This paper describes the qualitative methods and research process for translating evidence-based methods for managing type 2 diabetes in the US to the American Samoan context.

The US territory of American Samoa is 2600 miles southwest of Hawaii, about halfway between Hawaii and New Zealand. The independent country of Samoa lies just to the west. Together they form an island chain populated by the same ethnic group of native Pacific islanders. Before World War II residents used subsistence farming and fishing; diabetes was rare. More recently, non-comunicable chronic disease rates are rising in both adults and children.

Increases and changes in dietary intake and reductions in physical activity, the “nutrition transition,” began in earnest in both Samoas after World War II. These changes, which were rapid from 1970-2000, led to levels of overweight and type 2 diabetes, especially in American Samoa, the more economically developed of the two polities. Adults in American Samoa and Samoa now suffer from a high prevalence and 4-year incidence of overweight, obesity, type 2 diabetes, hypertension and lipedema and temporal increases in each location. These levels are higher in American Samoa, with >80% of men and >90% of women overweight, based on Polynesian BMI standards, BMI ≥ 26 kg/m².

Type 2 diabetes has reached epidemic proportions in American Samoa. The prevalence rate among men aged 25 to 54 years in 1990 was 12.9%, 17.2% in 2002. Among women of the same age range, the prevalence rate doubled from 8.1% in 1990 to 16.7% in 2002. Type 2 diabetes prevalence rates among adults aged 18 to 74 years in 2002 were 21.6% and 18.0% in men and women, respectively.

Socio-economic status (SES) plays a role. Samoans of higher SES in American Samoa have more favorable profiles of obesity and chronic disease risk. We speculate this is due to higher SES individuals and families learning about over-nutrition and health and having more access to high quality health care. We have much to learn about how non-Samoan foods are related to social prestige, from the earliest imported canned meats in the 19th century to fast-food today.

These rapid changes in obesity and associated health conditions occurred so quickly that health care systems, communities, families and individuals have not readily responded. Concepts such as the health risks of obesity, patterns of body image favoring substantial body size, and the low awareness of the need for lifetime management of chronic conditions, facilitate obesity and obesity-related disease such as diabetes.

**METHODS**

To tailor an intervention to local needs, the research team sought to learn about diabetes care as well as the experience of living with diabetes in American Samoa via several qualitative research steps. (Table 1)

**Preliminary meetings with community partners**

Our team met with community partners for extensive meetings before and after the grant funding was achieved. Subsequently, we chose a community health worker model where lay health workers served as a bridge between patients and health professionals to support diabetes self care.

**Qualitative interviews with diabetes care providers and focus groups with diabetes patients**

These steps sought to identify attitudes about food, exercise, self care, and the challenges of being diagnosed with diabetes, or caring for people with diabetes.

We conducted 15 in-depth interviews with providers and staff at the community health center where we worked. We also conducted 6 focus groups with 39 patients, both recently diagnosed and those living with diabetes for decades.

**Translation and adaptation of measures to the local context and language**

The randomized trial will employ a baseline assessment using diabetes belief and self care assessments, an assessment of depression symptoms, and the Patient Activation Measure. These instruments have been developed and psychometrically evaluated in English, but never used in American Samoa. Linguistic translation involved a forward and back process: one member of our staff translated the assessment questions. Another staff member back-translated the Samoan-language items into English. The original English question was compared against the English version translated from the Samoan. Where necessary, alterations were made for accuracy.

**Cognitive interviews**

We used cognitive interviews to find out whether participants understood the Samoan translation of the original English-language question. A researcher administered a sub-set of the survey questions to a participant, who answered using the required response format. Then, guided by questions and probes, the participant was asked to think aloud, explaining how and why s/he answered the question as s/he did. Through this process we clarified the meaning of words or phrases, probed the recall and retrieval from memory of information needed to answer the question, and considered whether the available response formats enabled the participant to provide an appropriate, accurate answer.

**Assessments of the planned intervention by local research staff**

We reviewed material from both focus groups and provider interviews with the local Samoan research staff who would be making home visits. These materials included flipcharts for teaching about diabetes, communication strategies, referral resources and documentation forms. This process identified where edits and revisions were needed.
Barriers to self care

Most diabetes patients understood that a high fat diet, lack of exercise, and stress caused or contributed to diabetes, and that the best control strategy was to limit high fat, sugar-laden food, and to exercise regularly. But many patients struggled to incorporate those strategies into their lives.

Many participants noted that healthy food is costly, and that much of the imported foods are processed, frozen and/or expensive. The inexpensive foods, such as turkey tails and mutton flaps, are very high in fat. Both patients and providers articulated how difficult it can be for patients to maintain a healthy diet. Patients worried they would not feel full or be satisfied eating healthy foods. Some patients had no control over the foods prepared by family members, and could not resist the foods at ritual family gatherings, called fa‘alavelaves. Others asked whether traditional foods, like taro and banana, could be eaten in moderation or should be avoided completely.

Providers identified other barriers to care; e.g., patients did not have enough money to pay for medication co-pays, clinic visits and blood draws. Some patients could afford to fill only one prescription at a time. Only those who were financially secure could buy glucometers and strips.

Patients often sought care only after a crisis, like hospitalization, blurred vision, or numbness. Some patients’ symptoms had reached an advanced stage, even to the point of blindness, or the need for amputation of a leg or foot. Many were aware of their symptoms for a long time, but did not seek help either because they feared learning they had the disease and would have to change their lifestyle or because they just did not want to believe they had diabetes.

Many patients did not understand the fluctuations in their blood sugar and why this happened, even while taking their medications. A participant remarked: “As of now, when I check my sugar level, I really don’t know what is high and what is low…”. At times, some participants found that the medications did not appear to relieve their symptoms. As a result, many stopped taking medications: they felt the medications were ineffective or even worsened their symptoms. In addition, many participants lacked transportation to get to the hospital or clinic for appointments.

The Role of family and family events

Many islanders live in extended family residences, a social organization that influences diabetes management. A few older participants noted that their children, who were responsible for preparing foods, were not receptive to the wishes of the family member with diabetes: “There are times for me because I am getting old now, all I want to eat is soup…but my kids fix something else and all that comes to my mind is that I am going to just throw it away because it’s not what I wanted…kids like to eat fried foods…and they don’t prepare it in favor of the person who wants it.”

Fa‘alavelaves are Samoan ceremonies and cultural gatherings, usually connected to a lifecycle event like a wedding or a funeral, which require significant donations of money or time. They are widely cited as central to fa’a Samoa, the Samoan way of life. Yet our interviews and focus groups pointed to the fa‘alavelaves as a source of stress as well as of social solidarity. Many participants indicated that the events were an obstacle to their diabetes care. One participant remarked, “the truth is that one of the causes of this disease called diabetes in our country is fa‘alavelave that happens within our own families.”

In addition to the stress accompanied by organizing and contributing money to these events, many participants said that it was very difficult to eat healthy during them. “Even though there are guidelines set for diabetics about what kinds of things to eat, there are times in our culture when fa‘alavelaves happen…when they serve the food, you are not thinking about what foods are restricted for eating and what foods are healthy. When the food is served at those times, you just eat it.” One participant described the cultural and social expectations related to food consumption: “If you don’t eat the food, there are also cultural feelings about this. You know, like you are not a man if you do not eat all the food.”

Stress, depression and Diabetes

American Samoans have said, anecdotally, that their blood sugar rises with stress. The most commonly cited source of stress is family financial obligations, including those

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INTERVENTION IN RANDOMIZED CONTROLLED TRIAL

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related to fa'aalavelave. Here a participant addresses the pull of these commitments:

if they are supposed to give something for the church versus the money to spend on the medication or the going into the hospital, [patients] will take the fa'aalavelave and church first and this is second. So when it comes to health, health is low priority as far as the Samoan. You’ve got to give to the church first, you’ve got to give to the fa'aalavelave… They will go borrow money to give to the fa'aalavelave, give to the church, but as far as something for themselves, [like] health…, it come at less of a priority.

Other sources of stress include lack of income; job difficulties; disagreement with a spouse; children; and illness.

Providers suggested that patients would not independently raise concerns about depression or stress, so research staff would need to ask about them directly. Patients might not even know of the link between stress and health. While our clinician participants articulated several sources of stress in their patients’ lives, some felt the patients did not recognize the linkage:

“I very seldom hear people talk about [stress] like it is a big issue or a big problem … most of the people [I] have encountered, they said ‘stress? what does stress have to do with it?’ It is like new to them when I say stress. So I think that is one thing that most of our healthcare providers need to try to talk about instead of just food and exercise …[they] need to mention that too, stress.”

As for older patients,

“. . . they don’t know what stress is. They think that when they get a lot of stress it’s from the fa’aalavelave, a lot of fa’aalavelave that [they] are involved in, something bad or someone in the family passed away. And all those things that they think of, it’s what but not from the disease that they have.

For Samoans, stress and depression are deeply private concerns, rarely discussed. Consequently, it may take several times to introduce the topic before people are willing to discuss it candidly, or at all.

How to be an effective Community Health Worker (CHW)

In interviews with clinicians and care providers, participants were positive, even enthusiastic, about our use CHWs. (They had been used on island for other health concerns.) Our participants had a variety of suggestions about how and when to visit patients. Particularly important was that CHWs needed to show cultural signs of respect, both to patients and to family members, including greeting elder family members first:

First and foremost in the Samoan culture you gotta learn to excuse yourself before the family. You know maybe they were doing something and we are there interrupting. So in a respectful manner you would excuse yourself and then introduce yourself and what you are doing.

Since the patient with diabetes may not be the person who cooks the family food, it is important to involve that cook—often a difficult task.

I think that one of the challenges is getting the family involved. Most of the time… I tell them to come in [and] please bring in your family members so we can teach them at the same time. Because the patients themselves aren’t cooking the meal…the family members are. So if we can get the family members to come in, and teach them as well, and educate them about diabetes, I think that is the biggest challenge I face now.

CONCLUSION

The transition from a traditional to a modern lifestyle has been rapid in American Samoa since WWII and especially since the 1970s. A similar transition has occurred among immigrant communities in the mainland US. Rhode Island has a variety of immigrant groups. Just as preparing for our research intervention in American Samoa required careful attention to cultural translation, clinical practice with patients also requires keen attention to the patients’ backgrounds, experiences, languages and beliefs.

The qualitative methods used in preparing for this diabetes intervention in American Samoa can guide clinical care and behavioral research in Rhode Island. Interviews with local community members helped us learn how patients sought out care. Interviews with care providers and focus groups with patients helped us learn about barriers and facilitators of care. Because we sought to design materials for CHWs, we needed to learn about both the patients’ perspective of living with a chronic illness and the providers’ experience of providing care. In our preliminary analysis, both patients and providers identified similar challenges, especially: healthy eating, exercise and understanding stress. Both sides stressed fa'aalavelave and the challenges these feasts offer to healthy eating, as well as the role of those feasts as a cultural stressor.

Whenever a research or clinical instrument is translated, back translation provides an opportunity to confirm and clarify the effectiveness of the translation. In this project we used cognitive interviews, commonly used in survey item development and design, to clarify not only the effective linguistic translation of the language used in the questions, but also to further understand the cultural elements that shaped participants’ understanding of, and answers to, the survey questions.

Reviewing our intervention materials with the staff who are going to implement them and inviting their insights was particularly useful. For example, the staff recommended using both English and Samoan on each page of materials, and we are now adapting our materials. Staff suggested hands-on teaching techniques and helpful logistical strategies for coordination of care. Additionally, our staff valued the opportunity to be treated as experts in their culture and appreciated their role in the design of the materials they would be using with patients.

In clinical practice with patients of different cultural backgrounds, it is important to assess patients’ and providers’ beliefs and understanding about the medical condition. We find that it is also important to inquire about patients’ own solutions, and to seek the expertise of health workers, because the integration of patients’ cultural elements with modern intervention practices ensure that the intervention will be most effective.
REFERENCES


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