research to be conducted in the future.

Based upon this dissertation research, the University of Arkansas for Medical Sciences will establish a Center for Pacific Islander Health. The Center for Pacific Islander Health will focus on research with Pacific Islanders in Arkansas, the United States and the US Affiliated Pacific Islands. There are three specific areas of studies that will be taken as next steps based upon this dissertation research.



First, based on the exploratory qualitative data presented in Chapter Two, I will conduct a broader quantitative study of health beliefs in the Marshallese population living in Arkansas. While a true randomized sample may not be feasible, I will utilize an institutional-level randomization method to create a church-based, clustered sampling design that will allow me to increase the total number of participants and the diversity of Marshallese participants. The survey will be based upon the qualitative work presented in Chapter Two, making the study an exploratory, sequential, mixed-methods design. The survey will be conducted in both English and Marshallese to allow those with limited language skills to participate. The quantitative data can be analyzed to determine if results vary by certain factors – i.e. age, insurance status, education, length of time in the United States. This future research, combined with the qualitative data in this dissertation, can be used to: identify policy barriers and their possible solutions, and construct health interventions to prevent and manage diabetes.

Second, additional interpretive policy analysis research is needed with Marshallese COFA migrants living in other parts of the United States. Specifically, qualitative research is planned for Hawaii, Oregon, Washington, and Oklahoma. It is important to understand if the Marshallese COFA migrants in those areas interpret the ACA and related health policies in the same way as COFA migrants in Arkansas. In addition, it is important to quantitatively document the number of COFA migrants who attempted to sign up for the ACA. Among those who attempted, it is important to understand who was and was not successful in gaining coverage. In addition to clearly documenting the number who have enrolled in the ACA, it is important to understand if they are able to maintain coverage or if they become uninsured because of a failure to pay premiums or other factors. To date, the Arkansas Department of Health has not been able to gain

access to this data, but I continue to work with them to acquire this information. Ultimately, this information would help inform both state and federal policies.

Third, based upon the article in Chapter Four (*Family Model of Diabetes Education with a Pacific Islander Community*), I have received funding to conduct a large comparative-effectiveness research (CER) study using a randomized control trial (RCT) design. The study will compare the family model of diabetes self-management education, using a culturally adapted curriculum, to a traditional group model of diabetes self-management education. The pilot research outline in chapter four was used to inform the larger RCT and adapt the curriculum to make it more culturally appropriate for the Marshallese community. Specifically, family models of motivational interviewing which includes the entire family in the educational process are used. Imbedded within the design is an examination of the role of the family encourager. While family encouragement is noted as an important factor in the pilot study, additional information is needed to document the specific behaviors of the family encourager and to determine if the presence and intensities of encouragement of this person has a statistically significant influence on participant retention and/or glycemic control. In addition, I have imbedded an examination of the barriers so that I can understand the barriers that constrain self-management behavior at the personal, interpersonal, organizational, community, and policy levels. The documentation of those barriers can be used for policy-oriented learning and policy advocacy.

Beyond my own research agenda and plans, this dissertation informs the need for additional research in four important areas. First, a broader examination of the impact of the ACA by subpopulations, including immigrant and migrant populations, is needed. While the ACA has significantly reduced the number of uninsured, it is clear that not all people benefit from the law. Second, an examination of family models of chronic disease management for other

Pacific Islander sub-populations and other minority communities is needed to understand if the research is generalizable beyond the Marshallese in Arkansas. Third, the reimbursement, cost/benefit, and policy implication of a family model of chronic disease management will need to be examined. Even if a family model is better at managing glycemic control, there may be barriers to broad implementation based upon current insurance reimbursement policies and health information and privacy policies. Forth, additional research is needed to test the Advocacy Coalition Frame (ACF) as a prospective model when paired with community-based participatory approach to implement policy changes identified by through CBPR. The ACF describes how political participants align themselves with others who have similar policy core beliefs to form advocacy coalitions.<sup>112-114</sup> This alignment is central to the methods of CBPR. Furthermore, the ACF describes the political system as being confined by stable parameters and systems, with two paths to policy change. The most relevant path to CBPR is policy-oriented learning. Policy-oriented learning can be facilitated through CBPR that provides information to advocacy groups.<sup>112-114</sup> Despite the apparent alignment, there is no documentation of a CBPR partnership using the ACF as a prospective model to implement policy change identified as part of the CBPR approach. Given the pace of CBPR and policy change, this would take a significant amount of time, but would be an important contribution to the literature.

## **CONCLUSION**

The three articles in this dissertation significantly contribute to the literature and set an exciting foundation for future research. This research, and my broader research agenda, seeks to improve health equality and decrease health disparities for the Marshallese community by providing information that can be used for policy-oriented learning. The combination of multiple lenses (Advocacy Coalition Framework, Community-Based Participatory Research, and Health Belief Model) were essential for this dissertation. Each model/framework/approach provided

important lenses to ground the research and allowed the research to coalesce with a highbred, combined model that allowed the issues of the Marshallese to be examined. Most importantly, The research can be used to inform health policy, health care services, and health education. Many of the health disparities were perpetuated because of public policy and must be addressed through public policy. Marshallese COFA migrants living in the United State experience many constraints because to actions and policies of the US federal government, including COFA, ACA, PRWORA, nuclear testing, recruitment of Marshallese into the US military, and the use of Republic of the Marshall Islands land for military purposes. These actions and public policies were made at the federal level; however, states and local communities must now struggle to care for COFA migrants living within their borders.

The research converges into a cohesive research agenda that is built on the principals of CBPR and is designed to fuel policy and programmatic action.<sup>115,116</sup> While posit that CBPR should be viewed on a continuum, and I embrace research that uses the level of engagement most appropriate for the community my research has used a pure CBPR process. Furthermore my research has been used to help give voice to health disparities that the Marshallese community faces with the goal of facilitating policy change.<sup>108,117-131</sup> CBPR is often effective in convening communities for political action.<sup>132,133</sup> Even though public policy is often difficult to change, and many external environmental factors constrain policy change, my research can be used for policy-oriented learning, facilitated through CBPR partnerships and advocacy groups, and over time, produce incremental changes.

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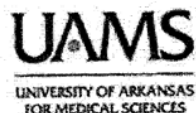
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Appendices:

- A. Map that shows location of the Republic of the Marshall Islands
- B. Institutional Review Board (IRB) approval







## Institutional Authorization Agreement



Name of Institution or Organization Providing IRB Review: University of Arkansas for Medical Sciences (UAMS)

- UAMS's IRB Registration #: IRB00000593; IRB00000742; IRB00000745; IRB00004852
- Federalwide Assurance (FWA) #, if any: FWA00001119

Name of Institution Relying on the Designated IRB: University of Arkansas (U of A)

U of A's OHRP Federalwide Assurance (FWA) #: FWA00001952

The Officials signing below agree that U of A waives jurisdiction of the research described below and shall rely on UAMS IRB for review and continuing IRB oversight limited to the following Studies:

**Name of Research Project:** An Exploratory Study of the Marshallese and their Beliefs, Perceptions, and Experiences as a Compact of Free Association (COFA) Migrant Related to the Affordable Care Act and Medicaid Expansion in Arkansas

**UAMS Protocol #:** 203816

**Name of UAMS Principal Investigator:** Pearl McElfish

**U of A Researcher:** Pearl McElfish

**Name of Research Project:** Pilot Study of Family DSME in the Marshallese Community

**UAMS Protocol #:** 202830

**Name of UAMS Principal Investigator:** Peter Goulden

**U of A Researcher:** Pearl McElfish

**Name of Research Project:** Prevalence and Severity of Type 2 Diabetes in the Marshallese Community

**UAMS Protocol #:** 202720

**Name of UAMS Principal Investigator:** Peter Kohler

**U of A Researcher:** Pearl McElfish

The review performed by UAMS will meet the human subject protection requirements of the U of A's OHRP-approved FWA. UAMS will follow written procedures for reporting its findings and actions to the U of A PI(s). The U of A PI(s) will be responsible for reporting to the appropriate U of A officials as appropriate. Relevant minutes of IRB meetings may be made available to U of A upon request.

PI is responsible for ensuring compliance with the Board's determinations. U of A remains responsible for ensuring compliance with UAMS's determinations and with the terms of its OHRP-approved FWA. This document must be kept on file by all parties and provided to FDA, OHRP, and/or other applicable regulatory agencies upon request. This Agreement may be executed in any number of counterparts, either in original or electronic form.



Institutional Authorization Agreement



Each party listed below is authorized to exchange information pursuant to this Agreement and agrees to treat such information as confidential (Confidential Information). No Party shall disclose Confidential Information received pursuant to this Agreement to any individual or entity other than another Party without prior written approval of all Parties. Notwithstanding the foregoing, nothing in this Agreement shall be construed to restrict a Party from disclosing Confidential Information as required by law, subpoena, court order, or other governmental order or request. Additionally, nothing in this Agreement shall restrict a Party from disclosing that UAMS reviews research for U of A.

UAMS or its authorized representatives shall be permitted to: (1) examine and inspect U of A's facilities used for the performance of this research, including storage and use of any investigational products; (2) observe the conduct of the research performed at U of A; (3) inspect and copy all documents relating to the Study, including study records and informed consent document, investigational product logs, required licenses, certificates and accreditations; and (4) interview all necessary personnel involved in the research conduct of the Studies.

Signature of Signatory Official (UAMS): [Signature]

Print Name: Lawrence Cornett Date: 5/18/15

Signature of Signatory Official (U of A): [Signature]

Print Name: ROSEMARY H. RUFF Date: 05/18/2015