Community Diabetes Initiative Evaluation of Disparities
Related to Race and Ethnicity

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Abstract

The purpose of this evaluation was to explore some potential preceding factors that may contribute to the disparity in ultimate health status of patients with diabetes from three ethnically or racially-defined populations served by certain clinics within Seattle/King County's Community Diabetes Initiative. This evaluation was conducted through face-to-face semi-structured qualitative interviews with 22 persons with diabetes from the Asian/Pacific Islander, African American, and Hispanic populations served by these clinics. Unavoidable selection biases in the recruitment processes may have an effect on the findings and are noted in the report. While the authors found no significant disparity based solely on race or ethnicity, we did discover that relative poverty, an attribute common to the populations served by these clinics, may have a significant effect on patients' ability to sustain self-management regimens common in diabetes care. We also found that, while the clinics and their staff were viewed quite positively by these patients, the clinics alone were not able to provide the social supports required by many patients to maintain their own self-management regimens and their emotional well-being. Finally, we found that, while these patients had a sound grasp of the self-management techniques required to control their diabetes, they lacked an integrated understanding of their disease through which to see the relationships among attributes of the disease, their own attitudes and self-management behaviors, and the physical and emotional outcomes they experience. We hypothesize that: 1) these patients require far more community and family knowledge about diabetes, community and family acceptance of its implications, and community and family social support than they now receive, 2) with few and well-defined exceptions, the medical, medication, and supply issues for these patients are being resolved, 3) these patients would be served better by increased conceptual grasp of the disease, increased awareness by the clinic staff of the real-life conditions which color the ability of patients to manage the diabetes, 4) formal and informal support group participation among these patients would considerably enhance their self-management behaviors and desired outcomes, and 5) that attention paid to patients' real-life conditions and cultures may positively impact their well-being. Further, 6) it likely that ethnicity and culture may predispose individuals to respond to disease and loss in ways that limit or enhance their desire and ability to be effective self-managers. These factors need to be understood if physicians and educators are to design regimens appropriate to individuals.

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I. Purpose of Evaluation

The purpose of this evaluation was to explore the preceding factors that may contribute to the disparity in ultimate health status of patients with diabetes from three ethnically or racially-defined populations served by certain clinics within Seattle/King County's Community Diabetes Initiative. This report, in combination with an earlier evaluation of a new multi-clinic registry of patients with diabetes, were intended to contribute to the design of care and support programs for minority populations. In particular, the CDI was interested in the prevalence of self-management goal setting and behaviors and supports and barriers to self-management in ethnic minority populations. Ultimately, these programs will work toward the goal of eliminating diabetes health outcome disparities among racial and ethnic minority populations.

II. Methodology

Preliminary research methodology developed for this evaluation included focus groups of patients with diabetes, individual interviews with such patients, or a combination of the two. The number of patients to be included, regardless of method, could not exceed 24 persons, drawn from different community clinics participating in the CDI. Given the intimate nature of the questions to be posed, the brief timeline for conducting the evaluation, and the different languages spoken by the patients, it was determined to conduct individual interviews, unless an existing support group were willing to act as a focus group and would be meeting during the evaluation period—no such group met these criteria.

As noted in the purpose, the evaluation was to be guided by findings from a preceding evaluation of the new diabetes patient registry (a report available from the CDI). The registry was found to be too new to draw conclusions to guide this ensuing qualitative evaluation. As a consequence, these two evaluations are not linked as closely as originally intended.

A. Research Questions

The authors developed a set of research questions and procedures in accordance with questions proposed in the federal Community Diabetes Initiative contract language:

- What clinical and personal barriers do patients with diabetes mention that interfere with receiving routine care for diabetes?
- What barriers do patients with diabetes mention that prevent them from managing their diabetes on a daily basis?
- What health center activities do patients mention that help them overcome these identified barriers?
- How would patients improve on existing health care services?

Investigators focused these questions on the experiences of ethnic and racial minority patients when self-managing their diabetes, and seeking health care services and self-management support. The resulting structured field questions were reviewed, amended, and approved by the CDI's Self Management Support Working Group, comprised of clinic staff, and appear as Appendix A of this report.

B. Recruitment and Selection

During the month of October 1999, research investigators at CCHCP were to conduct a maximum of 24 interviews with patients from specific ethnic minority communities. In order to identify these specific communities, CCHCP was to use indicators from a data analysis of the recently developed Community Diabetes Initiative Registry. Due to the young nature of the CDI Registry, CCHCP investigators sought guidance from Patricia Manuel and Mike Smyser of the Public Health—Seattle & King County. With their help and guidance from members of the Self-Management Support Working Group (a newly developed team of nurses and dieticians from the participating clinics who come together periodically to promote self-management as a tool for controlling diabetes), CCHCP selected three key ethnic minority communities: Asian and Pacific Islander, African-American, and Hispanic/Latino. Although broadly defined categories, these populations are consistently mentioned in diabetes literature as being at risk for diabetes, under-diagnosed and lacking appropriate support services. Given the broad, general nature of these ethnic categories, the investigators designed a recruitment strategy that would attempt to include a balance representation from all three populations.

Investigators contacted Working Group members and requested their assistance in the recruitment of four to eight patients from their patient panel to be respondents in evaluation. After addressing concerns of clinic management support, internal review board, and resource availability (time and space), meetings were held with each participating clinic that expressed interest. Only two out of the seven clinics were not able to participate for two main reasons: 1) Timing of potential interviews, and 2) Number of patients with diabetes going to the clinic in October. Each clinic was instructed in detail about their responsibilities in this project and the necessity of their commitment to this effort.

Recruitment strategies varied among clinics, based on their programs and operation; however, members of the Working Group with input from providers, identified known patients with diabetes from the target populations. They selected those who had scheduled appointments during the evaluation period and contacted them to see if they were willing to participate in the evaluation. They informed potential respondents of the evaluation purpose, procedures, compensation, and risks. (See Appendix B) Supplemental respondents were recruited from weekly foot clinics and a clinic's "Diabetes Day" activities. Since their collective efforts were not successful in recruiting eight patients from the Hispanic population, we over-sampled in the other two populations.

The investigators prepared and distributed English and translated versions (Vietnamese, Cambodian, Chinese, and Spanish) of recruitment materials and consent form. The Working Group members were responsible for reviewing these materials and designing a recruitment strategy appropriate for their clinic. Although each clinic was given the freedom to design how to recruit respondents, most modified already established patient clinic visits to include a 30 minute interview with a field investigator before or after an appointment. On 3 occasions, a field investigator conducted interviews at the patient's home. The success of recruiting these respondents was directly related to each patient's long-term relationship with the nurse or dietitian volunteering to help in the recruitment. The patient's trust in this person ensured a higher success rate.

Investigators successfully interviewed 22 individuals (see Appendix C for characteristics of respondent cohort). The authors find this resulting panel to be a somewhat unusual cohort, based on the manner of selection and recruitment. By definition, these persons are relatively poor, based on where they seek and find their care (community and public health centers) and afford their care (Medicaid, Medicare); also, many reported living conditions (e.g., being fed at a mission) that indicated that they are low income. Both their own statements and the number of visits they make to their clinics indicate that they are very attached to their clinics and clinic staff. Some reside within close proximity, even walking distance, from their clinics and use them with great regularity. Perhaps as a consequence of these foregoing factors, they appear very knowledgeable about the rules and techniques of diabetes self-monitoring and self-management, whether or not they follow them. *They also expressed that they are very well supported by their clinics and pharmacies in overcoming certain expected barriers, such as access to medication. It would be unwarranted to generalize from this panel to those minority populations who are far less attached to their clinics, use them far less often, may experience less immediate access, may receive less culturally and linguistically competent services, and so on*.

The 22 patients interviewed were typically over 50 (average 58, ranged from 28 to 78). Eleven respondents are categorized as African American, eight as Asian and Pacific Islander, and four as Hispanic/Latino. Closer examination of each respondent's self-identified ethnicity presents a spectrum of respondents within each ethnic group and several that might be categorized as multi-ethnic. An almost even representation of male (10) and female (12) respondents is present in the cohort. The respondent pool also represents patients with diabetes from 5 out of the 7 clinics participating in the Community Diabetes Initiative.

None of the respondents had been severely and obviously physically impacted by diabetes. None had lost vision, displayed severe paralysis, or experienced amputation. Most respondents fear these complications in the future. Several respondents, however, have been hospitalized for strokes. Most have high blood pressure. The patients vary in weight status from normal weight to obese. Several complained of numbness in their hands and feet, and arthritic pain.

C. Conducting the Interviews

Over a three-week period in October 1999, two field investigators interviewed patients with diabetes, namely, one of the authors and one experienced African American field interviewer. The interviews took place either in the clinics or in the respondent's home, whichever was more convenient for the respondent. Some of the interviews required the services of trained medical interpreters.[1]

On interview days, investigators arrived at the clinic early enough to prepare necessary materials and settle in. Only when visiting the patient's house was such preparation not available. Investigators conducted interviews that lasted anywhere from 20 minutes to one hour, in a private meeting space varying from a small office, counseling room, exam room, or the patient's living room. Only the patient, the interviewer, interpreter, and family members were present during the interview. This ensured that emotions, barriers, and other personal aspects of their diabetes could surface.

The interview began with the interviewer giving an introduction of himself/herself and the evaluation project. The main purpose of these interviews was explained to respondents—to better understand the experiences of patients with diabetes; that is, how do they manage/control their diabetes, what supports do they have, what barriers do they experience, and what are their needs as patients with diabetes. Then, the consent form was read word-for-word. Of particular importance, the interviewer obtained permission from the respondent to tape-record the interview. Only one respondent refused to use the tape recorder, but continued with the interview. Each respondent was given the necessary information to contact the investigator if they had further questions. The actual interview began with a series of demographic questions, used to help characterize the patient cohort. Of particular importance in this section of the interview is a question regarding ethnicity; respondents were asked to self-identify their ethnicity.

The core questions of the interview were designed and presented to the patients as open-ended. Patients were encouraged to expand on their thoughts, stories, ideas, opinions, and experiences. As necessary, the interviewer re-ordered the interview questions to be conducive to natural dialogue rather than linear closed-ended questioning. The majority of respondents spoke as openly and freely as was intended in the questionnaire design. Rarely did the interviewers use the designed probes for the open-ended questions.

Six interviews were interpreted, only two of which presented methodological concerns. The first was an interview with a Spanish speaking female; the interpreter's low but animated voice prevented clear communication with the patient. The second was an interview with a Mandarin-speaking male; the interpreter was including her own follow-up questions to those asked by the interviewer. Once she recognized that she was doing this, she corrected herself and modified her style of interpreting.

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[1] In one instance, a bilingual nurse from one of the clinics interpreted the interview and noted that she had learned much more about the patient than she had known from preceding routine clinic visits, a fact the authors found of interest.

Following each interview, the respondent was given a $25.00 gift certificate for his/her participation and questions directed to the interviewer were then answered.

Investigators transcribed and coded all 22 interviews using NUD-IST and other coding mechanisms, appropriate for recurring themes, concepts, ideas, and tendencies. Resulting coded data and interview notes were analyzed by the authors, resulting in findings presented in the next section.

D. Limitations of Evaluation Methodology

The authors found this project's methodology limited the scope of potential findings and addressed only some health disparities of ethnic and racial minority communities. *"Health disparities" in the context of this study refer to the clinically recognized differences in the health status and health outcomes of patients with diabetes by ethnic background.*

Our purpose, goal, and methodology addressed this issue by examining the perspective of a patient with diabetes and what preceding factors identified by patients might impact or shape their health status and outcomes. This evaluation did not assess racial or ethnic disparities in support and health care services (i.e., discrimination in health care services) at CDI community clinics. However, differences in services provided to patients based on ethnicity and race may be a cause for differences in health status. An inquiry focused on discrimination in access or service would require other comparative methods and respondent cohorts.

Since the membership of the CDI is mainly small community clinics designed to serve specific ethnic populations, it is *highly unlikely* that interviews with their patients would reveal significant dissatisfaction with these clinics or reported incidents of discrimination, based on race or ethnicity. The success of these clinics depends on their ability to appropriately serve specific populations or communities. Looking at health care institutions without such community focus may reveal experiences.

By interviewing patients instead of providers and clinic staff, investigators obtained a one-sided view of support systems and health care provided by CDI clinics. This deficiency prevents comparison of what is offered by clinics versus what needs were identified by patients with diabetes. It also does not provide a clear picture of the current diabetes care systems. Finally, although this methodology permits some weak comparison between ethnic minority populations in this study, it does not allow for a comparison with white populations.

III. Findings

These findings are ordered sequentially within the patients' real life conditions.

A. Looking for Racial, Ethnic, and Cultural Disparities

The authors found few discernible differences among respondents in terms of the impact of race, ethnicity, or culture on their access to services or their own stance toward their disease.

Far more profound within this panel were the similarities due to relative poverty of the individuals and families experiencing diabetes. The relative lack of economic resources made their concerns about being able to perform their paid work quite acute. Their roles as contributors to the family income or as sole supporters of their own lives were seen to be compromised by increased fatigue, pain and numbness, and the need to engage in routine glucose monitoring. Their household functions—cooking, cleaning, driving—are also compromised as their family and personal expectations are thwarted. And, finally, their inability to afford a variety of needed supports (described later in this report) often seriously compromise their day-to-day life.

Many of the respondents are recent immigrants, unemployed, elderly, speak little or no English, have little formal education, and have few marketable skills. Respondents uniformly reported low income level, hard and long physical labor, and a struggle to make ends meet for themselves and/or their family. As a result, those who could work long hours, frequently 7 days a week. Employment ranges from restaurant owner, taxi driver, grocery bagger, garage cleaner, to chef. Their low income level seemed to impact their diabetes and the management of their diabetes in different ways. First, treatment and clinic support is limited to what is covered in their insurance. Few supplemental supports are provided or affordable. Second, continuing paid employment challenges successful monitoring and management of their diabetes. Third, the support systems and work alternatives for these patients may not be as readily available as they are for people from higher socioeconomic classes.

Within their cultures, there are often well-defined family roles and structures that these respondents try strenuously to maintain and that place great demands on them, often far exceeding their physical and emotional capacity. However, we did not observe that differences in culture dictated these demands as much as the condition of poverty and the need for and drive to increased income and fulfilling household roles and tasks. In addition, the respondents seemed quite individualistic, based on who they are/were before being diagnosed, their work and family situations, their stance and emotional style when confronted by uncontrollable events and others aspects of life, their friends and social networks, their stress learning styles, and changing internal processes over time.

However, the interviews revealed that their cultures do have some impact on the treatment of their diabetes. We discuss three of these aspects briefly.

1) Age.

With an average patient age of 56, the advanced age of our panel of respondents presents unique considerations. These respondents tend to have less family and/or be the oldest members of their family. In their senior roles, they feel more responsible for their children and grandchildren. Those with older children find that these are their "golden" years without the required responsibility of caring for their children. Those with family commitments and other economic responsibilities—caused by poverty—continue to work at an advanced age regardless of having diabetes and having to ignore it.

> "I don't care whether I control better…manage [diabetes] better…I don't know why I get this disease. I feel like if I can die quickly…that is why I don't care. So someone in life from 60 to 80…if you have money and healthy, that is good. If you have money and not healthy, life is, no meaning to being alive. If no money and no good health, better just die." (63, Chinese male)

Those without familial responsibilities or economic needs can relax and focus more on treating their diabetes.

> "If I do not like to go anywhere I just stay at home and rest. That is it. I am just taking it easy. My life is...you know, I have seven kids and they are all grown up and I bring them all in college before and I sacrificed too much and now I want to rest a little bit." (68, Filipino female)

Age-related issues encompass the ability to get exercise, other health conditions not related to diabetes, familial responsibilities, and perspective of the future.

2) Gender.

For a few male respondents, sex was an issue, particularly sexuality and sexual performance. A younger respondent expressed concern for diabetes impacting his ability to have children and an older man reported difficulties in his ability to have intercourse. In light of these issues, diabetes has reshaped future family plans and future children. Another note is that fewer of the male respondents appeared overweight compared to female respondents.

3) Ethnicity.

The ethnic differences among respondents with regard to their coping with and management of diabetes is subtle. The ethnic Chinese respondents typically work very long hours, leaving little time for rest, self-monitoring, scheduled eating, and exercise.

> "Exercise, I joined a club…I am busy and I am working full-time job. Before, I work two jobs. One is full-time and one is part-time weekend. I work for…you know…learning English, lesson, and doing job, and trying to understand. So that is why I work for that grocery store packing food…it is for people to take out.

> And, anyway, helping the family have some money too… I have like seven days a week working." (41, Chinese female)

Given these working conditions, management of diabetes is limited to taking medication, monitoring glucose levels periodically, and modifying one's diet. However, changes in diet requested by physicians and dietitians are not always appropriate for the patients' lifestyle. All of the Chinese respondents reported having no real interest in "sweets," but were still advised to reduce their intake of high sugar foods.

African American patients appeared more frequently to be social isolates than the other ethnic groups. Most often, their extended family is not present in the home and lives outside of the state. Those with nearby family did not feel it was appropriate to request their support. The absence of family support structures is reflected by the patient's dependence on the clinic for advice and support.

> "I got a good doctor. She is a lady doctor and so she keeps pretty good tabs on me. You know. Otherwise…The way I feel about it, the doctor, he got a book on it. See, they know more about you, than you do yourself. You know, they know what is good for your health, than I do. So, I try to go along with the doctor and it is working out pretty good." (78, African American male)

African American patients also displayed differences in diet when compared to other respondents. Their typical foods eaten prior to learning they had diabetes were fried and high in fat. Particular changes in the African American diet for this group required modifications in cook techniques to include boiling, broiling, and steaming. African American respondents understand the basic dietary changes, but they infrequently or inconsistently follow these changes.

The Ethiopian and Ethiopian/Eritrean respondents expressed particular ethnic concerns. They noted that the issue of privacy in Ethiopia is different than in the United States, and it is not appropriate to treat oneself with insulin or otherwise in public. Employment and income come before treatment of the disease. Both respondents refused to modify work habits to address their need for self-monitor or management. In describing his desire to establish a schedule to check his glucose and give himself insulin injections, but not able to because these activities might (in his opinion) jeopardize his employment, one respondent stated:

> "For checking my glucose…morning and night. I have found it to me...lunch time, since I am not at home, I have too...you know I might be working so I will go to the break room. I won't have my privacy to do. To inject myself. To check and things you know. It is not comfortable because you need your privacy to do those kind of things. You need privacy…the restroom is not convenient because you would be afraid of the bacteria…So, all you have to do is go to the break room or to the locker room and try to, you know, and try to find enough privacy." (28, Ethiopian/Eritrean male)

In addition to this struggle to work, the respondents presented specific dietary issues related to treatment of their diabetes. For example, one Ethiopian respondent stated that Ethiopian bread, a central food source in the Ethiopian diet, is millet-based, which presented little problem to him in controlling his diabetes; he also said that, in the United States, the same bread is made from a wheat-millet mix which can be a problem for him. Both respondents said that some sauces (ingredients unknown) prepared by Ethiopians are not appropriate for the diet of a patient with diabetes. Of particular concern for these two patients is what is being eaten outside the home at work; there is not much control over these fast-food products.

What can be derived from these cultural differences is merely that they do exist and have an impact on self management. Patients will learn specific dietary modifications, but these changes might not fit into their current diet system or that of their family or life conditions. The cultural differences outlined here may be common among the majority of our respondents, but might not be consistent throughout that culture. In addition, there are likely to be more cultural-specific differences that did not emerge from these respondents.

B. Striving for Normalization

Most of the respondents did not exhibit severe outward physical manifestations of their disease—loss of limbs, vision, and so on. The physical losses with which they were dealing were less visible—pain, numbness, fatigue, inability to sleep, infections, allergies, mood changes, and so on. Even those who had suffered strokes and heart attacks exhibited losses largely invisible to others.

The respondents commonly attempt to be or appear normal, that is, without a complex disease. Some make themselves believe they are, in fact, normal and without diabetes, telling themselves that the disease is not present. Some patients also attempt to make others believe that they are normal. The lack of outward physical manifestations of the disease enables many respondents to *normalize* their lives, that is, to pass in the social and employment worlds as people without a limiting disease.

Normalization is related to trust. The less that respondents trust that others will see and treat them properly, after the diabetes is disclosed, the less they will disclose. While some respondents noted that their children and spouses supported them, others appeared to be socially isolated even within their families.

- “When you are ill, you look and feel like everyone else.”
- “Some of my friends do not know of my condition.”
- “I don’t tell my family much about what is going on.”
- “It affects my family because they hurt over what they see is happening to me and there is nothing they can do about it until I decide to do something. They are going to ask more questions than you are able to answer. Then they get

frustrated. They still look at you as a question mark. Or, you hear a question mark in their voice. (Patients with diabetes) who are in a fixed income or poor people (acquire) the status of "throw away" people."

- "You ask me if this is something I want to share with someone. No. It is a curse. It is very disgusting."

In some instances, these patients with diabetes do not inform their employers that they have diabetes, because they fear loss of employment. They may not take needed rest, eat on a regular basis, eat the correct foods, monitor their glucose level, or inject themselves for fear that someone will note this and place their employment in jeopardy. Their mood swings also remain inexplicable to others.

A large number of respondents did *not* inform their friends and family of their disease, its severity, or its demands on them. Thus, they would continue to exceed their energy levels, prepare and eat the wrong foods in the family setting, and eat the wrong foods at parties and other festive occasions in order to keep their disease a private matter. Not sharing this information with employers, co-workers, friends, and family members maintains them in their normal social roles but places them at increased medical risk. When others are unaware of the disease and its demands, they cannot alter their own behavior and expectations of the person with diabetes nor support the person with diabetes in his/her particular regimen of eating, exercise, stress reduction, and rest.

> "Sometimes, I get asked by different people to help move boxes, moving this or that. I cannot do it because I cannot depend on my feet." (45, Hispanic male)

Given that diabetes and its physical and emotional consequences already limit the social activity of these respondents, it is hard to recommend that they accentuate their "different-ness" by announcing their disease to those around them. On the other hand, *many of these respondents really require external supports to maintain their internal regimen and still feel good about themselves*.

C. Living with Social Isolation

In addition to the isolation associated with their physical and emotional limitations and their age and stage in life, a number of the respondents in this evaluation were persons who did not live with their families or have family members in the immediate area. This placed them at somewhat greater risk of social isolation and lack of effective emotional and practical support for their needed health maintenance behaviors. In one case, however, a single man was fed by a local mission that recognized and acknowledged his diabetes by giving him the meal tickets specifically for the diet of persons with diabetes.

D. Engaging in Self-Management

Among the respondents, there was a great commonality in their understanding of the rules and techniques that govern their lives as patients with diabetes—diet, exercise, self-monitoring. If they have accurately depicted their behaviors to us, they seem well-educated and well-equipped to manage the more *mechanical* parts of their disease. Most visited their clinic on a regular and frequent basis. Most of them said that they engaged in routine self-monitoring, insulin injections, and medication and managed, with some struggle, to overcome their cravings and habits and maintain their diet. Most indicated they would engage in more exercise if they were not limited by some other factor—fatigue, pain, numbness, the cost of an exercise program or equipment, and the distance from such programs.

The respondents' understanding of diabetes, in the scientific sense (e.g., insulin resistance or insulin dependent), varied greatly with their experience of diabetes, that is, length of time with the disease and willingness to accept or otherwise come to terms with the disease. Overall, the majority understand the fundamentals of the disease, the concepts of high or low blood sugar levels. Typically, they explain diabetes as a reflection of their measured glucose levels. In the same way that diabetes is defined by these levels, blood sugar is used interchangeably with diabetes; for example, "my diabetes is higher than normal and the doctors are trying to lower it." Those who seem to have a poor understanding of the disease initially stated that they had no idea what it is but would like to learn.

There were wide variations in the understanding of diabetes:

- "The disease is intermittent; one is sick for a unknown percentage of the time."
- "The disease is forever."
- "It is a disease that is never cured."
- "A lot of people have told me that there is no cure for it. That is why I try to do everything that I am told."
- "You can't get rid of it. I have been trying to get rid of it myself, because I don't like it."
- "You must monitor levels constantly or you don't know how you are doing."
- "I really don't know that much about diabetes, but I know one thing about me…my diabetes get up to 400 and something and I am still the same. It don't make me sick or nothing."
- "I really don't know (what diabetes is). It's something I have been wondering about myself."
- "I just take a medication. I do not even ask, "What is that?" I just take it."
- "If I continue medicating it over time, I will get rid of it. Get rid of it."

Regardless of their understanding of the disease, all of the respondents exhibited that they understood what actions they need to take to keep their diabetes under control or

managed. They know they are required to regulate the intake of "sweets" and "fatty foods." They understand the need to reduce weight and exercise regularly. They know how to check their blood sugar levels.

One challenge of self-monitoring and self-management is understanding how all of these techniques of managing diabetes fit together. Few of the respondents appeared to understand that treating/coping with diabetes requires a holistic approach. All appear well-informed as they get the same messages over and over again; however, the techniques and rules are not linked into an over-arching concept of self-care but to the avoidance of specific implications; while there are lifestyle changes, reluctantly giving up certain things and incorporating new things, the core required lifestyle change seems elusive.

At present, educators, dietitians, and physicians appear successful in conveying self-management techniques but fail to embed these techniques into a more complete understanding. It is like teaching someone to drive a car. You can show them the brake, then the speedometer, then the blinkers, then the gear shifter, and then the accelerator; however, understanding these individual components will not make someone a successful driver, no matter how knowledgeable of each part. Many of the respondents fail to understand that the entire constellation of required techniques constitute a single management approach. They spend their initial period following diagnosis mastering these self-management techniques. Only later do some come to realize, apparently on their own, that coping with diabetes requires entire life changes.

Investigators asked respondents to explain what diabetes is, as a disease, and what diabetes is to them, as individuals. While some of the respondents claimed that they did not know what the disease was, all of them knew that it had to do with sugar in the blood and the need to control that sugar through diet, exercise, self-monitoring, and insulin and other medications. Some knew that diabetes occurred in families; many of them have lost numerous family members to one of the many complications of diabetes. Others thought that the disease was produced by an event—a stroke, a pregnancy, birth control pills; at least one respondent, thus, felt that she could "get rid of the disease."

For many, their understanding of the disease is essentially mechanical—a set of behavioral rules and measures by which to control (or try to control) their blood sugar. Only one of the respondents seemed to have a conceptual grasp of the disease which integrated the various aspects and attributes of the disease into a whole picture, in which each of the parts were related to one another—genetic, predisposition, life stage triggers, diet, exercise, rest, mood control, emotional states, and physical losses.

It may be that many of these patients, with language difficulties, emotional problems, minimal education, other life priorities and demands, or advanced age have not achieved the foundation upon which this more integrated conceptual grasp needs to be based. It may also be that they have less interest in understanding the disease as much as knowing the rules by which it is controlled. Finally, it may be that providers do not invest as much

in explaining the disease, but focus on stating and reiterating the rules and supports for managing diabetes.

Focusing on each of the rules, one at a time, results in a scattered idiosyncratic set of behaviors, in which individuals do not see the implications of breaking some rules on other aspects of their lives. They often seem surprised when they encounter a significant physical or emotional event, not linking it to some preceding failure to perform. They interpret these events as something out of control with their disease, not something to which they actually contributed in some other part of their life. Self management, if described only as a set of rules, often produces resistance on the part of patients and others, resistance in the form of occasional or systematic noncompliance. Further, if patients do not understand their disease, they cannot explain it to others in terms that would turn others into useful supporters. And, finally, because the disease progresses as an insidious and silent process, they often do not see how both uncontrollable forces and compromised rules can finally result in what they fear most—loss of vision, limbs, and even life.

E. Adopting a Stance Toward Diabetes

Among these respondents, diabetes self-management appeared based, in large measure, on 1) the stance that patients take toward their disease, 2) change, and 3) their ability to exercise control over their daily activities.

1) Stance

All of the respondents feared diabetes. Almost every respondent expressed fear of the future, the complications of diabetes. Most know exactly what these complications are and also realize that the extent of these complications are a direct result of their response and control of their diabetes. However, the disease appears to have immobilized some, while others take some form of action.

Integration. Each of the respondents took some kind of the stance toward the disease as their way of dealing with it. Some dealt with it as a part of who they are; they integrated the disease into their explanation of themselves. They would say “I am a diabetic”. Diabetes has taken their body over and created a new identity, the diabetic. This seemed more common among those with a long history (that is, decades) of dealing with the disease and accommodating to it.

- “Most of my years I was in denial about it. I don’t like anything to take control of my life. Being in denial as long as I was, that is what happened. I had to cater to that disease just to maintain life. Thank God I did have enough sense to be afraid. It was threatening and made me angry. I am very angry because I feel like I was being attacked. I am very resentful to that part of me. I am a work in progress. I am

dealing with it as a positive thing to get under control [and not be] so consumed."

- "[Because the symptoms have intensified], I am no longer borderline. I am not becoming the person I was prior to having this, but even better because I will be very wise and knowledgeable and cautious."
- "I like to think that I am reasonably young and vital and that has changed immeasurably. I am not the same person I was two years ago even."
- "If you are not adaptable, this disease will consume you. So, learn how to be an expert in being adaptable. That is the key to survival."
- "Accepted it, accepted that I am a diabetic, I can work with it."

These respondents would talk about issues of control and lack of control, having a future and not having a future, and so on.

> "I was really shocked. It hurt me so bad when they told me I had it. That really hurt my feelings. Because that stuff is bad, that is bad stuff. It messes up everything about you. I think about it all the time. I know I am going to die and I think about it and it kind of upsets me, sometimes. And I get hyper. The doctor gives me some pills to calm me down." [Woman who said diabetes had not made significant impact on her life.] (58, African American female)

Encapsulation. Others deal with the disease as something separate from themselves, "I have diabetes", a thing external to themselves that they can control through behaviors and medications and that does not need to be incorporated into their self-identity. Of these respondents, those with very positive up-beat attitudes, take-action types were not yet in advanced stages of the disease. The important distinction here may be that the person "with diabetes" is fighting the disease to treat and/or get rid of it, while the self-described "diabetic" is fighting to live with it.

> "You will hear quietness in my voice. I am not proud of it [diabetes]. I don't like it. I hate it, actually. I have no use for it. I am tired of it using me, most of all." (48, African American female)

Rejection. There are others who deal with diabetes by denying to themselves or others that they actually have such a disease. These patients were recently diagnosed with diabetes. Denial of the disease was expressed in several forms: 1) "I think they are wrong. I am not a diabetic;" 2) "I am not a diabetic. I don't feel it. I don't have anything wrong with me;" 3) "It's not a big deal. I have so many other problems in my life;" 4) "The symptoms are not debilitating"; or 5) "I am too busy." These persons do not ignore the diabetes. Indeed, they alter their behaviors (e.g., diet, exercise, self monitoring), but in a minimalist way.

Surrender. Finally, there are a few who believe they can't stop the progress of the disease and, in many ways, throw in the towel. Feeling they have no future, they eat what they want, and as much as they want; they fail to exercise, and they ignore their glucose levels. They focus separately on their weight gain, infections, pains, surgeries, and high blood pressure as if these all were unrelated to their diabetes.

- "I don't do nothin' different. I ain't even on no diet [does take medication to reduce weight]. I don't believe in that…they say eat three little meals a day. Sometimes I don't…I am so fat and I don't eat nothing. And the doctor tells me that it [weight gain] was the insulin."
- "I changed a little since I got this [tracheotomy tube]. It ain't the diabetes that changed me, it is this here that changed me."
- "It is getting worser and worser because I eat regular food and I eat what I get. People are like "Don't eat that! Don't eat that !", so I eat the same."
- "I eat what I want. When I want to eat, I eat. They always tell me, 'Mommy, be cautious about your food. You have to be on a diet.' But, you know, I don't think I have the diabetes."

These stances may be expressions of personality types, being in different stages in the progression of the disease and in their own lives, or may represent predisposing cultural responses to disease and loss..

2) Change

All of the respondents noted a wide array of changes that diabetes has produced in their lives. Patients with diabetes experience a diverse range of changes that depend on what is under their control and not under their control. Commonly noted areas of change are in family relationships, emotion and personal identity, activities, diet, and physical condition. The core emotional impacts or changes caused by diabetes include:

- "It produces worry."
- "Self-management is constantly on your mind."
- "The need for the mind to control the body."
- "Depression, loss of interest in many things, loss of interest in life."
- Stop eating many kinds of foods (fat, sugars), avoid alcohol

Like emotion, diet is one of the most commonly identified changes for patients with diabetes. Dietary changes include specific inclusion and exclusion of foods, redesigning of recipes, modification of cooking habits, and loose to rigid scheduling.

- "Have to read food labels carefully."
- "Drink water all day."
- "Cook the same food but in a different way."

- "The biggest things for me to have given up are fruits. It is almost like an alcoholic food."

Changes in activities and physical exercise are secondary to those changes mentioned above in the minds of many respondents. Diabetes forces patients to reorganize their day, set schedules, exercise more, lose weight, and reduced mobility. Activity, physical exercise, and health condition were aspects in which respondents felt their life had changed; although these aspects were not foremost in the minds of patients with diabetes when asked about change, they are equally important to some.

3) Control

One of the key features of self-management is to become empowered, self-motivated, and in control of one's actions. Almost all of the respondents reported reliance on their clinician for assistance, guidance, education, and treatment. Given that most rules for diabetes management require life changes, physicians are limited in their ability to provide support. Consistently, respondents stated that the help from the clinics and their family was great, but to treat this disease would require them to take control of their actions and take a commanding position over their disease. With this knowledge provided by physicians and health educators, the person with diabetes becomes an authority on diabetes and methods of managing diabetes.

Self-empowerment is limited to control of one's own behaviors, but not the disease itself, which partly takes its own course.

> "You know that is the thing when you have good and bad days...good and bad months...and, if you are fortunate, you will have a lot of good days, and it may go on for months or years and it may not. It is almost like...overlapping...it is one of those kind of things that what the problem is diet and that you eat certain things, diet control that is best to manage it. If you say that stress level is causing it...you know...or, whatever, anger or other diseases are enhancing that. Again, you can't control the diabetes. But, if you are fortunate, you can maybe it may be under control. Some people that will work for them. But, then there are some of us...In other words, sometimes that is not even an issue, it is other things that are really the issue." (48, African American female)

However, the more self-empowered seem to be doing better in life and emotionally more well-off.

Patients with diabetes described control in two key ways: 1) Control of oneself and one's emotions, and 2) Control of actions to meet particular requirements of managing their

diabetes. Respondents reported be very concerned about control and their ability or inability to have control. Emotional control was described as follows:

- "Telling herself to be careful."
- "Watch yourself."
- "Sticking to your 'self rules'."
- Avoiding becoming emotionally upset, keeping general life stress under control.
- Keep calm, manage the everyday stress.
- Being more conscious and cautious of everything.
- "I am just taking it easy. I am still always lazy. Now I want to rest a little bit."
- Keeping busy (e.g. housework) to avoid thinking about diabetes.

Control, also, focused on compliance with clinician-defined rules for managing/ controlling diabetes. Some comments were more general and other addressed control of specific parts of their lives, such as blood glucose monitoring, scheduling, medication, exercise, weight, and diet. Their comments are categorized as follow:

General Control

- "If you control it well, you are very good. If you do not control it well, you have problems and sickness."
- Listening to the doctor. Following his directions exactly.
- "Doing all of the right things that I know I am supposed to do."
- "In order to live longer and keep diabetes under control, I must do what I am told."

Glucose Monitoring

- "Check diabetes" daily, before and after meals
- Take monitor machine wherever I go.
- Enters information into notebook.

Medication

- Takes insulin.
- Maintain glucose level, to avoid highs and lows.
- Takes pills.

Scheduling

- Having a regular daily schedule
- Walking/cycling every day.
- Schedule monitoring precisely around time of day, eating, and medications.
- Establish routines and schedule self-monitoring, exercise, and other behaviors.

- "Doing certain things consistently. I just always do them. A fixed schedule. It doesn't fit my lifestyle well, maybe I have to fine tune it. I don't like it."

Diet, Exercise, and Weight

- "I walk a lot but not necessarily for my diabetes."
- Maintains her weight.
- Do my own cooking.
- Excludes items from diet.
- Avoiding over-eating at parties.
- Cooking for family members with same ingredients as she uses for herself.
- Getting used to a different diet.
- Ease in finding the right foods.
- "When I am invited to have a drink, I refuse it."
- "People who have diabetes like me suffer a lot, there are a lot of things I would like to do and eat, but I know they are not good for me. I don't even have the least temptation to do it."
- "I only buy one or two of an item and pace myself as to when I can have them as a reward. There are foods that I am going to eat in moderation. When I want something [sweet], I am not going to overindulge in it, I am going to have a piece of dessert when I visit my family."

For some respondents, *failing* to follow particular clinician-prescribed rules gives them control, but negatively impacts successful management of their diabetes. Most commonly, this failing is presented as a struggle to maintain a particular diet. It is not that they can't control their diet; they can't control their behaviors.

- "I cheat a lot on my diet."
- "Sometime, I have a taste for hamburger and I go and eat a hamburger and fries. It got all that greasy stuff. And sometimes, I want to fry me a chicken. I have fried chicken and eat it. I sometimes go and get a submarine and eat a whole submarine when I haven't eaten all day."
- "I don't do a very good job of monitoring."
- "I have ate (sic) some diabetic stuff. I have gone to the store and bring a lot of diabetic stuff here and sat and ate. It's not bad. I thought that stuff would be nasty. I went and got some ice cream. What is that stuff? Pecan, butter pecan. A gallon. Man, that stuff is good. It's diet. It says 'no sugar' and 'no cholesterol.' I get that stuff and I eat it."
- "I have been here to talk to a dietitian; it doesn't work. It is kind of hard. I give up on myself. I eat food that doesn't go with my diabetes."

It is one thing to fail to exercise control over things that can be controlled, but respondents noted a number of factors which they felt can *not* be controlled:

Exercise

- Joined gym but can't go.
- Too busy to exercise. [too busy means having a full-time job, a part-time job, going to school]
- Different amounts of physical exercise on working and not-working days.
- Advanced age limits ability to walk and do other exercise.

Schedule and Diet

- Lack of control over personal or transportation schedule.
- Work and school complicate self-management time
- Time is unavailable.
- Timing of eating and monitoring is irregular.
- Different eating schedules on working and not-working days.
- Different amounts of food on working and not-working days
- Difficulty in controlling diet when going to parties.
- Lack of willpower, "falling off" the diet
- "I am a chef so I get a lot of tasting, probably have a lot of food I shouldn't Forgetfulness (to take medication, watch food intake, eat). "Right now, I am not having a good memory."

Emotion and Energy

- Lack of motivation.
- Fatigue and falling asleep, while driving to work.
- Not enough time in the home/work schedule to get sufficient sleep.
- "Sometimes I cannot control, especially when my problem is my family. I am always thinking (about dying, caring for family) and then my blood pressure is higher."
- "I just can't get it together."

In attempting to exercise control of their diabetes, the respondents listed many *supports*, many of which are provided by their families and clinics:

Family and Child Support

- Childcare.
- Family members who understand how diabetes works and how it affects your mood.
- " My son helps with my floor exercises, exercises with me, encourages exercise."
- Son does more of the vacuuming around the house.
- Someone else in the car to alert the sleepy driver.

Clinic Support

- "Doctors and support staff who tell me of all of the adverse things I should be aware of, what diabetes has done to me, and how I can make some changes."
- "I come here to the clinic for everything [monitoring, injections]. That is what they are here for."
- A doctor who has "a book on it", who "knows more about you than you do about yourself"
- Routine quarterly medical checkups and blood panels.
- Annual eye exams.
- Foot care.
- A good doctor, "keeps tabs on me".
- The doctor helped me to see better.
- Good communications and information from doctor.

Educational Support

- Initial classes on self-management techniques.
- Semi-annual visits with dietitian, good reminders.
- Diets developed by their dietitian.
- Learning everything that might be able to improve my condition.
- Good glasses.
- Learning how to operate the monitoring machine.
- Books on planning meals.

Monetary

- Pharmacists helping to reduce the price of self-monitoring supplies.
- Medicare and Medicaid covering the costs of medications and monitoring strips.
- Clinic helps to cover the costs of medications.

Spiritual Support

- Prayer, belief in God's will.

Unlike what is not controllable, the respondents cited numerous *barriers* to managing/controlling their diabetes. Many of these barriers are individualistic in nature and are a reflection of particular circumstances. These are areas in the patient's life that he/she would like to have control but is failing or struggling to do so as a result of a barrier. Examples of these barriers are listed below:

Services

- Lack of sufficient dental care.
- Lack of timely dental care [i.e., appointments vs. infections]
- Lack of dental insurance.
- Lack of access to traditional herb remedies (only one person mentioned this, in passing)
- Feedback on improvement would be good.
- Switching plans and providers.

Time

- "Work interferes with having an exercise program. My main job is just to make a living before I do this [diet, exercise]. I make sure that my job and everything are right."

Support

- No help or support in keeping on the diet.
- Family is too busy to help her with chores and/or diabetes and/or diet.
- Lack of a car or driver to take the patient to exercise class or the clinic.
- "My family is too busy to really help."
- No one to remind her to take her medications.

Costs

- The relatively high cost of glucose level strips for those on fixed incomes.
- Not having the amount of income to obtain the proper foods, exercise programs, shoes, that I need.
- "The pharmacy used to deliver my meds free, now they charge for it. It is a cost to me…because I can't always order all my meds at once."

Emotion, Environment, and Physical Condition

- Bad weather inhibits walking or getting to exercise class.
- Boredom in exercise.
- Too ill, interferes with regular exercise.
- Medication-induced fatigue.
- Being overweight blocks exercise.
- "They looked at my heart and they didn't make me do exercise. They wanted me to work on it with shots and all that because the heart is too weak."

Diet

- Don't know how to prepare some healthy food.
- Time consumed in reading food labels.
- Measuring foods

F. The Need for External Social Supports

What is striking is the degree to which patients admit that they are unable to manage their emotional or psychological relationship to the disease and to their changing lives. The disease itself, its uncontrollable progression, the immediate losses, the unavoidable outcomes, and some of the medications taken often produce extreme emotional swings. Some respondents described uncontrolled behavior, in the forms of extreme anger, apathy, and depression.

Thus, the most common theme for all respondents was their need for emotional and other support. Each respondent reported on their own, highly individual systems of support or non-support, depending on the presence or absence of family and friends, and their social isolation relative to work, family life, and physical and emotional conditions.

Family support appears crucial. Those without family or with unsupportive family expressed many difficulties. Family can provide emotional support and act as reminders to facilitate making the life changes required for diabetes. While diabetes and its threat to these patients' lives and well-being are in their foregrounds, these do not seem to be in the foreground of many of their family members or friends. Thus, emotional and psychological problems related to the disease tend not to be part of the social exchange with others.

- The family members dislike what patient eats, the patient cannot eat what family members eat.
- "They don't see it that way" [Younger family members don't help much, resulting in a lack of emotional support, bonding, closeness.]
- "A lot of diabetics complain, they make it sound so…they can drain you just telling you about it. But, if you could really feel their feeling, you could feel that pain. Some of things we go through is like being hit with a car. That is how intense it is."

There are many reasons why others, such as family members and friends, are not providing this social, emotional, and psychological support. In some cases, they are uninformed about the disease and its implications. Lack of information may be common within the community; as well, the person with diabetes may not inform others about diabetes, to the degree that he/she understands it. In some cases, family members who are informed by the patient may be more concerned about their own risk of the disease and tend to forget about the identified patient.

The initial response to diabetes by the respondents was typically fear resulting from the constellation of foreseen changes in their life including the obvious physical complications of blindness, amputation, dialysis, etc.; and the social implications of affecting the family and economic status of the family, and uncertainty of the future. Those with a history of diabetes in the family carried this fear before being diagnosed with diabetes—"When will I get diabetes and lose my limbs or my eyes or my kidneys." After diagnosis, some respondents felt that the more important impact of their diabetes on the family was that it caused the children of the respondent to fear diabetes—the respondent becoming something to be feared by his/her children. Thus, this transfer of fear is imposing a barrier to support because the children or relatives are more worried about themselves than the person who has diabetes.

If, for these and other reasons, family members, friends, and others cannot provide this support, the family members of a patient with diabetes are placed at significant risk, such as ceasing important self-management behaviors. As noted above, the willingness and ability to control their own behaviors was understood to be key to continuous self-management of diabetes. For many, this means relying on both an *internal and an external locus-of-control*.

As with many other disorders, some patients need to have persons outside of themselves exercise control over aspects of their lives, moving them to do the right things through the force of expectations and demands. For example, one man was supported by a food mission in his maintaining a diet for a person with diabetes.

> "The mission gives tickets for diabetic meals; they learn you are a diabetic so they give you the proper food. I used to get hungry but not any more. I have lost weight and the physician told me that it is good for me because I feel a lot better now. When I am outside of the mission, I feel like eating anything that comes to me." (45, Hispanic male)

Once away from the mission, he gave in to all of his cravings. In another case, a mother asked her young son, a karate student, to manage and support her exercise regimen. Family and friends can provide important direct supports.

- "Sometimes, if I tell my friends that I am a diabetic, they will make me some kind of soup that doesn't have too many things like fat and oil in there. [They respect his situation and don't force him to do anything. They tell him to eat whatever his is supposed to eat.] Sometimes it is hard to get your friends to help you. So I have to do everything on my own."
- "Especially my little daughter helps me. She always advises me. It is OK. Just drink your drink. Drink your medicine."
- "My husband is OK with my changes in diet and is helping me. When I am tempted, he reminds me not to eat certain foods."
- "You shouldn't have that, you shouldn't do that." [Friend is a buffer or reminder]

Not having anyone available and willing to be an external locus-of-control shifts the entire burden of self-management to the patient only. A solitary patient, subject to wide variations in mood and energy, preoccupied with thoughts of pain, fatigue, illness, loss, and death, and craving the simple pleasures of eating and drinking, is less likely to engage in continuous and rigorous self-management.

Respondents mentioned little about receiving such emotional supports from physicians, clinics, and others. It is possible that the clinics lack sufficient resources to diagnose and address these emotional conditions. It may be these unmet needs of respondents may be what health care institutions have the most difficult time in providing.

Where at all possible, clinics are encouraged to take the extra time necessary to understand the personal dynamics, family conditions, and other life situations which block the ability of their patients with diabetes to alter their behaviors and lifestyles. Understanding these challenges, providers and clinic staff must identify and devise alternatives to help them succeed. It may be that, to the degree that clinics cannot provide the supports directly, they may need to increase both the volume of the message about social supports and explore alternative ways for patients to build or access these supports.

The majority of respondents find support from other persons with diabetes highly desired, based on being better able to communicate, trade suggestions and insights, and share emotions, problems, and frustrations. The form of such contact and support can vary widely, to include formal and informal support groups, individual contacts, a community of persons with diabetes, and clinics and athletic centers.

There are potentially three different support groups—professionally directed and formal, patient directed and informal, and impromptu informal. Informal exchanges, such as at foot clinics, allow patients to casually exchange information with one another and the professional staff, discuss perhaps more "current" practices, and share advice and direct experience. More formal support groups comprised wholly of persons with diabetes were suggested. These group meetings comprised of patients who are in different stages of the disease might provide a safe support system

> "We need a group of people to come together, who are not selected but who choose to come together. There may not be some level where I can be completely honest with you. If they could talk to someone like me, I know the research, I can say 'This is a book on what you do if you are under stress and what is going to set off your diabetes.' Something they can identify with. So they can help themselves. Then, they can feel in charge and in control. That, in itself, can add to people wanting to live, people wanting to conquer this, feeling like there is actually hope…we are talking about hope." (48, African American female)

There is also a need for the community at large to have a better idea of what diabetes is and how this silent and invisible disease changes peoples lives. What can the community

do? What supports can they provide? Who can offer help? The effects of diabetes are not widely known, and very few persons without diabetes understand this disease beyond its end-stage complications. From a public health perspective, diabetes awareness can positively impact the diabetes population through encouragement of patients with diabetes to seek support and those who can give support to provide it. The more open and accepting the public is to the disease, more conscious and specific supports and accommodations can be made.

In summary, solutions to help persons with diabetes is based on the premise that one size does not fit all, including across or within cultures, racial groups, or ethnic groups. Education, information, medications, services, and supplies are all necessary but not sufficient elements to enable a person to manage their diabetes. The respondents indicated the following as necessary supports:

- increased social and family and employer support,
- reduce or avoid social isolation,
- regular talking groups to vent emotions safely and knowledgeably among others with diabetes,
- preparation for the probable next stages in the advance of the lifelong progressive disease, continued access to the authority figures on rules (physicians, dietitians, educators), and
- more real-life understanding by these figures.

IV. Hypotheses and Recommendations

The authors hypothesize that: 1) these patients require far more community and family knowledge about diabetes, community and family acceptance of its implications, and community and family social support than they now receive, 2) with few and well-defined exceptions, the medical, medication, and supplies issues for these patients are being resolved, 3) these patients would be served better by increased conceptual grasp of the disease, increased awareness by the clinic staff of the real-life conditions which color the ability of patients to manage the diabetes, 4) formal and informal support group participation among these patients would considerably enhance their self-management behaviors and desired outcomes, and 5) that attention paid to patients' real-life conditions and cultures may positively impact their well-being. Further, 6) it likely that ethnicity and culture may predispose individuals to respond to disease and loss in ways that limit or enhance their desire and ability to be effective self-managers. These factors need to be understood if physicians and educators are to design regimens appropriate to individuals.

V. Appendices:

Appendix A. Field Questions

Guide for Interviews/Focus Groups 9/28/99

(some of the demographic information may be provided by clinic staff prior to contact)

Pre-Interview Questions

1.Gender: M F

2.Age: (in years)

3.Ethnicity: (self-defined)

4. Primary/Preferred Language:

5. Language Used in this Discussion:

6. Interpreter Used: Y N

7.Clinic Used by Patient (select one):

(International Community Health Services
(Country Doctor
(Carolyn Down's
(Pike Street
(High Point
(PH--S&KC, Downtown
(PH--S&KC, North

8. Number of Clinic Visits in the Past 12 Months:

With Doctor ___________________

With Others (who) ___________________

9. Apparent Functional Disabilities:

Interview Questions

11. Could you tell me, briefly, what diabetes is? Could you tell me, briefly, what diabetes is to you, personally?

12. How long ago were you told you had diabetes (Type 1 or Type 2)?

13. Since that time, how has diabetes affected your life? Please tell me everything you can about any changes:

Probes:

- Do you see yourself in a different way?
- Do you see the future in a different way?
- Do you have to do things differently?
  - Diet
  - Medication
  - Self-Monitoring
  - Physical Activity
  - Work, Recreation, etc.
- Does it limit what you want or need to do? (list and explain – who, what, why, when, where, how, how much))
- Has it affected your family in any way? (list and explain – who what, why, where, when, how, how much)
- How important are these effects to you or your family?

14. Do you find it easy or difficult to manage your diabetes?

Probes:

- What kinds of things make it easier for you now ? (list and explain – who, what why, where, when, how, how much)
- What kinds of things make it difficult for you now? (list and explain – who, what, why, where, when, how, how much)
- Do you think you are managing your diabetes well (i.e. under control)?

15. Could you manage your diabetes better?

Probes:
- What would help you to manage it better?
- What would that take? (who, what, why, where, when, how, how much)
- Have you tried that?
- If not, why not? Please explain.
- If yes, did it help? Please explain.

16. Is there anything you would like your doctor or other clinic staff or family and friends to do that would make your life better or managing your diabetes easier?

In the event that individual patients, family members, or groups have difficulty in spontaneously identifying or articulating barriers or supports, the following list will be available to interviewers/moderators to stimulate issues and discussion:

Location of clinic
Finding needed services:
- Dental care and dentures
- Vision care and glasses
- Foot care
- Exercise and swimming facilities
- Mental health
- Chemical dependency
- Classes or support groups

Classes or support groups at a convenient location and time
Classes or support groups made up of people of a similar culture
Childcare during classes or support groups
Incentives and support (such as a meal) to attend classes or support groups
Location and timing of support groups and classes:
- Nutrition
- Smoking cessation
- Self-management

Transportation issues: (money, time, timing, modes – car, bus, cab, van, foot, driver, parking)
- To clinic
- To grocery
- To support groups and classes
- To exercise facilities

Language difficulties
- Lack of bilingual doctor, nurse, or educator
- Lack of interpretation

Lack of health care insurance or money to pay for services, monitoring supplies and medications
Lack of money to buy healthy food
- Child care – availability, affordability

Lack of support from family members or friends
Competing life and family priorities
Difficulty in changing behaviors
Lack of time
Lack of knowledge or information
Your culture not being respected or understood by educators/providers
Cultural issues (i.e., traditional eating habits)
Providing care and educational materials in a language you can easily understand
Providing useful or useable educational materials
Incorporating your culture into the care plan and educational materials

Appendix B. Recruitment Tools

Dear Colleague in the Community Diabetes Initiative,

We are asking your assistance in recruiting 4-8 persons with diabetes who would be willing to spend about 30 minutes in a discussion with one of our interviewers or as part of a focus group to discuss the perceived barriers and supports to disease management. The persons we are looking for would be drawn from African American, Hispanic, or Asia/Pacific Islander populations. Within the last two groups, we would like to interview both English-speaking and limited/non-English speaking patients.

We would be happy to interview individuals at their convenience, at their homes, as part of their clinic visit, as part of their support group or class, or at any other comfortable setting. We need to complete all interviews by October 2929, 1999.

We will provide interpreters as needed to accommodate each patient's primary or preferred language. If the patient is concerned about being interviewed by two people, our interpreters will be trained to conduct the interview on their own. We will try to match interviewers and patients for gender.

We will provide a $25 Safeway gift certificate to each participant to compensate them for their time, candor, transportation, and childcare costs. If we conduct focus groups, we will allow provide refreshments. Focus groups will require about 60-90 minutes of their time.

We would be happy to include other family members in the discussion, but will not compensate them for their time.

No names of respondents will be recorded, to protect their anonymity and privacy. We will provide each with a copy of the attached confidentiality consent form statement translated into his/her own language. The interpreters will read and explain the statement to them, as appropriate.

This is a qualitative research project, not a survey. We intend the experience to be an open focused ended discussion with each person, just as if they were talking to you. In order to make the discussion feel natural, the interviewer will take minimal notes and tape record the session. This way, he or she can go back to pick out the findings. All tapes will be erased at the end of that review. If respondents object to being recorded, they will not be, although this may reduce the quality of the experience and the data.

Clancy Clark will remain in touch with you on this activity and try to accommodate to all of your needs and those of your clinic and patients, particularly their privacy. Thank you for your help in this research.

Sincerely.

Clancy Clark and Thomas Lonner

WE NEED YOUR HELP!

We are holding private individual or group discussions with a small number of persons with diabetes who live in King County. We hope that these persons will share with us those things that are helpful to them in managing their diabetes and those things that they need but are not getting now.

The results of these discussions will be used to design improvements in the services that support people with diabetes, particularly people from minority communities.

A $25 Safeway gift certificate will be given to each patient who spends about 30 minutes with our interviewer and interpreter. The interviews can take place at a time and place most convenient to you, during October 1999. Other family members can participate if they wish.

You do not have to write anything down. We will tape record each discussion so that we do not miss anything you say. But we will not ask for your name, address, phone number, or any other identifying information.

You may refuse to answer any questions that you wish. If you wish, we will send you a copy of the report we prepare. The report will be written in English, but we will be happy to explain the results to you in your preferred language.

Thank you for your help.

Confidentiality Form
Community Diabetes Initiative

Purpose

The purpose of this discussion is to find out from you those things that are helpful to you in managing your diabetes and those things that you need but are not getting now.

The results of this discussion will be used to design improvements in the services that support people with diabetes, particularly people from minority communities.

Procedure

You are invited to participate in one 30 minute interview (or one 90 minute discussion group). During this interview, we will ask you questions about changes in your daily life because of diabetes, the things you do to manage your diabetes, what people or things are helping you manage your diabetes, and what else you need to make your life with diabetes better.

You will be interviewed by one or two people. If you prefer to speak in a language other than English, a qualified interpreter will accompany the interviewer. Only the interviewer and the interpreter will listen to the tape; after they have listened to it, they will erase it, to protect your privacy. If you wish, you may have one or more family members or friends with you during the discussion.

At any time, you may refuse to answer any question. You may also tell the interviewer to turn off the tape recorder.

Risks

You will not experience any risk, stress, or discomfort during this discussion. If you feel stress or discomfort, the discussion will stop. We will not use your name, address, or any other personal identifier in any report. No one but you will know you have helped us in this study.

We are grateful for your help. Thank you.

Clancy J. Clark
The Cross Cultural Health Care Program
Date:

Appendix C. Demographic Data Summary

#	Interview Code	Gender	Age	Ethnicity	Ethnic Group	Language	Interpreted	Clinic	# of Doctor Visits	# of Other Visits	Yr. Diagnosed
1	Int14AA	Female	48	African American	African American	English	No	High Point	11	0	1979
2	Int12AA	Female	58	African American	African American	English	No	High Point	52	1	1992
3	Int1API	Female	41	Chinese	API	Cantonese	Yes	High Point	4	4	1990
4	Int2AA	Male	78	African American	African American	English	No	Carolyn Downs	6	7	1989
5	Int3AA	Female	65	African American	African American	English	No	Carolyn Downs	10	9	1994
6	Int4Hisp	Female	65	Mexican	Hispanic	Spanish	Yes	Carolyn Downs	3	1	1993
7	Int11AA	Female	64	African American	African American	English	No	Carolyn Downs	3	30	1992
8	Int13Hisp	Male	45	Mexican	Hispanic	Spanish	Yes	Pike Street Clinic	10	1	1996
9	Int4GAHisp	Male	63	Mexican	Hispanic	English	No	Country Doctor	18	0	1985
10	Int1GAAA	Male	75	African American	African American	English	No	Country Doctor	12	0	1998
11	Int2GAAA	Male	54	African American	African American	English	No	Country Doctor	16	9	1994
12	Int3GAAA	Male	53	African American	African American	English	No	Country Doctor	80	35	1996
13	Int15AA	Male	28	Ethiopian	African American	English	No	Downtown Public Health	6	3	1993
14	Int16AA	Male	42	Ethiopian	African American	English	No	Downtown Public Health	6	3	1997
15	Int21Hisp	Male	30	Hispanic/Jewish	Hispanic	English	No	Downtown Public Health	5	3	1997
16	Int22API	Male	63	Chinese	API	Mandarin	Yes	ICHS	6	0	1994
17	Int10API	Female	68	Chinese	API	Cantonese	Yes	ICHS	13	1	1992
18	Int5API	Female	62	Filipino	API	English	No	ICHS	10	0	1999
19	Int6API	Female	57	Filipino	API	English	No	ICHS	1	1	1988
20	Int7API	Female	68	Filipino	API	English	No	ICHS	6	1	1995
21	Int8API	Female	60	Chinese	API	English	No	ICHS	9	0	1968
22	Int9	Female	54	Chinese	API	Cantonese	Yes	ICHS	6	1	1999

Summary of Data

Gender	Data	Total
Female	Count	12
	Percent	54.55%
Male	Count	10
	Percent	45.45%
Total Count		22
Total Percent		100.00%

Data	Total
Average of Age	56.41
Max of Age	78
Min of Age	28
StdDevp of Age	12.78

Language	Data	Total
Cantonese	Count	3
	Percent	13.64%
English	Count	16
	Percent	72.73%
Mandarin	Count	1
	Percent	4.55%
Spanish	Count	2
	Percent	9.09%
Total Count		22
Total Percent		100.00%

# of Doctor Visits

Data	Total
Average	13.32
Max	80
Min	1
StdDevp	17.67

Ethnicity	Data	Total
African American	Count	8
	Percent	36.36%
Chinese	Count	5
	Percent	22.73%
Ethiopian	Count	2
	Percent	9.09%
Filipino	Count	3
	Percent	13.64%
Hispanic/Jewish	Count	1
	Percent	4.55%
Mexican	Count	3
	Percent	13.64%
Total Count		22
Total Percent		100.00%

Interpreted	Data	Total
No	Count	16
	Percent	72.73%
Yes	Count	6
	Percent	27.27%
Total Count		22
Total Percent		100.00%

# of Other Visits

Data	Total
Average	5
Max	35
Min	0
StdDevp	9.14

Ethnic Group	Data	Total
African American	Count	10
	Percent	45.45%
API	Count	8
	Percent	36.36%
Hispanic	Count	4
	Percent	18.18%
Total Count		22
Total Percent		100.00%

Clinic	Data	Total
Carolyn Downs	Count	4
	Percent	18.18%
Country Doctor	Count	4
	Percent	18.18%
Downtown Public Health	Count	3
	Percent	13.64%
High Point	Count	3
	Percent	13.64%
ICHS	Count	7
	Percent	31.82%
Pike Street Clinic	Count	1
	Percent	4.55%
Total Count		22
Total Percent		100.00%