

The Patient's Perspective: Diabetes Self-Management in Ethnic Minority Populations

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Abstract

Background:

As a follow-up to a quantitative study of diabetes patients at seven (7) Seattle-area community clinics, researchers explored potential preceding factors that may contribute to the disparity in ultimate health status of patients with diabetes in three ethnic minority populations.

Methods:

Researchers conducted this investigation through face-to-face semi-structured qualitative interviews with twenty-two (22) persons diagnosed with diabetes mellitus (types I and II). Nurses, social workers, and case managers from Seattle-area community clinics recruited respondents who self-identified themselves as Asian/Pacific Islander, African American, or Hispanic.

Results:

While researchers found no significant contributing factors causing 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. 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. And, 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.

Conclusions:

Socioeconomic status and social support overshadow ethnic and cultural factors with regards to successfully managing diabetes and might explain disparities in health outcomes among different populations. However, without controlling for socioeconomic status, we do not know the extent ethnicity shapes health outcomes, and ultimately how physicians, educators, and social workers can mitigate ethnic-based disparities in the diabetes population.

Introduction

Ethnic disparities among the diabetes mellitus population are striking. African Americans are more likely to develop diabetes compared to non-Hispanic Whites.^{1,2,3} Hispanic adults are at an increased risk of retinopathy than non-Hispanic Whites.⁴ The incident rate of non-insulin-dependent diabetes mellitus among Asian Americans is

significantly greater than native Asians.⁵ Few conclusive explanations are available to explain these disparities. Potentially, higher incidence of obesity among African American women may influence this disparity.⁶ Poor glycemic control is more common in non-Hispanic black women and Mexican American men compared with other ethnic groups.⁷ In addition, those who find it difficult to communicate in English and/or are from an ethnic minority community are less likely to monitor their blood glucose putting them at high risk of diabetes related complications.⁸ Still health care workers and diabetes educators do not have a clear understanding of the perspective of their patients have on self-care and management of their diabetes.

Researchers working with Seattle-area community clinics conducted a preliminary study of a multi-racial cohort of adults with diabetes mellitus (Type 1 or 2) to understand the preceding factors that may contribute to these disparities. In particular, we were interested in gaining the patient's perspective on self-management goal setting, and behaviors, supports and barriers to self-management.

Methods

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, researchers elected to conduct individual semi-structured interviews.

Research questions and procedures were developed in accordance with questions proposed by the Community Diabetes Initiative (CDI), a Seattle community clinic-based initiative aimed at improving diabetes health care services and self-management support. In 1999, with guidance from Public Health—Seattle & King County and the CDI's Self-Management Support Working Group, research investigators selected three ethnic minority communities: Asian and Pacific Islander, African American, and Hispanic. Recruitment strategies varied among the five participating clinics, based on their programs and operation. Typically, recruiters with help from health care 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. Since these collective efforts were not successful in recruiting an adequate number of patients from the Hispanic population, researchers chose to over-sample the other two populations. The 22 patients interviewed were typically over 50 (average 58, ranged from 28 to 78). Eleven (11) respondents are categorized as African American, eight (8) as Asian and Pacific Islander, and four (4) as Hispanic. An almost even representation of male (10) and female (12) respondents is present in the cohort. The respondent pool only represents patients with diabetes from 5 out of the 7 clinics participating in the Community Diabetes Initiative.

Although researchers did not have access to patient records, several general health related observations were made during the interview. None of the respondents had been severely and/or obviously physically impacted by diabetes. None had lost vision, displayed severe

paralysis, or experienced amputation. Several respondents, however, have been hospitalized for strokes and most are being treated for hypertension. Several complained of numbness in their hands and feet, and arthritic pain.

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 (19) or in the respondent's home (3), whichever was more convenient for the respondent. Six of the interviews required the services of trained medical interpreters. The core questions of the interview were designed and presented to the patients as open-ended (Table 1). Patients were encouraged to expand on their thoughts, stories, ideas, opinions, and experiences. The majority of respondents spoke as openly and freely as was intended in the questionnaire design.

Field investigators obtained consent from all respondents and they were compensated for their participation with a \$25.00 gift certificate. Investigators transcribed and coded all 22 interviews using NUD-IST© and other coding mechanisms, appropriate for recurring themes, concepts, ideas, and tendencies. The authors analyzed the resulting coded data and interview notes.

Results

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 respondents' 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—were also compromised as their family and personal expectations are thwarted. And, finally, their inability to afford a variety of needed supports often seriously compromised 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, work long hours, frequently 7 days a week. Their low-income level seems 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.

Culture

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 have some impact on the treatment of their diabetes.

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 (over 60 hours), leaving little time for rest, self-monitoring, scheduled eating, and exercise. 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. 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.

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. African American respondents understand the basic dietary changes, but they infrequently or inconsistently follow these changes.

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.

Social Support

A large number of respondents have not informed their friends and family of their disease, its severity, or its demands on them. Thus, they continue to strain themselves physically, 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. 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.

In addition to the isolation associated with their physical and emotional limitations, 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. 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.

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 as, 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.

Although social support is highly valued by the respondents, family members, friends, and others fail to provide the necessary support and might explain why these patients are less likely to employ successful self-management behaviors.

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 to 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. Those who seemed to have a poor understanding of the disease initially stated that they had no idea what it is but would like to learn.

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. 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.

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.

Conclusion

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 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 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 and ultimately effect change in the health disparities among patients with diabetes.

Table 1 Core Interview Questions

1. Could you tell me, briefly, what diabetes is? Could you tell me, briefly, what diabetes is to you, personally?
2. How long ago were you told you had diabetes?
3. Since that time, how has diabetes affected your life? Please tell me everything you can about any changes:
 - Do you see yourself in a different way?
 - Do you see the future in a different way?
 - Do you have to do things differently?
 - Does it limit what you want or need to do?
 - Has it affected your family in any way?
 - How important are these effects to you or your family?
 - Do you find it easy or difficult to manage your diabetes?
 - What kinds of things make it easier for you now?
 - What kinds of things make it difficult for you now?
 - Do you think you are managing your diabetes well?
 - 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?

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