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Voices

From the Community
Focus Groups with African American,
American Indian, Hispanic, and Hmong
People with Diabetes

August 1998

A special project completed by the
Minnesota Diabetes Control Program
Center for Health Promotion

Division of Family Health
Minnesota Department of Health



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Upon request, this publication can be made available in alternative formats such as Braille, large print or audio tape.

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Preface

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Diabetes and its complications occur among Americans of all ages and racial and ethnic groups. The burden of this disease, however, is heavier among elderly Americans and certain racial and ethnic populations, especially for people that have lower incomes, education levels, and social class.

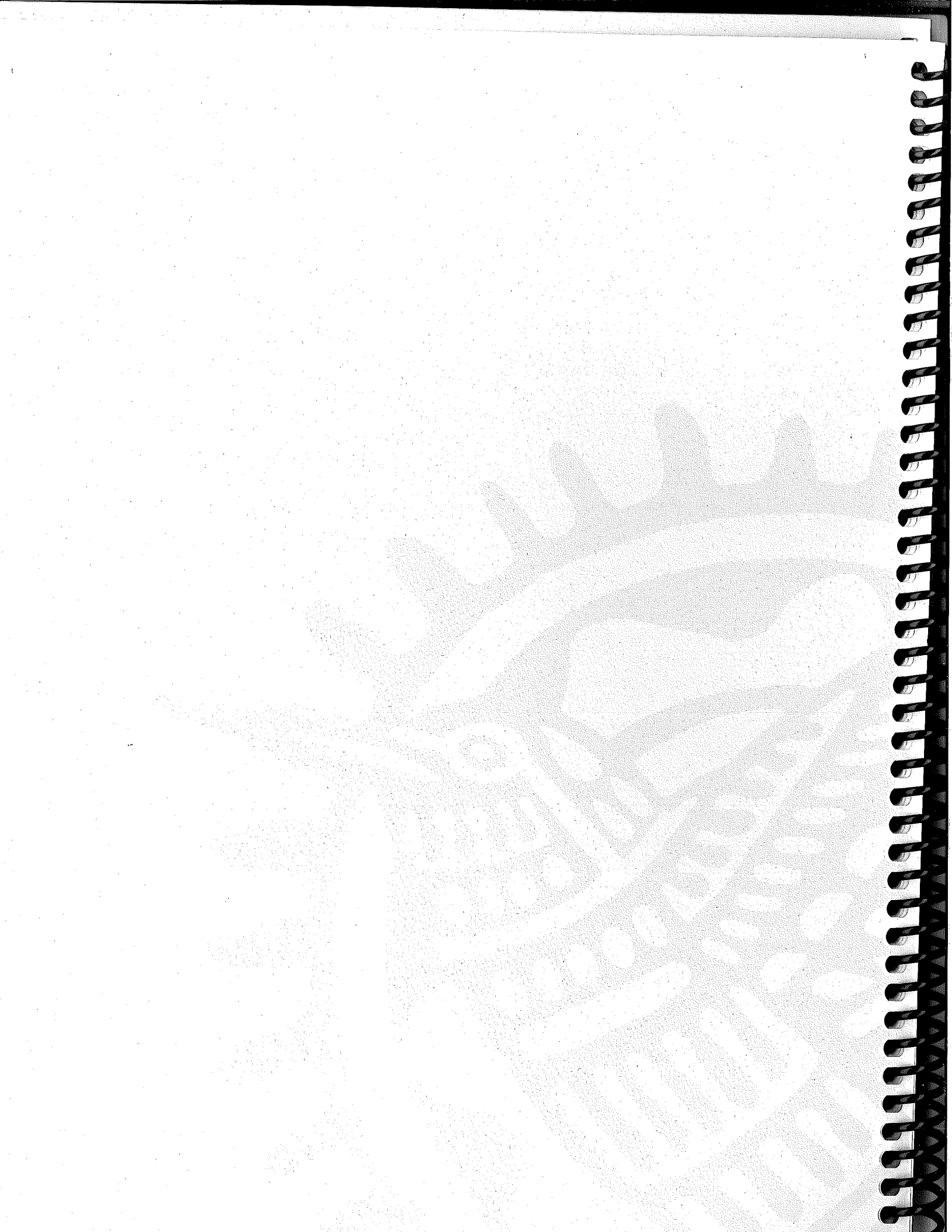
In response to this critical public health issue, the Minnesota Department of Health's Minnesota Diabetes Control Program is working to engage local communities and health care systems in developing a state plan to improve diabetes education and health care services for people of color in Minnesota. To initiate this process, in March 1997, the Diabetes Control Program sponsored 12 focus groups with African American, American Indian, Hispanic and Hmong (Southeast Asian) people with diabetes in Minneapolis and St. Paul. Participants described their experiences with diabetes and identified strategies to address diabetes within the health care system and in their local communities.

The focus group results showed that many participants felt people from their communities were healthier before they adopted modern American life-styles, including high fat diet and reduced physical activity. They also indicated a strong need for improved diabetes education and support, and had difficulty translating diabetes concepts from the medical health care system into their cultures. Those that were most satisfied indicated that they received culturally-specific education from respectful, knowledgeable health care providers.

This focus group report summarizes recommendations from the focus group participants. They suggest methods for improving diabetes education and health care quality by enhancing cultural competency and community action. These recommendations will be shared and discussed with health care providers and community leaders and then integrated into a state plan of action for improving diabetes education and health care services for people of color in Minnesota. The plan will be developed and implemented through a collaborative effort between people with diabetes, community organizations, health care systems, The Minnesota Diabetes Control Program, and others who are interested in promoting the health and well-being of ethnically and racially diverse populations in Minnesota.

"Those who suffer losses due to diabetes are not just statistics on a chart. They are people whose talents and wisdom are needed and whose problems deserve our unified efforts. Together we can join to make life more just and more joyful for generations to come."

-- David Satcher, MD, PhD
US Surgeon General
(Formerly Director, Centers for Disease Control and Prevention)



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Thank You to All Who Helped

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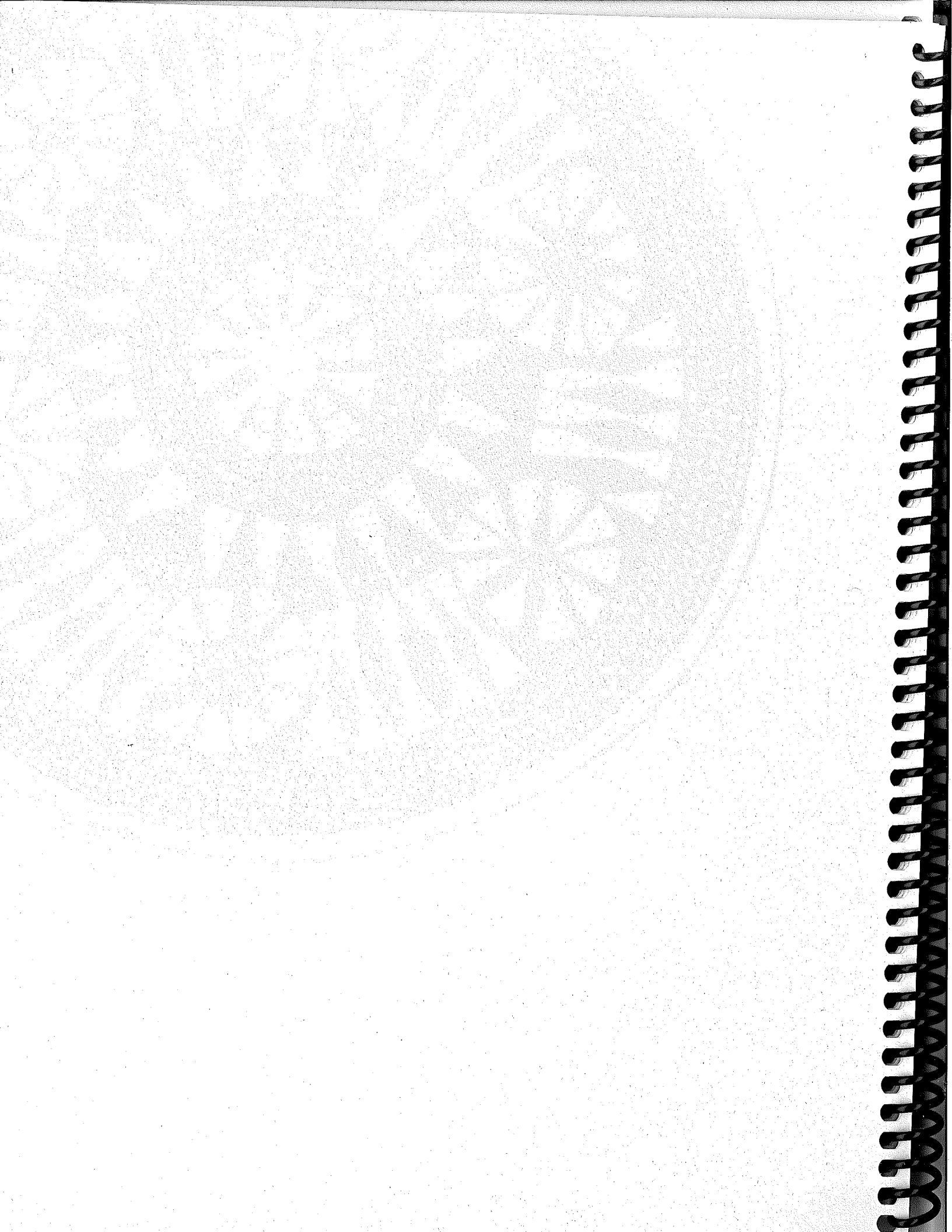
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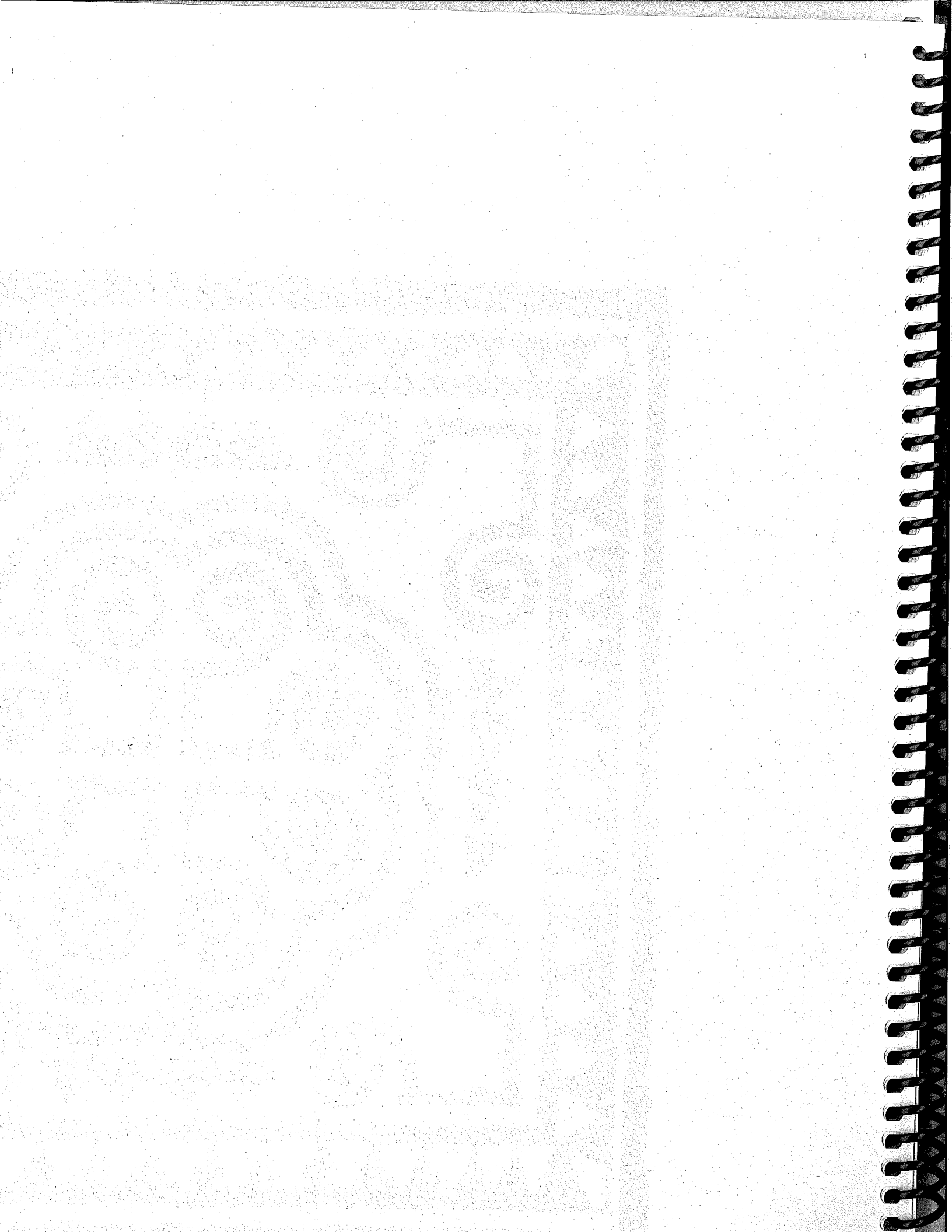
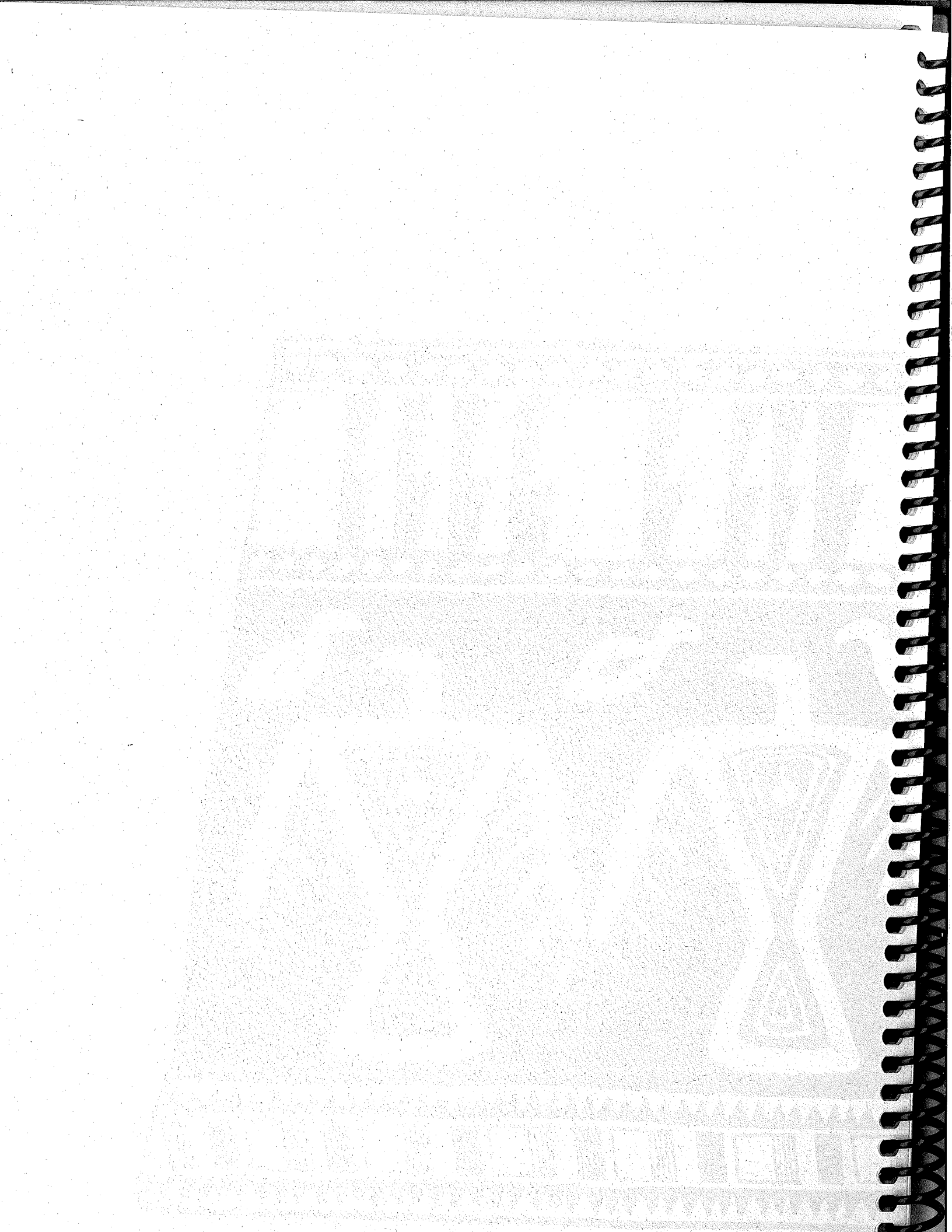


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Executive Summary

Common Themes

What Participants Experience

- ◆ Most participants knew diet, exercise, glucose monitoring and regular doctor visits were important, though making dietary changes was difficult for many people.
- ◆ Some did not receive adequate or accurate information about diabetes and proper self-care from their health care providers.
- ◆ Participants' experiences with providers differed greatly, depending on the provider's degree of respect, concern, knowledge about diabetes and cultural sensitivity.
- ◆ People often lacked economic resources, health insurance, and transportation, which hindered them from obtaining medical care, healthy food and medicine.

How Participants Feel

- ◆ People with diabetes often felt self-conscious, misunderstood, isolated and depressed.
- ◆ At times, people felt they were restricted access to quality health care and other resources because of their ethnicity.
- ◆ People felt their communities were healthier before they were affected by modern American life-styles and diet.
- ◆ Some mistrusted western medical providers and the government to act in their best interests.

How Participants Manage

- ◆ Many adopted a positive attitude and became more health conscious as a result of having diabetes, including making changes in diet, exercise and stress management.
- ◆ Some gained strength from their sense of spirituality.
- ◆ Some supplemented or replaced prescribed medicines with home remedies and medicines from non-western traditions.
- ◆ Many sought additional information about diabetes through the media or classes.

What Participants Want

- ◆ People want respectful health care providers who are knowledgeable about diabetes, understand their culture and speak their language.
- ◆ Participants want more information about diabetes and self-care from their providers.
- ◆ People wish they could afford healthy food and medicine to properly care for themselves.
- ◆ People with diabetes want to gather with others for support and information-sharing.
- ◆ People want to raise diabetes awareness in their communities, and to prevent the disease in future generations by educating their children about healthy lifestyles.

Community Profiles

African American participants saw managing diet and stress as ongoing challenges - experiencing a sense of pride in meeting these challenges or guilt when they fell short. Those that had family members with diabetes (referred to as "the sugar") were usually more familiar with the disease, and many received support from their families in taking care of themselves. Health care providers who showed genuine concern and who provided useful information were greatly appreciated. People who went to Pilot City Health Center were especially pleased with their care. Participants felt that information about diabetes would be best conveyed orally - building on their community's strong oral tradition - and through public awareness events.

American Indian participants often had relatives with diabetes, and saw diabetes as an important issue for their community as whole. Within the family, children often help their parents manage their diabetes. Those who attend Indian diabetes education groups and who receive health care at the Indian Health Board felt very satisfied with these services. All expressed a strong desire to organize within their community to raise awareness about diabetes and prevent diabetes in future generations.

Hispanic participants were highly motivated to make diet and lifestyle changes, and stressed the value of exercise - especially walking. Many supplemented their treatment regime with traditional medicines and home remedies. Participants frequently mentioned that their health declined during the winter. Some reported that unfamiliarity with using the medical system for preventive care, confusion about health insurance, changes in the welfare system, and language barriers are obstacles to Hispanic people in accessing appropriate health care.

Hmong participants said that diabetes (translated "sweet blood") was a new disease that they acquired after moving to the United States. Participants often struggled with western health concepts and practices. Most had difficulty accepting that diseases like diabetes have no cure. Some felt a mistrust of the western medical system and suspected that their health providers were withholding appropriate treatment. Elders in particular were prone to feelings of isolation and depression. Some noted that opportunities for traditional forms of exercise, such as gardening, were extremely limited due to the Minnesota climate. As in other communities, coming together for mutual support was seen as highly beneficial.

Recommendations

Diabetes Education:

- ◆ Organize culturally-specific diabetes support and education groups
- ◆ Provide diabetes education to individuals and their families
- ◆ Train and support people of color as diabetes lay educators
- ◆ Provide practical information, such as adapted traditional recipes
- ◆ Develop and disseminate culturally-specific diabetes education materials
- ◆ Use oral communication in diabetes education efforts

Health Care:

- ◆ Assure access to health care by providing transportation and interpreter services
- ◆ Improve the quality of diabetes health care and increase cultural competency by:
 - ✧ enhancing professional knowledge and skills in diabetes care
 - ✧ increasing providers' awareness of the historical experiences of people
 - ✧ educating providers about different cultural beliefs and concepts of disease
 - ✧ acknowledging and discussing non-western treatments with patients
 - ✧ meeting needs for culturally-specific diabetes information and assistance
 - ✧ recruiting, training and hiring more providers from diverse populations

Community Action:

- ◆ Highlight diabetes at cultural events and teach children about diet and exercise
- ◆ Provide meeting space, refreshments and transportation for diabetes support and education groups and assure transportation to medical appointments
- ◆ Facilitate mentor programs for newly-diagnosed people with diabetes
- ◆ Advocate for healthy food options at local restaurants and grocery stores and develop safe and enjoyable exercise programs for all seasons, especially winter



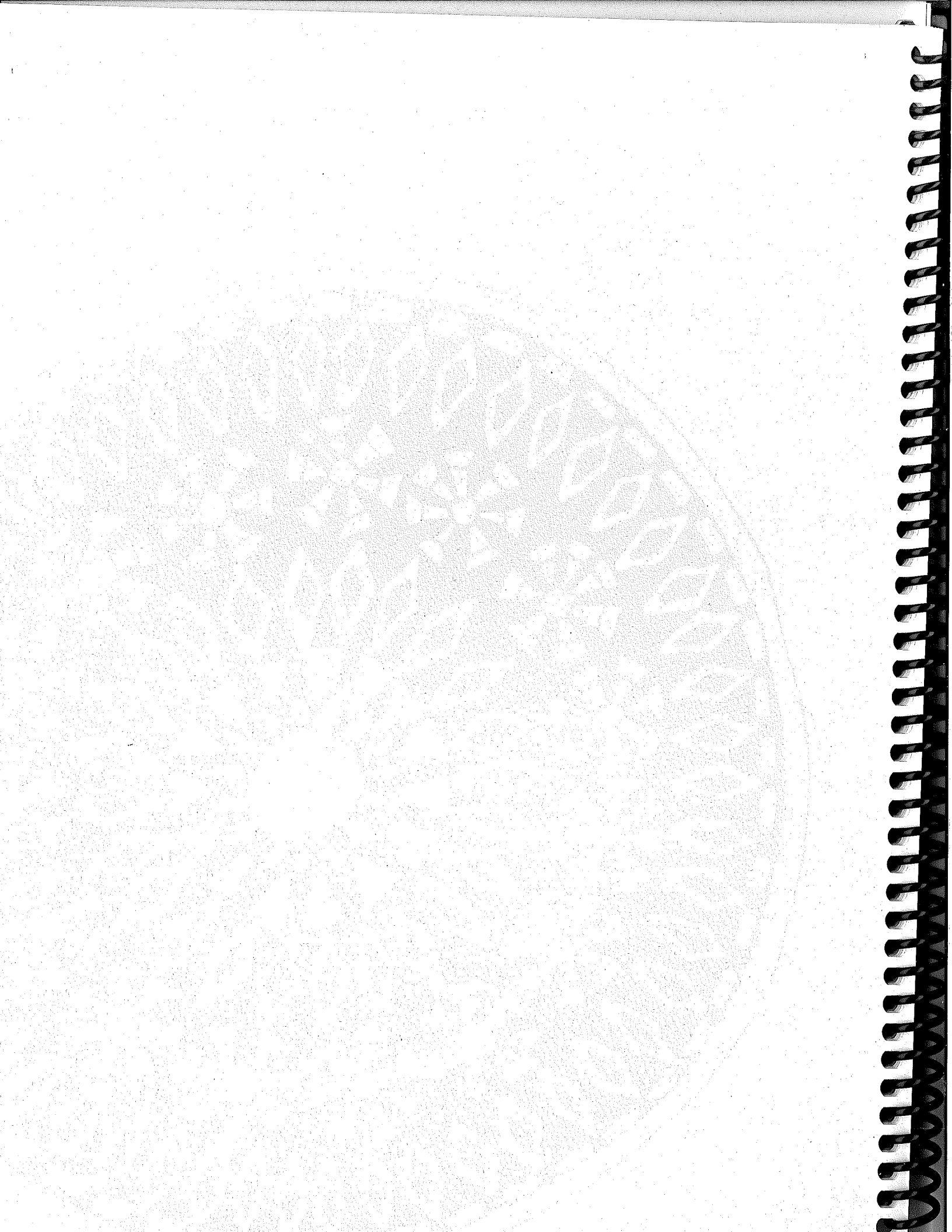
Project Overview

People of color often face special challenges in maintaining health and coping with disease. This project asked adults with diabetes from the African American, American Indian, Hispanic and Hmong communities in Minnesota about their experiences with diabetes, and invited them to think of strategies to address diabetes in their communities. The purpose of the project was to find ways to improve diabetes education and health care services for people of color in Minnesota.

During February and March of 1997, eighty people participated in twelve community-specific focus groups held in Minneapolis and St. Paul. Three focus groups within each community were facilitated by experienced moderators from each of the communities.

Focus groups lasted two hours and were conducted in English, Spanish and Hmong languages. Participants were recruited through clinics, health professionals, diabetes education groups, community organizations and media, churches, moderators and assistant moderators and by word-of-mouth. A University of Minnesota focus group expert and independent consultant provided consultation on the research project.

The focus groups were coordinated by staff from the Minnesota Department of Health, under the direction of the Cardiovascular Disease Implementation Work Group, a subcommittee of the Minnesota Diabetes Steering Committee, which advises the Minnesota Diabetes Control Program.



Common Themes

What Participants Experience

- Participants had varying levels of understanding of diabetes, but most knew about the importance of diet, exercise, glucose monitoring and regular doctor visits.

Many of the participants understood that diabetes affects different parts of the body. They most often mentioned kidneys, feet, and eyes. Other health conditions that they experienced and associated with having diabetes included heart disease, high blood pressure, compromised sexual performance, lupus, Bell's palsy, bronchitis, pneumonia, feeling angry, moody or emotional, hearing loss, sores, and arthritis. In addition, some participants mentioned that it is better not to use tobacco and alcohol, if you have diabetes.

- Making dietary changes was difficult for many people, especially cutting back on sweets and portion sizes.

Sweets and Rich Foods: Hispanic and African American participants often said that they missed eating sweets and rich foods. They felt deprived and craved foods that they were told not to eat.

Diabetes - An Invisible Disease: People mentioned how little others understood their experiences. The impact of diabetes tends to be hidden for many years, until a visible sign of the disease, such as a foot amputation, occurs.

- Some did not receive adequate or accurate diabetes self-care from health providers.

"It's like a big circle; diabetes touches everything, the way you feel, everything; it can infect your legs, heart, eyes, hearing, feet."

(American Indian)

"Diabetes works on your weakest thing and tears it down even more."

(African American)

"It's a battle with the sweets. You can only go so long without sweets."

(African American)

"...I was raised on sweets! My mother made caramels and other candies [for a living]. I just can't give them up!"

(Hispanic)

"Some doctors won't even caution you much about diabetes; they say, well, 'take the medicine,' or 'take the shot,' and they won't say nothing about your feet."

(African American)

"A lot of Indian people can't afford the diets. If I were an Indian on welfare and on a limited income, it would be very hard for me to meet the dietary guidelines."

(American Indian)

"The biggest change I had was acceptance... When you're married, your children, your husband, they don't know when you're having good days and when you're having bad days... Your work... You pretend you feel all right."

(African American)

"They can tell you about your diabetes with a finger prick; but sometimes when I get mad, I just let them take as much blood as they want; it's bad blood anyway."

(Hmong)

- Experiences with providers differed greatly, depending on the provider's degree of respect, concern, diabetes knowledge and cultural sensitivity.
- People often lacked economic resources, health insurance and transportation, which hindered their access to medical care, medicine and healthy food.

One African American woman did not receive health insurance from her employer, so she only went to the doctor if she had an emergency.

An American Indian woman was disabled. At the beginning of each month, when her disability check came, she would buy healthy foods. By the end of the month, however, there was not enough money to cover food expenses, and she was forced to survive on whatever was available.

How Participants Feel

- Participants often experienced feelings of depression associated with having diabetes, especially when first diagnosed.

The topic of depression came up often as people shared stories of their loneliness. Many participants talked about feeling depressed, upon being diagnosed with diabetes and as they struggled to accept the disease and to cope with it, with or without the support of those around them.

- At times, people felt they were being restricted access to quality health care and other resources because of their ethnicity.

Negative stereotypes from society often hinder people from maximizing use of important services and information that are essential for their health.

In the discussion groups, some participants were keenly aware of how other people outside their own community perceived them. One person commented that African Americans do not get the best care. Because many are poor, they go to the county hospitals and get treated by interns. Experienced professionals are not there for them.

Another story came from an African American woman with diabetes who was visiting a medical center and felt her blood sugar drop (a hypoglycemic reaction). She had no money to buy a snack, so she asked a receptionist at one of the desks to help her. The receptionist ignored the request for help because she assumed the woman with diabetes was drunk, and the woman was forced to seek assistance elsewhere.

■ **Members from all four communities felt people from their communities were healthier before they were affected by modern American lifestyles and diet.**

Our Lives Were Healthier Before... Our Activity Decreased: Several people noted that they were more active before the change to a sedentary lifestyle in America. In Mexico, people relied less on motor transportation and walked to reach their destinations. In Laos, farming provided adequate exercise for many Hmong people.

Our Lives Were Healthier Before... Our Diets Changed: Many people spoke about how much their diets have changed as they adopted American lifestyles and eating habits. Some African American participants mentioned how beneficial it would be to return to a diet of more traditional foods, such as beans, vegetables, and very little meat.

"The hardest part is trying to figure out how to cope, deal with the kind of depression that you go through when you realize you have a disease that will never go away and which will get progressively worse."

(American Indian)

"Where I live it's too dangerous to walk. You go to the mall [to exercise] and people are going to follow you around because you're Indian."

(American Indian)

"In Laos, we could work and sweat; we had places to go be active and we could eat anything."

(Hmong)

"In my country [El Salvador] in 1978, very few people had that diagnosis. It was different from other diseases."

(Hispanic)

"We were told that this is a good country... Perhaps it is not good for us to live here."

(Hmong)

"In the first place, they're [the government] what started it, you know. First they gave us all this funny food to eat when we were on the reservation, and now they want to come back and do something new. We never had no vegetables on the reservation. Commodities - we had nothing but starches and meat. All of a sudden they want to educate us?"

(American Indian)

"In my own country, there wasn't anyone with sweet blood [diabetes]."

(Hmong)

"We had to fight in the [Vietnam] war; if they really wanted to help us, they would."

(Hmong)

"Do they just not want to sell good medicine to us?" (Hmong)

Participants talked about how much easier it was to control diabetes when they lived and worked on the farm. A Hispanic participant managed her diabetes for nine years on the farm with diet only. The move from the farm to the city involved changes in her diet and made it harder for her to take care of herself.

One American Indian person noted that Indian people have a history of healthful foods, traditions and exercise, but this was taken away from them. They didn't have the diseases they have now. Europeans introduced fats and took a way their medicine bundles. The participant felt it was important for Indian people to return to their natural diet of elk and buffalo.

Our Lives Were Healthier Before... We Came to This Country: Especially for the Hispanic and Hmong participants, the move to the United States brought about changes to their way of life. Many claimed that diabetes was rare or that it did not exist among their people before they immigrated to the U.S.

■ **Some mistrust western medical providers and the government to act in their best interests.**

Some participants were skeptical of the intentions of governmental organizations. They felt that the government was withholding the best medical care from them. African American participants mentioned the Tuskegee syphilis study as an example of how government had historically withheld medical treatment from African American people. One man theorized that diabetes was a conspiracy against African Americans on the part of the United States government and noted that the disease has become a multimillion dollar industry for drug companies.

How Participants Manage

- A number of participants adopted a positive attitude and became more health conscious as a result of having diabetes.
- Most people do their best to care for themselves, including making changes in the way they manage diet, exercise and stress.
- Some gain strength from their sense of spirituality.

Despite some of the barriers that people with diabetes must overcome in order to be healthy, many of them have found ways to cope with diabetes, through various forms of spirituality, including the use of alternative treatments and/or spiritual healing.

American Indian. Consultation with medicine men was common among some members of the American Indian community. Often, people sought help from a medicine man when western medicine was not helping them get well.

For example, an Indian woman found her regular doctor was not treating her congestive heart failure successfully. So she went to a medicine man who performed a ceremony with rattles, and she was visited by a spirit. The next week she felt better, and when she returned to her (clinic) doctor, she said an ultrasound showed that indeed her heart was strong again, and she was healed.

African American. The value of spirituality was discussed in all three African American discussion groups. Many people said they relied on prayer and their belief in God to help them deal with diabetes.

"Don't be afraid - this is a disease that can be controlled, and with proper care we can live long, healthy lives."

(Hispanic)

"Even though I'm young, I don't like to exercise. But I've discovered it is very important. I walk every day now."

(Hispanic)

"I live in a high-rise. One of my friends lives on the sixth floor, another on the fourth, I live on third. I take the stairs to each one. I walk up to my friends on the tenth floor."

(Hispanic)

"Now I'm exercising on a stationary bike for 10 minutes in the morning and my (blood sugar) level goes down."

(Hispanic)

"Medicine controls [diabetes], but doesn't cure anything; only God cures it."

(African American)

"I'm gonna live as long as God wants me to live."

(African American)

"I lost my sight. I couldn't see anything - not my Bible, nothing. I couldn't sew, and could only recognize faces by voices. I went to the evangelization group. I told the priest I couldn't see. The priest prayed for me, and thank God, I regained my sight. Only God returned my sight." *(Hispanic)*

"Nothing more than faith in God - much faith in God. He's the only one who can help and get us out of where we are." *(Hispanic)*

Hispanic. For Hispanic participants, spirituality was also very much a part of how they coped with diabetes. They talked freely about the role of God in their lives and his ability to restore health.

Hmong. After moving to the United States, some Hmong immigrants have converted to religious faiths common to this country (such as Christianity), or integrated new faiths into their spiritual practices.

Traditionally though, Hmong people follow an animistic religion and believe that there is a spirit world that interacts with people in the living world. Spirits can belong to inanimate objects, like mountains, trees or rivers, or they can be the spirits of the dead. Shamanistic spiritual rituals are designed to appease ancestral and other spirits who make people sick because they want something or are upset. It is also believed that these ceremonies can retrieve a soul, which has been lost during a traumatic event. Only when the soul has been retrieved can an ill person become well.

Some of the focus group participants were Hmong shamans (spiritual leaders), and they explained that shamanistic practices will only heal illnesses that involve the soul. If a person has a "physical illness," use of spiritual rituals will not cure them.

It was noted that diabetes is considered a "physical illness." This is because diabetes is associated with known physiological parts of the human body. For example, Hmong people know that diabetes is associated with high levels of "sweet blood," kidney failure, obesity, and other complications. These symptoms are considered "physical," or related to the human body. Thus, diabetes is not treated as a "spiritual problem," as other unknown physiological or psychological symptoms, such as pale skin, depression or delusions would be.

- **Others supplement or replace prescribed medicine with home remedies and medicines from non-western traditions.**

The American Indian, Hispanic, and Hmong groups turned to their own home remedies and non-western treatments to help them live with diabetes. Some used their remedies instead of their prescriptions, while others used them in combination with their prescribed medicines.

Hispanic participants described consuming herbs and mixtures of fruits and vegetables to manage their diabetes. The Hmong participants mentioned a root that was used to control diabetes and other unprescribed medicines. Teas from medicine men were also used by some American Indian participants.

- **Many said they seek additional information on diabetes through the media and educational classes, if available.**

What Participants Want

- **People want health care providers who respect them, who are knowledgeable about diabetes, who understand their culture and who speak their language.**

Participants described ways that health care providers could become more culturally sensitive:

- take more time to explain diabetes to patients;
- follow up on how patients are doing;
- treat patients with respect, because they will avoid places that do not treat them well;

"As long as I ate herbs and garlic, I didn't have diabetes."

(Hispanic)

"Indian people are very conscious about the negative attitudes that some people have about us, especially doctors and nurses in clinics who look down their noses at us. We're not going back to [those places], no matter how committed we are to eating well or taking care of ourselves."

(American Indian)

"In Mexico, there are some doctors who have no tact in telling a patient they're sick. They told me, 'You have diabetes. If you don't take care of yourself, you'll die,' and it's true - I was dying in that terrible shock. It affected me very, very much... At first I thought I should commit suicide. I thought, 'I'm not going to wait around to die - I'll commit suicide.'" (Hispanic)

- learn about other cultures and the historical experiences of ethnic communities in Minnesota, as this will enable providers to better understand the lives and struggles of the people they serve,
- learn about and provide resources for alternative medicine--recognize their use (and importance) and document what is available, and
- hire providers from ethnically diverse backgrounds, who are bilingual and share cultural heritage with those they serve.

A Hmong person talked about how helpful it was to have a doctor explain to him in detail what diabetes was. This knowledge helped him better understand why he needed to care for himself.

■ **Participants want more information about diabetes and self-care from their health providers -- not just a prescription for medicine.**

Focus group participants said that they respond best to diabetes education which:

- conveys positive, hopeful messages to patients;
- provides consistent health messages;
- emphasizes how to maintain good health, and stresses prevention--not just medicines;
- provides basic information about diabetes causes and symptoms, and gives practical advice about how to care for oneself.

People would also appreciate practical advice from their providers. For example, they would like to learn how to read food labels, how to cook healthy food, and how to care for their feet and their sores.

Consistent and accurate health messages are very important. Some participants said that they were told that they were “borderline diabetic” or dieticians gave them conflicting dietary information.

Note: It is inappropriate to tell a patient that they are “borderline diabetic” or that they “have a touch of sugar,” because this implies that they have a minor health problem. The current medical definition of diabetes and its associated conditions, such as “impaired glucose homeostasis” or “impaired glucose tolerance,” clearly emphasizes that any physical condition in which the body is no longer using and/or secreting insulin properly, puts a person at greater risk for acquiring diabetes and its complications in the future, especially cardiovascular disease (heart attack and stroke).

People who have diabetes, or related conditions, should be closely monitored by their health care provider and should be taking action to improve their health habits, by eating a balanced, nutritious, low-fat diet and exercising regularly, with the goal of maintaining a healthy body weight.

- **People want to be able to afford healthy food and medicine so they can properly care for themselves. They want providers to take into account the economic limitations they may face.**

“When we have to use our own money [to buy medicine], we may not be able to care for ourselves anymore.”

(Hmong)

“You have a lot of people living in your house who eat up all the food.”

(American Indian)

“There needs to be funds available for treatment. Cost barriers prevent people from taking care of themselves.”

(Hispanic)

"After talking about it, your heart feels calmer, and that's good for something, too."

(Hmong)

"Our culture is not a culture of letters and words; we're a vocal people. We need more opportunities to be vocal."

(African American)

"Word-of-mouth travels faster than telephone in the Indian community."

(American Indian)

"Now that I've gone through the Health East training with my husband, I have my diabetes under better control, and it's nice because my husband... understands a lot better how diabetes affects the whole family."

(Hispanic)

"It's hard to get young people involved. They won't listen because this is 'old folks' stuff -- so start young."

(African American)

- **Participants want more opportunities to gather with other people in their communities who have diabetes for support and information-sharing.**

People from all four communities felt very strongly that talking with others who have diabetes is very helpful, and that word-of-mouth is an effective tool to use in raising awareness about diabetes. They wanted more opportunities to come together to talk in support groups.

- **People want to raise awareness in their communities about diabetes, and to prevent the disease by educating their children about the importance of a healthy diet and lifestyle.**

Participants were asked to list strategies that would help their communities better cope with diabetes. Many felt it was important to start with families and with communities as a whole.

Family-Centered Care. The whole family is affected when one member has diabetes. Families are involved with food preparation, transportation, and providing emotional support. It is crucial to involve the entire family in diabetes education. For example, some patients may prefer to have other family members present at their medical appointments and when they receive diabetes education and nutritional counseling.

Prevention for Children. In each of the communities, people talked about the importance of educating children about diabetes in an effort to prevent the disease. Education should occur at home, in the schools and in the community.

Involve Schools. Many participants agreed that children have poor diets at school. They thought lunch menus and snack machines should provide healthier food choices. People would also like to see schools incorporate diabetes education into health class curricula.

Community Ownership of Solutions.

Participants also had a desire to raise awareness in their communities. They were interested in organizing, developing and implementing their own methods for addressing diabetes.

"Mothers should feed their children nutritious foods and make sure their children get adequate exercise instead of just watching TV and playing with computers." (Hispanic)

"Children have poor diets at school with fries, Cheetos, Doritos, pizza and sweets."
(Hispanic)

"Young people should be challenged to come up with a different life-style."
(American Indian)

"We need community awareness of the problem of diabetes; it should be statewide."
(American Indian)

"The Hispanic population needs to work in the political sphere and speak up for the rights of Latinos and others."
(Hispanic)

"The community could help by removing all the junk food lined up in the stores -- too much is available at the counters."
(African American)



Community Profiles

African American participants saw managing diet and stress as ongoing challenges -- experiencing a sense of pride in meeting these challenges or guilt when they fell short. Those that had family members with diabetes (referred to as "the sugar") were usually more familiar with the disease, and many received support from their families in taking care of themselves. Health care providers who showed genuine concern and who provided useful information were greatly appreciated. People who went to Pilot City Health Center were especially pleased with their care. Participants felt that information about diabetes would best be conveyed orally -- building on their community's strong oral tradition -- and through public awareness events.

Family History of Diabetes: African Americans often refer to diabetes as "the sugar." Many of the focus group participants were familiar with diabetes because relatives had the disease, their mothers, grandmothers, uncles and other family members. This familiarity made many of the participants more comfortable with diabetes, even though they knew the long-term health complications associated with it.

Family Support: Family members play an important role in supporting individuals with diabetes. Many people mentioned that family members and relatives were important in helping them take care of themselves. Having understanding family members made it easier to live normal lives.

For example, one woman's sister took her to the doctor and told her that if she didn't take her medicine, she would be hurting the family, not just herself. Another person said that his children and grandchildren were used to him having diabetes and were concerned that he took care of himself and that he received his daily injections. One man's daughter helped him watch his diet and his wife helped by cooking him low-fat foods.

Stress: Participants noted that reducing anxiety and stress in their lives helped them to better manage their diabetes.

"Black people are quicker to get it than other races because we've been eating rich foods all our lives."

"I was calm [when I found out I had diabetes]. With my mother being diabetic, I knew it was hereditary."

"Most of my diabetes is stress... As long as I'm calm and at ease, my sugar stays still."

Food, Guilt and Anxiety: Some of the most difficult changes people made in their lives as a result of having diabetes were food-related. People told stories about hiding sweets, such as Twinkies™, so that they could satisfy their cravings. They also talked about the discomfort of having family members watching and regulating what they ate.

What's Working: Participants noted that health professionals who show genuine concern and understanding for their patients make a tremendous impact. Many participants praised the care that they received from a nurse practitioner at Pilot City Health Center in Minneapolis. They said that the nurse was sensitive to their needs and consistently provided useful information, checked their feet often and gave them creams for taking care of their feet. Pilot City Clinic also provided participants transportation to medical appointments.

Community Strategies: Participants identified ways communities could help people with diabetes and their families in the African American community to eat healthy diets and to get adequate physical activity.

Food -- Communities should encourage:

- restaurants to provide low fat menu items and
- grocery stores to identify low fat food sections for people with diabetes

Exercise -- Communities should promote opportunities for exercise:

- walking in shopping malls
- walking events, such as "a day in the park" for people with diabetes

Spreading information: The following communication methods were suggested for spreading diabetes information in the African American community:

- **Media:** Advertising and public service announcements on billboards, television (public and cable television), African American radio shows and stations, and in newspapers and magazines like *Diabetes Forecast* and *Ebony*.
- **Celebrities:** Show famous people with diabetes who can influence others in a positive way.
- **Churches:** The church remains an integral part of the African American community and provides a center for distributing information on health and diabetes.
- **Malls and Schools:** Emphasize the importance of diabetes prevention by having diabetes screening available in public locations such as malls and schools.
- **Pamphlets:** People wanted access to more literature about diabetes.
- **Alert Bracelets:** Participants agreed that people with diabetes should wear medical alert bracelets for their own safety, so that they receive proper care in the event of an emergency.
- **Drug Companies:** Pharmaceutical companies often enclose educational videos or audiotapes with their products and some participants found these materials to be helpful.
- **Black History Month:** Use Black History Month to promote diabetes awareness. Also, have a Diabetes Awareness Month.
- **Word of Mouth:** Participants encouraged using word of mouth as a means of educating one another.

"It's a battle with the sweets. You can only go so long without sweets."

"The more I can't have it [sweets], the more I wanted it."

"I think sometimes you can make yourself real nervous, uptight if you hear too much of, 'You a diabetic; you can't eat this; you can't eat that.' We know this!"



American Indian participants often had relatives with diabetes and saw diabetes as an important issue for their community as whole. Within the family, children often help their parents manage their diabetes. Those who attend Indian diabetes education groups and who receive health care at the Indian Health Board felt very satisfied with these services. All expressed a strong desire to organize within their community to raise awareness about diabetes and prevent diabetes in future generations.

Community: Diabetes is recognized as a serious disease in the American Indian community. Participants noted that American Indians are more prone to getting diabetes. Many people in the American Indian community are connected through formal and informal social networks, and they would like to organize their community more to address diabetes.

Family: Participants were familiar with diabetes because family members had the disease. Family members passed on knowledge about diabetes, and children helped their parents manage the disease. One woman's daughter bought her an organizer for her pills, drove her to different appointments and cooked for her. Some participants said that they learned about diabetes through their children reading to them.

Modesty: American Indian participants mentioned the importance of health professionals respecting a patient's personal modesty. Health care providers need to be aware that some patients may feel uncomfortable talking about health issues that are related to private areas of their bodies. In addition, some patients may not feel at ease being unclothed in front of a health care provider.

Traditional Healing: Participants talked about other non-western treatment methods that helped them manage their diabetes. They mentioned the use of sweat lodges and told stories of their encounters with medicine men.

"It [diabetes] didn't bother me because I expected it. [Her mother had diabetes but continued to work and live well.] I think I could live like that, too, if I watch what I eat."

"No doctor tells you to expect that. You go in... and you've got this yeast infection; you don't know what it is, and it's embarrassing to you. He could have told you beforehand that might be a possibility. I was raised pretty traditionally. I don't like to talk to doctors about very personal, hygiene kind of things... It's really something doctors need to consider. I know Indian guys that won't go to a doctor because they have to take their clothes off for an examination. They would rather sit there and suffer... I see it as a real barrier to them getting health care for themselves."

What's Working: The American Indian community is proactive in educating themselves about the disease. They have developed culturally specific diabetes health care and education groups at the Indian Health Board and the Division of Indian Work, which are used by American Indian people who have diabetes. This culturally specific health care was very important to participants.

Spreading the Word: Family members provide information to one another about diabetes because it commonly runs in families. Many people also learned about diabetes from their health care providers and from participating in educational groups held at the Indian Health Board, the American Indian Center and the Division of Indian Work. They also suggest other ideas for spreading the word:

- **Community Gatherings:** Many American Indian participants liked the idea of raising awareness through powwows and suggested using money raised at such events to run support groups for people who have diabetes. Others mentioned providing information at gatherings such as Little League Baseball games and other community events.
- **Word of Mouth:** Oral tradition is very important, especially for passing information from parents and grandparents to their children and grandchildren.
- **Distribution of Literature:** At the discussion groups, Minnesota Department of Health staff provided diabetes literature to all of the focus group participants. For the American Indian Focus groups, materials were ordered from the Indian Health Service that were culturally appropriate, with art work and descriptions of food directed to American Indians. People had positive comments about the pamphlets and suggested that such literature should be made more available.

- **Media:** Strategies related to the media were suggested, such as internet access to information about diabetes, television shows about diabetes, and promotion of diabetes awareness through advertisements.
- **Advocacy:** People discussed the importance of advocating for Indian people with diabetes by being politically active.
- **Bulletin Boards:** There are many organizations which serve the local American Indian community. It was suggested that diabetes information could be posted on bulletin boards at these organizations.
- **Statewide:** Participants said that any attempt to increase awareness about diabetes should be initiated on a statewide level, so that both urban and rural American Indian people are served.

"... I thought 'Gee that's [seeing the clinic doctor] not doing any good. I better go somewhere else'... so I contacted a medicine man... While I was being doctored [by the medicine man], the spirit that doctored me came and... tapped me with rattles and he was going, and I said, 'Get back here! You didn't do my heart good.' He come back and he whacked me with a rattle. I said, 'Clean my heart out good and I'll do something for you. I'll make you 102 yellow ties and I'll tie-hang them way out in the wilderness.' I don't know why I said that, and he scratched on my back... then after the ceremony, the medicine man said, 'The lady who was doctored, her heart problems... the spirit said to tell her she'll be better after two weeks.' But I was better right next week. I quit having that gurgling... chest pains. So I didn't go to the clinic for two weeks. And when I went there, [the clinic doctor] says, 'Where were you? You've been coming in here every week, and you were trying different things.' I said, 'I don't need that anymore... because I got healed.'"



Hispanic participants were highly motivated to make diet and lifestyle changes, and stressed the value of exercise -- especially walking. Many supplemented their treatment regime with traditional medicines and home remedies. Participants frequently mentioned that their health declined during the winter. Some reported that unfamiliarity with using the medical system for preventive care, confusion about health insurance, changes in the welfare system, and language barriers are obstacles to Hispanic people in accessing appropriate health care.

Motivation: Participants were highly motivated to make healthy lifestyle changes in order to control their diabetes. People cared for themselves through exercise, foot care and changes in diet.

Many mentioned the importance of walking for exercise, and wanted more opportunities to walk, especially during winter. They emphasized the importance of good foot care. Some people managed their diabetes through a careful diet, which made medicines unnecessary.

Most participants agreed that eating less meat and more vegetables helped. One person drank a large amount of water to reduce the effects of eating sweets, like ice cream. Another suggested buying frozen vegetables, which are less expensive and often just as nutritious as fresh vegetables.

Traditional and Home Remedies: Several people used plants and herbs to help control their diabetes. Some remedies they named included: *garlic*, *rodiciosa* (a bitter herb; make it like tea), *salcuacia*, *la chaya* (in tea), *diabetina*, and *nopal* (cactus, as pills and as the plant). These plants and herbs were easily accessible in Mexico and San Antonio, Texas, but most were hard to obtain in St. Paul. They learned of the remedies from friends. Some people took the herbal remedies in place of medical prescriptions and others used a combination of prescribed medicines and home remedies.

Some other examples included the following: One person drank an infusion of eucalyptus leaves, or banana peels when eucalyptus was not available (he said eucalyptus is better). This person took his prescription medicine in combination with this tea of leaves and it lowered his blood sugar levels. Another drank a mixture of fruit juices (lime, sliced pineapple and papaya). She also drank a juice consisting of carrots and brussels sprouts. Someone else treated her diabetes with three tomatillos and *nopal* (cactus) in the morning.

"You need to be very hygienic - even if you don't bathe, wash your feet!"

"I take care with my diet and medications, and I exercise regularly, walking 10 blocks a day."

"Don't be scared; watch what you eat, and exercise, because you can continue to do everything even if you have diabetes."

"I went to a natural clinic and took those pills instead of my doctor's medicine, and the doctor told me my diabetes had practically disappeared."

Stress: Participants discussed how emotional stress raises their blood sugar and negatively affects their diabetes. They related stress to the initial diagnosis of diabetes, work, family, and, for men, changes in sexual function.

Accessing Health Care: Participants mentioned several issues that affect how they access health care.

- **Reluctance to Seek Medical Advice:** Hispanic participants agreed that they tend not to seek medical advice until the situation becomes an emergency. Hispanic people often did not previously have access to preventive care before immigrating to the U.S.
- **Confusion about Health Insurance:** Many people agreed that the United States' complicated health care system posed barriers. Often, they were unsure if diabetes care, such as an eye exam, was covered under their insurance.
- **Lack of Interpreters:** Being unable to communicate with health care providers hindered patients' ability to understand the health issues affecting them and how they could best care for themselves.

Community Strategies: Participants discussed common communication strategies for spreading diabetes information within the Hispanic community, including the following:

- health care providers,
- family and friends who have diabetes,
- Spanish language television shows,
- literature (especially about foot care),
- health food and herbal stores, and
- educational classes.

In addition to the sources of information listed above, participants suggested additional strategies for educating Hispanic people about diabetes:

- **Churches:** Churches should be used more often as places for sharing information.
- **Existing Groups:** Some seniors already meet for other activities. These existing groups can be used to spread information. English as a Second Language classes can also be used for the same purpose.
- **Help with Diet:** Many people realize the importance of managing their diet, and continue seeking ways to cook tasty, low-fat, healthy foods. People would like diabetes recipe books that provide more diverse and flavorful ways to cook ethnic foods.

"I've often felt very depressed, to the point of even attempting suicide. Emotional difficulty, like when I moved to another state. No one has helped me to deal with my emotional problems.... I believe emotional stress raises my blood sugar level and makes it difficult to control my diabetes."

"Psychologically, don't think you have such a terrible sickness.... Two weeks ago a lot of people came to my house...I checked my blood sugar and it was very high.... the more I worried, the higher my blood sugar rose. My friend told me my diabetes is more psychological. I keep thinking, 'I have diabetes, I have diabetes'. I need to attend to what's going on in my head as much as in my body."

"The Latin man doesn't ever want to admit to the problems diabetes can cause, especially in the area of sexual performance."

"Many Hispanics don't go for health care exams unless they feel very ill."

"Sometimes I go to the hospital and they say there will be an interpreter, but there isn't."

- **Diabetes Clinic:** Participants suggested creating a diabetes clinic which serves the Hispanic population.
- **Political Activity:** Participants emphasized the importance of participating in the political process in order to promote better health care and health education for Hispanic people with diabetes.
- **Diabetes Statistics:** Statistics on diabetes morbidity and mortality should be publicized to show the serious consequences of diabetes for the Hispanic community.
- **Spanish Language Media:** Provide educational messages about diabetes.
- **Awareness Raising:** Sponsor a walk for diabetes and highlight Hispanic/ Latino celebrities who have diabetes and are positive role models for successful diabetes management and healthy living.

Hmong participants often struggled with western health concepts and practices. Most had difficulty accepting that diseases like diabetes have no cure. Some felt a mistrust of the western medical system and suspected that their health providers were withholding appropriate treatment. Elders in particular were prone to feelings of isolation and depression. Some noted that opportunities for traditional forms of exercise, such as gardening, were extremely limited due to the Minnesota climate. As in other communities, coming together for mutual support was seen as highly beneficial.

Translating Health Concepts: In addition to the basic challenge of translating health information back and forth between the English and Hmong languages, Hmong patients and western-based health care providers face the challenge of translating theoretical concepts between two cultures with very different health beliefs, practices and treatments.

The term "diabetes" in the Hmong language is literally translated as "sweet blood." Many Hmong people said that diabetes did not exist in their homeland (i.e., Laos), before they immigrated to the United States. The concept of having a "chronic disease," which has no permanent cure and must be managed over a lifetime, is also difficult for many Hmong people to accept and understand.

Mistrust of Western Medical System: Hmong participants talked about how uncertain they felt when they visited their doctors. They wondered about the large amounts of blood that they were asked to give up for lab tests and about the intentions of those who took their blood. They said they often did not receive information or feedback on why their blood was taken and how it was used.

Hmong people often fear invasive medical procedures, such as lab tests for blood and urine or surgery. They worry that such procedures will weaken or harm them rather than cure them. Some also question whether they are provided the best medical care possible, or worry that they may even be subject to medical experimentation. This is especially true if they know of friends or relatives who have not recuperated or even died following a medical procedure. Because Hmong people traditionally worked as farmers, and often continue to depend on their ability to perform physical labor for an income, they see strength, health and work efficiency as vital to their survival.

"When I first found out, I didn't know what it was. All I knew then was the words 'sweet blood.' After I saw the doctor, I came home and spoke with my children and others who had been in this country longer and understood it better. Friends told me that this disease was not curable and that I had to take care of myself. So I wasn't afraid because even though I knew I had the disease, I also knew I could take care of myself."

"It makes me angry. You're not old yet, but they keep saying that there is no cure; they just give you medicine so that you can cope."

"The doctor told me that such a disease had no cure. You can cope with it by caring for yourself but if you don't do that, your hands and feet could become paralyzed. I realized I could die, so I said to the doctor, 'If there is no cure, please give me some kind of medication so that I can die. I don't want to live like this.'"

- **Taking Time and Building Trust:** Despite some of the skepticism associated with the western medical system, some Hmong people had positive experiences with their health care providers. They appreciated health care providers who took the time to clearly explain diabetes to them. In one instance, a physician spoke Hmong and was able to explain to a patient how diabetes affects the body. This helped the patient to accept having diabetes and motivated him to care for himself.

Isolation: Hmong participants described feeling alone in their struggle with diabetes and its impact on their lives.

- **Individual Burden:** Hmong people saw managing their diabetes as an individual burden and were less likely to see a role for community support of people with diabetes.
- **Despair and Depression:** Many participants expressed despair about having diabetes. Feelings of loneliness and emotional pain were discussed in detail. Tears came readily for some. For many, it seemed that their struggles went beyond diabetes--probably related to the challenges that they face daily, being immigrants in a foreign country, where they are forced to adapt to a new culture, a new language and a new way of life.

- **Generational Differences:** Many Hmong elders struggle to adjust to the changes that have occurred in their lives since immigrating to the United States. Traditional survival skills such as farming were important in Laos, but no longer apply to survival in urban Minnesota. This situation displaces elders from their traditional leadership roles, and undermines their ability to share their wisdom and gain a sense of respect and self-worth. Many elders find themselves left behind by younger generations, who have adapted more quickly to American culture.

Participants described how family relationships added stress to their lives. Diabetes affected relationships within their core families as well as relationships with other relatives outside of their home. Support from the family seemed extremely important, and those who lacked it seemed to be the least happy.

- **Changes in Diet:** People talked about how diabetes changed their eating habits and made their interactions with their families more complicated and emotional.

"They take so much blood, it makes me angry; they take so much blood that by now they should be able to figure out what is wrong."

"There is nothing that will help. If we can't help ourselves, then there is nothing that can help."

"There's nothing that will help... I almost killed myself two times, but my wife cried and cried and wouldn't let me... If I didn't have my wife, I would not be living..."

"Old people are living in [emotional] poverty; they [young people] have forgotten all about us."

"My daughter-in-law is impatient. When I get up so often to eat, she scolds me and says, 'Why do you old people have to get up so often to eat? You can't even do anything. Why do you eat so much?' It's better to die...[than to live this way]."

"I learned how to measure foods and follow a schedule. My wife and daughters cook for me, and they have to measure everything I eat. This routine hurts my feelings. They don't have to measure anything they eat, but they do have to measure what I eat. In your heart, you know you're not separated from your family, but at the meal table you see how different your food is from theirs. My wife and children don't say anything but just looking at the food lets me know of a certain separation between us. I realized this disease would always divide my family in this way."

"In the summer, you can go to the gardens and gain some strength... staying around the house makes you so weak."

"In the winter, our sugar is high because of less activity; if the weather weren't so cold, running is so much more effective than taking medications."

Physical Activity, Gardening and

Problems with Winter: Several people talked about how exercise helped them manage their diabetes and mentioned their enjoyment of gardening. They also noted that cold weather in Minnesota makes such activity difficult during the winter.

Community Strategies: Hmong participants had the following recommendations for helping people with diabetes in the Hmong community:

- provide support groups,
- education on Hmong TV and radio stations, and
- education through oral communication.

Focus Group Recommendations

The following recommendations come from people with diabetes who participated in the focus groups. These recommendations will be shared with health care providers and community leaders, who will be asked to review them and to add any important missing issues. This broader list of recommendations will be used to develop a state plan for improving diabetes education and health care services for people of color in Minnesota, under the guidance of a representative, state task force. The plan will be implemented through continued collaboration between the Minnesota Diabetes Control Program, community organizations, health care systems, businesses, schools, spiritual and religious organizations, individuals with diabetes and their families and other groups who share an interest in promoting the health and well-being of ethnically and racially diverse populations in Minnesota.

Diabetes Education

- ◆ Organize culturally-specific diabetes support and education groups
- ◆ Provide diabetes education to individuals and their *families*
- ◆ Train and support people of color as diabetes lay educators
- ◆ Provide practical information, such as adapted traditional recipes and recommendations of products for self-care
- ◆ Develop and disseminate culturally-specific diabetes education materials
- ◆ Use oral communication in diabetes education efforts, such as storytelling, community radio, churches and one-to-one contacts

Health Care

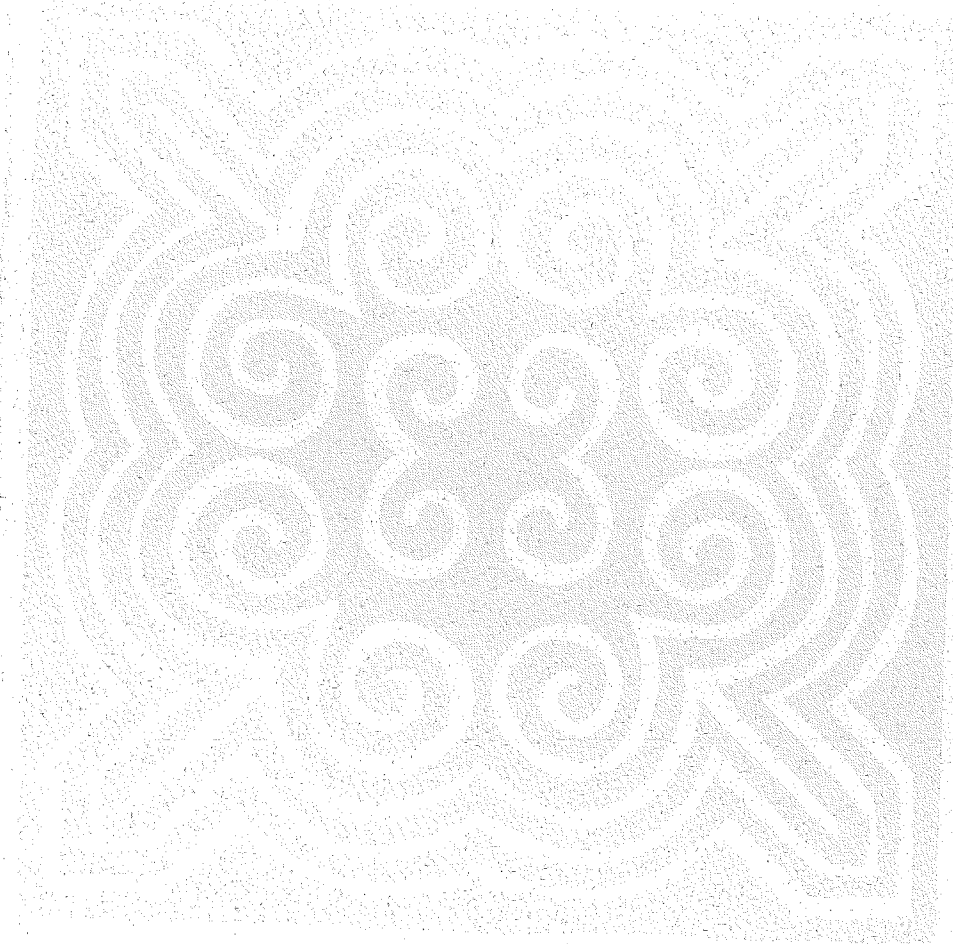
- ◆ Assure access to health care by providing transportation and interpreter services
- ◆ Improve the quality of health care by:
 - ✧ enhancing professional knowledge and skills in diabetes care
 - ✧ supporting long-term relationships between patients and their health care providers
 - ✧ promoting effective communication between patients and their health care providers
 - ✧ taking into account the emotional impact on patients that accompanies a diagnosis of diabetes

- ◆ Increase health care cultural competency by:
 - ✧ increasing providers' understanding of and sensitivity to the historical experiences of people of color
 - ✧ educating providers about different cultural beliefs and concepts of disease.
 - ✧ acknowledging and discussing non-western treatments with patients
 - ✧ creating culturally-specific tools for providers to guide their communication and interactions with people from cultures different than their own
 - ✧ meeting needs for culturally-specific diabetes information and assistance
 - ✧ learning from health care providers that are respected among people of color
 - ✧ recruiting, training and hiring more health care providers from diverse populations.

Community Action

- ◆ Involve community organizations that already serve people of color with diabetes, including:
 - ✧ media
 - ✧ seniors programs
 - ✧ churches
 - ✧ community service organizations
- ◆ Promote community awareness of diabetes at cultural events
- ◆ Educate children about diabetes, healthy diets and exercise
- ◆ Sponsor diabetes support and education groups and provide meeting space, refreshments and transportation
- ◆ Facilitate mentor programs for newly-diagnosed people with diabetes.
- ◆ Advocate for more healthy food options at local restaurants and grocery stores
- ◆ Develop safe and enjoyable opportunities for exercise in all seasons, especially during the winter
- ◆ Assure transportation to medical appointments

Appendices



Appendix A: Diabetes Focus Group Questions

1	What was your reaction to the news that you had diabetes?
2	When you found out you had diabetes, what kind of changes did you make, if any?
3	What makes it hard for you to take care of your diabetes?
4	Since you've had diabetes, what has helped you to take care of yourself?
5	How have you learned about diabetes?
6	Suppose that a friend of yours found out that they had diabetes. What would you want them to know about diabetes?
7	What would you want your friend to know about the relationship of diabetes to other health conditions?
8	What advice would you give your health provider about how to help their Hmong/African American/Native American/ Hispanic patients with diabetes?
9	What would help you and other people with diabetes in our community to be healthier?
10	Are there things that we can do in our community to help people with diabetes?
11	What's the best way to spread information about diabetes to people in our community?
12	As the Department of Health works on trying to improve diabetes education in the Hmong/African American/Native American/ Hispanic community, what advice do you have for them?



Appendix B: Questions Focus Group Participants Had about Diabetes

... What is Diabetes?

1. What causes diabetes? Is diabetes hereditary?
2. Can you explain the different types of diabetes?
3. Can you prevent diabetes?
4. Is diabetes more prevalent in African American, American Indian, Hispanic and Hmong people than in the white population? How common is diabetes for each of these groups?
5. Why do American Indian people get diabetes? Is it biological or lifestyle-related?
6. Why can't diabetes be completely cured? What are the prospects for a cure?

... Food

7. If you have diabetes, is it bad to eat sugar (e.g., candy, fruit juices, dried fruit, etc.)?
8. Are there any other choices for sweeteners?
9. Are artificial sweeteners bad for you?
10. Is it better to eat regular foods in moderation than to eat foods specifically for diabetics? (Can low-fat and low-sugar foods actually have more calories and sugar than regular foods?)
11. Is it all right to eat "live blood?" (blood pudding, a Hmong food)
12. Is it bad to drink alcohol if you have diabetes? Why?

... Diabetes Awareness

13. Why isn't there a "Diabetes Awareness Month?"

... Health Care and Managing Diabetes

14. What is Rezulin and what kinds of diabetes can it manage?
15. Is warm weather better for people with diabetes than cold weather, as far as helping with circulation?
16. What do blood thinners do to one's blood sugar level?
17. Why do health care providers draw so much blood and take urine samples at clinic appointments?
18. Why does the doctor change my medicines so often?
19. What is the difference between Medica and Medicare?
20. How does welfare reform affect people with diabetes (their health care, etc.)?



Appendix C: Additional Resources

Diabetes in African Americans, March 1997 - NIH Publication No. 97-3266

Diabetes in Hispanic Americans, April 1997 - NIH Publication No. 97-3266

National Diabetes Information Clearinghouse, National Institutes of Health

Tel: 301/654-3327

Fax: 301/907-8906

E-mail: ndic@aerie.com

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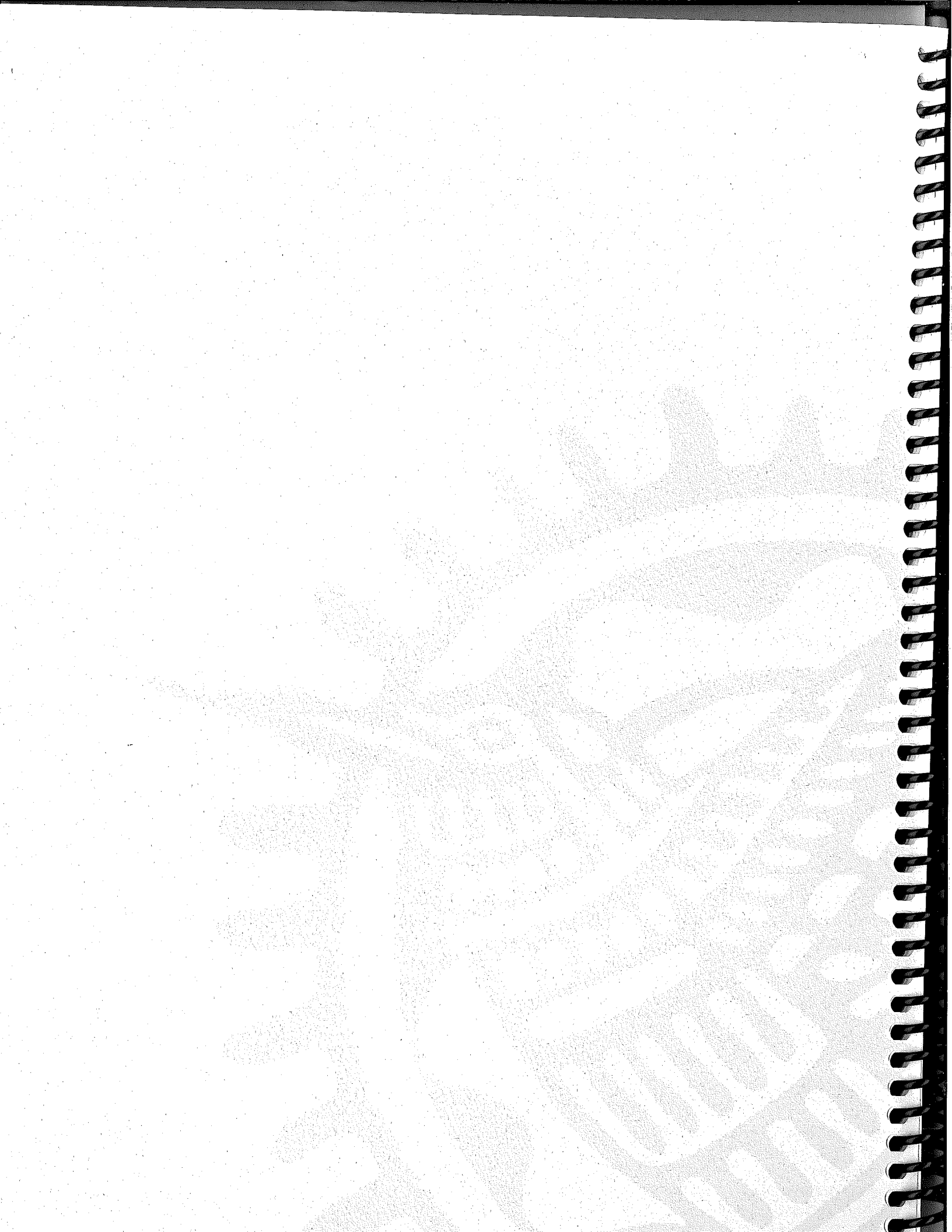
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