Listening to the community: a first step in adapting *Diabetes Today* to the Pacific

Abstract: Diabetes is a growing problem among Pacific Islanders, but few community-based groups in the Pacific are actively working on diabetes prevention and control. The Pacific Diabetes Today Resource Center (PDTRC) was established in 1998 to adapt the *Diabetes Today* (DT) curriculum for Pacific Island communities in Hawai'i, American Samoa, and Micronesia. To gather data to guide the development of the *Pacific Diabetes Today* (PDT) curriculum, a year was spent listening to Pacific communities. First, data were gathered from health professionals on how the DT curriculum should be modified. Second, health and community leaders in 11 sites were trained and supported to conduct discussion groups with people affected by diabetes. Third, site coordinators evaluated the discussion group process. A Pacific-wide Advisory Council (AC) was established to guide the project, and the AC used findings from the first year to generate guidelines for staff to follow in adapting the DT curriculum to the Pacific. These guidelines directed staff to: a) realize that Pacific communities need to build awareness about diabetes; b) train and support local community leaders as co-facilitators in the PDT curriculum, using a learn-by-doing approach, with the goal of developing them as independent trainers; c) encourage the involvement of a broad range of community members in PDT training, including the involvement of local physicians to counter medical misconceptions about diabetes; d) give the PDT curriculum a Pacific "look" and "feel;" and e) keep the training logistically flexible to accommodate differences in communities across the region. Other programs and agencies that want to develop training programs in the Pacific may find these listening strategies and guidelines helpful. **Key Words:** American Samoa, community development, cultural competence, diabetes, focus groups, Hawai'i, Micronesia, Pacific, program development, training

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Introduction

Health educators believe that communities can be trained and mobilized to identify their own problems and to develop and implement their own solutions.[1] This is the philosophy of the *Diabetes Today* (DT) program of the Centers for Disease Control and Prevention (CDC), which offers training in needs assessment, planning, and evaluation related to diabetes prevention and control.[2]

Health educators believe that communities can be trained and mobilized to identify their own problems and to develop and implement their own solutions.

The Pacific Diabetes Today Resources Center (PDTRC) was established by CDC in 1998 as a regional *Diabetes Today* training center for Hawai'i, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands (CNMI), the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau. Although the region is very large, covering three million square miles of ocean, these Pacific islands and atolls share a history of rapid westernization of their economies and diets and a shift in the cause of death from acute illnesses to chronic conditions.[3-4] Diabetes has become increasingly prevalent and is a growing cause of morbidity and mortality in the region.[4-6] Goals of the five-year PDTRC project were to adapt the DT curriculum to the Pacific, to offer training and follow-up support to 14 communities, and to evaluate the effectiveness of the program. The work of PDTRC was guided by an Advisory Council (AC), which included representatives from the seven U.S. Pacific jurisdictions, regional and community-based organizations serving the region, and community representatives (Table 1).

The first year of the project was dedicated to listening to the Pacific Islanders that we hoped would benefit from this project. Other investigators have found that this is an important first step for entering a community, exploring its perceptions about a health issue, and generating ideas to increase awareness and develop interventions about it.[7-14] This paper describes the listening strategies used by PDTRC and offers a summary of the findings from this process. Based on findings from the first year, the AC generated guidelines for PDTRC staff to follow in developing the *Pacific Diabetes Today* (PDT) curriculum, and these also are presented.

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Table 2. Summary of Recommendations from Health Professionals for Modifying Diabetes Today for the Pacific

Characteristics of successful training programs
- Involve trusted community leaders.
- Ensure the program is well coordinated and adequately funded.
- Engage people over an extended time period (rather than just once or twice)
- Required personal involvement, small group work, and a chance to practice skills
- Pay attention to the local culture.
- Incorporate cultural traditions.

Recommendations for modifying Diabetes Today for the Pacific
- The content is good.
- Pacific communities need skills in assessment, planning, and evaluation.
- There is too much information.
- The writing is dense, technical, and boring.
- Incorporate stories, myths, religion, diet, values, etc.
- Use local examples to illustrate concepts.
- Focus on positive outcomes and options.
- Use people-helping-people strategies.
- Teach in the local language

cal. They recommended that staff simplify the writing, add white space, incorporate pictures and stories of the Pacific, and illustrate concepts with Pacific-based examples.

Community discussion groups

Method. Discussion groups were used to gather information from people affected by diabetes in each community. Rather than having PDTRC staff conduct the groups, the decision was made to train and support community members to lead discussion groups. Because a goal of the DT program and PDTRC was to increase skills within Pacific communities, this approach would give community leaders an opportunity to begin learning and practicing skills from the project's start. It was proposed that this same learn-by-doing approach would be used throughout the PDT curriculum. Thus, training community leaders to lead discussion groups allowed PDTRC to pilot test their training strategy—learn by doing—while gathering data about community perceptions of diabetes and needs for programs.

With the help of AC members, 11 community-based organizations were identified to coordinate discussion groups, including: five Native Hawaiian Health Systems (health promotion and outreach entities dedicated to improve health of Native Hawaiians, one system on each of five Hawaiian islands); the CDC-funded Diabetes Control Programs based in the health departments of CNMI, RMI, and American Samoa; non-profit health agencies in FSM and Palau; and the cooperative extension service of the University of Guam. A subcontract was established with each entity, which received about $3,500 to cover expenses related to staff time, meetings, and data transcription. Training was based on the *Community Assessment Guide* developed by PDTRC that included step-by-step instructions, a script for facilitators, prescribed data-capture procedures, and copies of data collection forms.[15] Site coordinators recruited people with diabetes and their family members to participate.

Community discussion groups were conducted between August and October 1999. Discussion group questions included: a) What are the major problems in your community? b) How big a problem is diabetes? c) What is easy or hard about managing diabetes? d) How does your family support you or not support you? and e) What programs and services need to be developed and by whom? When discussions ended, participants were encouraged to ask questions about diabetes. Audiotapes and newsprint notes of the discussion were transcribed, either by the subcontractor or by PDTRC staff and analyzed for themes. Site-specific findings were returned to the community leaders who led the discussion groups so they could share findings with participants and use them in subsequent work.

Findings. In all, 102 people with diabetes (mean age 55) and 109 family members (mean age 47) participated in discussion groups. About 40% of participants were male and 60% were female.

Participants were asked to identify problems in their communities. Although general, this question was asked to start people talking and to help place diabetes within the larger context of community concerns. Two themes emerged—health-related issues and other issues. All 11 sites were concerned about the general lack of knowledge about health and diabetes; 9 (82%) mentioned poor lifestyle behaviors; and 8 (73%) talked about the inadequacy of health services. However, all groups spoke of other issues that concerned them as community members, some of which may present barriers to diabetes prevention and control. These included economic issues (lack of jobs, high cost of living, cost of care, overcrowding, decreasing access to land and sea); substance abuse; other youth-related issues (teen pregnancy, school drop-out, violence, lack of meaningful activity/employment for youth); environmental issues (drought, pollution, decreasing productivity of land and sea); and literacy issues.

Others realized that westernization had changed cultural norms related to diet. A Marshallese participant noted, "The reason the young are getting diabetes is because of the changes in our local diet. During World War II, we ate fish, bananas, and other local foods. Now we have all kinds of food, such as corn beef and spam. So the diet is not balanced...the children eat junk food." Economic reasons for poor diet also were cited. A Palauan said, "The income is very limited, and good food costs so much. When old people are advised by a doctor to buy healthy food, their monthly retirement check is less than what the doctor recommends they eat. Local food is healthy, but in Koror [the capital] there is no place for farming or fishing for local food."

Participants in eight sites said they lacked knowledge about food composition (e.g., proportions of protein, fat, and fiber) and appropriate serving sizes. Participants noted that the whole family should eat a good diet instead of trying to cook separate meals for the person with diabetes. Others spoke of avoiding fiestas or eating a salad before going to a food-filled event. Others requested support for food co-ops and community gardening projects.

Respondents noted that exercise was difficult to do, especially alone. However, they said that the availability of exercise infrastructure (e.g., free activities, classes, equipment, walking paths), a steady exercise partner, and a daily routine helped them exercise. Participants realized that farming and fishing were good forms of exercise, but that few did these activities with any regularity. Some people with diabetes noted that health conditions limited their ability to exercise. For example a Pohnpeian said, "I don't want to move around because my feet are numb. I don't have proper shoes, and I might cut my foot in the garden." Respondents from nine sites admitted a lack of discipline, saying, "It's much easier to watch TV." Respondents in other groups felt that "exercise is pointless work."

A participant in Guam said, "Many people are fatalistic. They feel like no matter what they do, they are going to die from it, so why do anything. The other problem is people don't admit they're diabetic."

Regarding following the physician's advice, respondents in all 11 sites reported barriers related to fatalism and denial. They noted that some people were afraid of having their finger pricked, scared about having their blood sugar checked, and embarrassed that others may find out the diagnosis. A participant in Guam said, "Many people are fatalistic. They feel like no matter what they do, they are going to die from it, so why do anything. The other problem is people don't admit they're diabetic." Others brought up problems with getting adequate or proper care, citing poor relationships with providers, lack of medication, and lack of transport in their communities. Participants reported a need for insurance coverage of prescription drugs and medical supplies. Good relationships with providers also were important.

Respondents in every site identified available medical services, and some identified diet and exercise programs as well. When services were not used, respondents said it was due to service scarcity, inaccessibility, high cost, personal discomfort, fear, or embarrassment. All locations identified services that needed to be expanded or developed. Medical programs included: diabetes education; outreach; transportation; and subsidized, low-cost care, medicine, and supplies. Lifestyle programs included: exercise programs; subsidized, low-cost healthy foods; food selection and preparation classes; and land for community gardening. Participants in most sites called for public education campaigns to alert their communities about diabetes. Many sites felt that schools should provide more health education and promote exercise and healthy eating to prevent the next generation from succumbing to diabetes. Four sites spoke to the importance of engaging traditional leaders in diabetes control, and three sites wanted to establish a non-governmental, non-profit agency to focus on diabetes.

Soliciting feedback on the discussion group process

Method. Coordinators from each of the 11 sites completed a questionnaire about the discussion group process, including: a) their ratings of the usefulness of the *Community Assessment Guide* and training; b) ways in which they modified the process to fit their communities; c) reports of knowledge and skills gained through their participation; and d) preferences for topics and learning strategies for future training.

Findings. The overwhelming majority of respondents agreed that the *Community Assessment Guide* and training provided by PDTRC staff were helpful. All 11 reported that the participants enjoyed the experience and that many participants expressed interest in continuing to learn about and take action around diabetes. They all agreed that community discussion groups were a good way to collect data and that they would feel comfortable conducting them in the future.

All sites made adjustments to the focus group process. As suggested in the *Community Assessment Guide*,[15] all sites modified the opening session to increase its cultural and social relevance. Some sites held separate discussion groups for diabetics and family members while others split groups by gender to hear the specific issues of each constituent. Seven sites had trouble with recording the data, mostly with transcribing the audiotaped conversa-

members, diabetes was just one of a number of problems they were facing. Communities must learn more about diabetes and must be free to develop interventions that address diabetes within larger community issues, e.g., programs that target chronic disease rather than diabetes alone or programs that address issues related to the price of food or access to land and sea.

- Train and support local community leaders as co-facilitators in the PDT curriculum, with the goal of developing them as independent trainers. Community members know their cultures and communities, but they want skills and guided opportunities to apply skills to their communities. Local leaders and participants need and want to be engaged in planning and delivering future training. The learn-by-doing approach was well received, as were the technical and financial assistance provided by PDTRC.
- Encourage the involvement of a broad range of community members in PDT training, including the involvement of local physicians to counter medical misconceptions about diabetes. Training needs to occur in the community and involve people at all levels, including those with diabetes, family members, traditional leaders, healthcare providers, clergy, business leaders, and government officials.
- Give the PDT curriculum a Pacific "look" and "feel." Incorporate stories that reflect the values of the region and refer to traditional social structures, foods, and lifestyle. Include more white space, pictures, and graphics. Use real, local examples in the work assignments. Teaching methods should include opportunities for community members to share stories, to work in small groups, and to practice new skills. People-helping-people strategies are effective.
- Keep the training logistically flexible to accommodate differences in communities across the region. Create modules that can be used independently or in sequence. Allow communities to determine the timing of training (e.g., daytime, evening, weekend) and the time frame over which it is offered (consecutive days, in several weeks or month.

PDTRC staff members followed these guidelines as they developed the PDT curriculum, which was piloted in five Pacific communities during the project's second year.[4-5]

Discussion

As noted by other investigators, spending time listening to communities is an important first step for community developers, especially "outsiders" hoping to develop and institutionalize a new program in a new community. Listening to the community can help outsiders gain access to it, explore its perceptions about the issue that the outsider is bringing to the community, and generate ideas to increase awareness and develop interventions about the issue.[7-14]

PDTRC's entry into the community was facilitated by the AC, which included representatives from each jurisdiction, and the health professionals that reviewed the DT curriculum and provided recommendations for its adaptation. AC members also identified community health leaders to run discussion groups on diabetes in their communities. These health leaders recruited discussion group participants through their own networks, thereby engaging people in a process that increased their awareness about diabetes and identified a cadre of individuals that may be interested to develop interventions for diabetes prevention and control.[1,8,11] Discussion group leaders received training, technical assistance, and financial support to convene groups of people with diabetes and their family members to learn about their perceptions of diabetes, its burdens, and needed interventions. At the same time, discussion group leaders served to pilot PDTRC's proposed training strategy—learn by doing—which was deemed successful. From data gathered through the listening process, the AC developed guidelines for adapting the DT curriculum to the Pacific.

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Programs and agencies that enter the Pacific region to develop and implement programs should begin by listening to the community. To gain the broad support that is necessary for the acceptance of new programs, this process of listening to the community is a critical first step in assuring success.

Notes

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