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Illness Perceptions among Adults at Risk for Diabetes

Shiela M. Strauss, Ph.D.,

New York University College of Nursing, 726 Broadway, 10th floor, New York, NY 10003,
Telephone: 212.998.5280, FAX: 212.995.3143, ss4313@nyu.edu

Mary T. Rosedale, Ph.D., and

PMHNP-BC, NEA-BC, New York University College of Nursing, New York, NY.

Navjot Kaur, BSN, RN

New York University College of Nursing, New York, NY.

Abstract

Purpose—The purpose of this study is to examine diabetes illness perceptions among a sample of at-risk adults according to specific characteristics that make them vulnerable to diabetes.

Methods—At-risk adults (n=372) were participating in a study investigating the potential to screen them for diabetes at a large, urban dental college. Socio-demographic and individual-level diabetes risk-related characteristics, A1C measures, diabetes-related symptoms, diabetes knowledge, diabetes illness perceptions and perceived causes of diabetes were collected and reported for the study sample. T-tests were then used to determine whether there were statistically significant differences in each of 8 dimensions of these perceptions according to the presence or absence of 6 diabetes risk factors.

Results—Average A1C values were 5.6% (38 mmol/mol), and 46% of the study sample had A1C values in the pre-diabetes or diabetes ranges. Participants had various diabetes knowledge gaps and misperceptions, and there were differences in dimensions of diabetes illness perceptions depending on specific diabetes-related risk factors.

Conclusions—In view of differences in the diabetes-related illness perceptions of persons at risk for diabetes, it is important for diabetes educators and other healthcare providers to personalize their diabetes-related education, management, and support to the specific needs and vulnerabilities of at-risk patients.

Illness perceptions, or organized cognitive representations and beliefs that people have about an illness, are important determinants of self-care behaviors and outcomes in persons with medical conditions.¹ These perceptions have also been found to be related to satisfaction with, and future use of healthcare to address these conditions.^{2,3} Much of the research on illness perceptions has been based on Leventhal's Self-Regulation Model,⁴ which measures these perceptions along several dimensions: identity (perceptions of the label and symptoms of the illness), timeline (perceptions of the length of the illness), personal cure/control (perceptions of the curability or controllability of the illness), consequences (perceptions of

the expected effects and outcome of the illness) and cause (perceptions of the cause of the illness). Later research added additional dimensions to this model: illness coherence (perceptions of an understanding of the illness), treatment control (perceptions of how much treatment can help to control the illness), and emotional representation (perceptions of how much patients are emotionally affected by the illness).⁵

Among persons with diabetes, one or more of these dimensions of illness perceptions have been found to be related to diabetes-related self-care and outcomes. For example, (a) persons with diabetes who believe that their diabetes is more controllable have been found to practice greater diet, exercise, and glucose testing self-care, whereas those who believe that their diabetes is less controllable have been found to be less likely to receive regular diabetes care; (b) persons with diabetes who have higher diabetes identity beliefs have been found to have poorer metabolic control; and (c) those with diabetes who have greater perceived illness coherence (understanding of diabetes) have been found to have a better quality of life.^{6–11} Illness perceptions have also been found to vary among subgroups of persons with diabetes according to various American Diabetes Association-identified modifiable and non-modifiable diabetes risk characteristics.¹² Specifically, diabetes illness perceptions have been found to differ according to minority vs. majority race/ethnicity, younger vs. older age, presence vs. absence of a family history of diabetes, limited vs. regular physical activity, and low vs. high body mass index.^{6, 13–18}

To the authors' knowledge, however, no studies have examined illness perceptions among persons who are *at risk* for diabetes according to the presence or absence of the specific characteristics that make them vulnerable to diabetes. Such an examination could inform diabetes education, management and support individualized to specific diabetes vulnerabilities in order to maximize self-care behaviors and outcomes. It could also empower the development and implementation of potentially efficacious interventions to modify diabetes-related thoughts, beliefs, and perceptions, and to change at-risk persons' usual patterns of behavior relative to specific risks. This is especially important for persons with early metabolic abnormalities (impaired glucose tolerance or impaired fasting glucose) that characterize pre-diabetes, a frequent diabetes precursor,¹² given the association of illness perceptions with self-care behaviors and outcomes. In this paper, an examination is made of 8 dimensions of diabetes illness perceptions among a sample of at-risk adults (N=372) according to specific diabetes risk factors.

Methods

The Study Sample

Study recruitment, participation, and data collection took place in the comprehensive care clinics at the New York University College of Dentistry (NYUCD) from June 2013 to April 2014. Study participants were involved in research that was investigating the potential to screen at-risk persons for diabetes at the dental visit.

Persons were eligible for the research if they indicated that their gums bled on brushing or flossing and if they: 1) were at least 18 years old; 2) did not require antibiotics before dental treatment; 3) did not have a history of severe cardiovascular, hepatic, immunologic, renal,

hematologic, or other organ impairment; and 4) had been told by a health care provider that they had diabetes or they were at risk for diabetes according to American Diabetes Association (ADA) criteria.¹² These criteria include (a) being at least 45 years old or (b) being between 18 and 44 years old, having a body mass index (BMI) $\geq 25\text{kg/m}^2$, and having at least one additional diabetes risk factor, including: little/no exercise on a given day; first degree relative (parent or sibling) with diabetes; Latino ethnicity; Black, Native American, Asian, or Pacific Islander race; or being a woman who gave birth to a baby ≥ 9 lbs. Because this paper focuses on individuals who are *at risk* for diabetes, persons were excluded from the present analyses if they indicated that they had been told by a health care provider that they *had* diabetes.

Study Procedures

NYUCD patients were recruited into the study by trained research assistants (RAs) in the clinics' waiting areas before their scheduled dental appointments. Persons who provided written informed consent were each given unique study identification codes for all collected data and were screened for eligibility in accordance with the inclusion criteria. If eligible, the RAs oversaw the participant's completion of a 30-minute survey before the dental visit. Among the variables assessed in the survey were socio-demographics, symptoms (both diabetes-related and not diabetes-related), general diabetes knowledge, and diabetes-related illness perceptions. When the patient was seated in the dental chair for the dental procedure, blood samples were collected for determination of hemoglobin A1C (A1C) levels in the laboratory. Promoted by the ADA for diabetes diagnostic purposes and providing an average measure of glycemic control over a 3-month period, this test was especially advantageous in the dental setting as it does not require fasting prior to obtaining a blood sample.¹² Further details about subject recruitment and study procedures are provided elsewhere.¹⁹ The study was approved by the IRB at the NYU School of Medicine.

Measures

Hemoglobin A1C (A1C)—A 10-micrometer blood sample was collected from the patient's finger using a micropipette. The sample was placed on Whatman 903 filter paper and allowed to dry for one hour at room temperature. It was then sealed in a plastic bag, stored at 4°C, and transported to the laboratory. A1C analysis used a High Performance Liquid Chromatography (HPLC) D-10 program, which is traceable to the reference methods of both the National Glycohemoglobin Standardization Program and the International Federation of Clinical Chemistry and Laboratory Medicine.

Diabetes-Related Symptoms—Participants were provided with 10 symptoms of illness and asked to endorse those they experienced in the past week, with 5 being related to diabetes (D) and 5 not diabetes-related (ND). As used in the study by French and colleagues²⁰ that assessed the psychological impact of diabetes screening, these symptoms included “frequently feeling thirsty” (D); “sore throat” (ND); “blurred vision” (D); “frequent visits to the toilet” (D); “stiff joints” (ND); “frequent headaches” (ND); “weight loss” (D); “breathlessness” (ND); “upset stomach” (ND); and “lack of energy” (D). Diabetes-related symptoms were examined separately and also tallied, with the latter generating a total number of symptoms ranging from 0 to 5.

General Diabetes Knowledge Assessment—The Assessment contained 6 items concerning the effect of diabetes on blood glucose, diabetes diet, types of diabetes, awareness of diabetes status, causes of diabetes, and high blood glucose levels. Used in previous research,²¹ the items had been reviewed for appropriate wording and face validity by persons with expertise in diabetes, and pilot tested with 51 periodontal patients who participated in an earlier research study at the NYU College of Dentistry Periodontics and Implant Clinic.²² The first 2 items of the Assessment were multiple-choice type questions with 2 answer options, and the remaining four items were true/false type questions along with a “don’t know” option. Correct answers were totaled, generating a possible range on the Assessment of 0 to 6.

Illness Perceptions—Diabetes illness perceptions were measured with the Brief Illness Perception Questionnaire as applied to diabetes (Brief IPQ – Diabetes), a brief scale designed to rapidly assess participants’ cognitive and emotional representations of diabetes.⁷ For each of 8 dimensions of diabetes illness perceptions, the Brief IPQ - Diabetes uses a single-item scale from 0 to 10. The scale has demonstrated good test-retest reliability and concurrent and predictive validity among patients with diabetes.⁷ In an open-ended format, the Brief IPQ - Diabetes also asks the respondent to list 3 of its most important causal factors. These were then grouped into categories and are reported when endorsed by at least 10% of respondents.

Statistical Methods

The study sample is first described in terms of its socio-demographic and individual-level diabetes risk-related characteristics, A1C measures, diabetes-related symptoms, and diabetes knowledge. After describing the diabetes illness perceptions and perceived causes of diabetes for the entire study sample, t-tests are used to determine whether there were statistically significant differences in each of 8 dimensions of these perceptions according to the presence or absence of 6 diabetes risk factors.

Results

A total of 518 individuals volunteered to participate in the study, and 454 were eligible. Of these 454 adults, 379 indicated that they had never been told they had diabetes, and 372 completed the Brief IPQ - Diabetes. These 372 individuals constitute the study sample.

Study Sample Characteristics

Of the 372 persons in the study sample, 57.8% were female, 27.7% were between the ages of 18 and 44, and 72.3% were at least 45 years old. While approximately one third (32.6%) had no more than a high school education, 43.6% completed technical school, college or beyond. Almost one third (30.3%) were Latino, and 37.1% were of Black, Native American or Pacific Islander races. Most (70.2%) were overweight, with a BMI $\geq 25\text{kg/m}^2$, and 3 in 5 (59.2%) indicated that they had little or no exercise on a given day. A large minority (40.9%) had a first degree relative (parent or sibling) with diabetes, and 6% of the women in the study sample had a baby weighing at least 9 lbs. at birth.

A1C Values

Ranging from 4.2% to 9.1% (22 mmol/mol to 76 mmol/mol), the average $\pm$ SD A1C value was $5.6 \pm .44\%$ (38 ± 4.8 mmol/mol), with a median of 5.6% (38 mmol/mol) and an interquartile range of .5% (5 mmol/mol). A total of 44.4% of participants had A1C values in the pre-diabetes range (i.e., between 5.7% and 6.4% [39 mmol/mol and 46 mmol/mol]), and 1.6% had A1C values in the diabetes range (i.e., 6.5% [48 mmol/mol] or greater).

Diabetes-Related Symptoms

Regarding the 5 diabetes-related symptoms experienced in the past week that were assessed in the study sample, 43.4% reported lack of energy, 41.8% reported frequent visits to the toilet, 35.8% said they frequently felt thirsty, 28.0% said they had blurred vision, and 11.3% reported weight loss. In all, 28% reported that they did not experience any of these diabetes-related symptoms in the past week. Overall, the average number $\pm$ SD of these 5 symptoms that the study sample reported they experienced was 1.6 ± 1.4 , with a median of 1 and an interquartile range of 3.

Diabetes Knowledge

Most respondents knew that the diabetes diet is a healthy diet for most people (86.0%), that not everyone who has diabetes knows that they have it (83.9%), that there is more than one type of diabetes (83.1%), and that diabetes causes blood glucose to be too high (76.6%). A much smaller proportion of respondents knew that a fasting blood glucose level of 250 mg/dL (13.875 mmol/L) is too high (48.7%), and that eating sweet foods is not a cause of diabetes (25.3%). Overall, scores ranged from 0 to 6, averaging 4.0 ± 1.2 , with a median of 4, and an interquartile range of 2.

Perceptions about Diabetes

As can be seen in Table 1, the study sample believed that if they had diabetes, it would affect their lives substantially (mean $\pm$ SD of 37.2 ± 2.7); that it would last for a long time, but not forever (6.9 ± 3.3); but that they would have considerable control over it (7.3 ± 2.6); and that treatment could substantially help their illness (8.5 ± 2.1). Overall, they believed that they had a moderate understanding of diabetes (5.2 ± 2.8), and indicated that the possibility of having diabetes affected them emotionally to a moderate extent (5.3 ± 3.3). They were not very concerned about possibly having diabetes (4.1 ± 3.4), nor did they believe that they had many symptoms that made them think they had diabetes (2.0 ± 2.2).

The most commonly identified causes of diabetes were diet or eating habits (identified by 87.9% of respondents), heredity (42.5%), having a sedentary lifestyle (31.7%), and being overweight (27.1%).

Differences in Diabetes Illness Perceptions According to Diabetes Risk Factors

As can be seen in Table 1, there were no statistically significant differences in any of the 8 illness perception dimensions between those who exercised daily and those who had little or no daily exercise. However, as compared with persons with BMI $< 25\text{kg/m}^2$, those with BMI $\geq 25\text{kg/m}^2$ indicated that diabetes would have a greater effect on their lives if they

developed it, and that they had a greater understanding of diabetes (7.4 vs. 6.6, respectively; $p=.009$ and 5.4 vs. 4.8, respectively; $p=.035$).

When non-modifiable diabetes risk factors were considered, there were statistically significant differences in two of the illness perception components for the younger and older participants. Persons 18–44 years of age reported having more symptoms that made them think they had diabetes, and they were more concerned that they had diabetes than those at least 45 years old (2.5 vs. 1.9, respectively; $p=.019$ and 4.7 vs. 3.8, respectively; $p=.030$). With regard to differences in components of diabetes illness perceptions according to whether or not they had a first degree relative with diabetes, study participants without this risk factor were less concerned than those having such a relative that they might have diabetes (3.7 vs. 4.6, respectively; $p=.017$), reported poorer understanding of diabetes (4.9 vs. 5.6, respectively; $p=.024$), and were less emotionally affected by the possibility of having diabetes (4.9 vs. 5.9, respectively; $p=.003$). These three components of illness perceptions were precisely those for which there was also a statistically significant difference according to Latino ethnicity. In particular, those of Latino ethnicity were more concerned than those not of Latino ethnicity that they might have diabetes (4.8 vs. 3.8, respectively; $p=.012$), reported that they had better understanding of diabetes (5.7 vs. 5.0, respectively; $p=.039$), and were more affected emotionally by the possibility of having diabetes (6.2 vs. 4.9, respectively; $p=.001$). Finally, persons of at-risk races (Black, Native American, Asian, Pacific Islander) as compared with those whose race did not place them at risk for diabetes believed that diabetes would continue for less time (6.3 vs. 7.2, respectively; $p=.011$), that they would have more personal control over diabetes (7.9 vs. 6.9, respectively; $p<.000$), that treatment would help their illness (8.9 vs. 8.3, respectively; $p=.005$) and that they had a better understanding of diabetes (5.7 vs. 4.9, respectively; $p=.017$).

Discussion

While all of the adults in the study were at risk for diabetes, almost half (46%) actually had A1C values in the pre-diabetes or diabetes ranges, with an average A1C value of 5.6% (38 mmol/mol), just below the elevated range of 5.7% (39 mmol/mol). It is therefore likely that many of these adults will ultimately develop diabetes, suggesting the importance of attending to their diabetes illness perceptions. With regard to those perceptions, large proportions of the adults in the study identified heredity, a sedentary lifestyle, and being overweight as causes of diabetes. In addition, diet or eating habits were inappropriately identified by the vast majority of the study sample as *causing* diabetes. A diet high in calories contributes to weight gain and potentially to being overweight, but such a diet is not, in and of itself, a cause of diabetes.²³ Thus, to prevent or delay the onset of diabetes, education about diabetes and its causes is clearly needed by persons at risk.

Overall, adults at risk for diabetes were not especially concerned that they might have the illness and reported that the possibility of having diabetes affected them emotionally in a moderate way. They thought that diabetes would last for a considerable period of time, but not forever, and that if they contracted it, diabetes would affect their lives substantially, but not severely. They also thought that they would have substantial but not complete control over it, although they were quite secure in the knowledge that treatment would help their

illness. Consistent with their low diabetes identity perceptions, these at-risk adults reported between 1 and 2 of 5 diabetes-related symptoms. They also reported only a moderate understanding of diabetes, consistent with their performance on the knowledge assessment scale. These latter two consistencies suggest the accuracy of their diabetes illness perceptions, and suggest the importance of improved education about diabetes for those at risk. Diabetes education should especially focus on the impact that diabetes is likely to have on their lives, the ways in which diabetes can be controlled, and the fact that diabetes is almost always a lifelong condition.

When examining differences in diabetes illness perceptions according to diabetes-related risk factors, some study findings are consistent with those obtained from persons with diabetes. For example, just as older persons with diabetes have less diabetes-related distress than younger ones,¹⁸ current study findings indicate that older at-risk persons are less likely to have symptoms that make them think they have diabetes and are less concerned about having diabetes. In addition, in the current study, persons of races that place them at greater risk for diabetes are more likely to view diabetes as having a shorter duration than those of races not specifically at risk. Abubakari and colleagues²⁴ found similar differences in perceptions of diabetes duration between whites and blacks in their study of persons with diabetes. However, in contrast to research that demonstrated no statistically significant differences between persons with diabetes of majority and minority ethnicities regarding perceived understanding of the illness,¹⁴ the current study found such differences among at-risk Latinos as compared with non-Latinos. In addition, while current study findings regarding greater diabetes-related emotional response for persons with a first degree relative with diabetes are consistent with those of Scollan-Koliopoulos and colleagues,¹⁷ this was not the case when examining diabetes understanding. Persons in the current study who had a family history of diabetes were more likely to indicate that they had a greater understanding of the illness, whereas Scollan-Koliopoulos and colleagues' sample of persons with diabetes reported such persons as having less diabetes understanding. Thus, education and communication with persons at risk for diabetes needs to take into account (a) differences in diabetes-related illness perceptions from those with diabetes, as well as (b) differences in specific diabetes-related risk factors among at-risk persons.

Some study limitations are acknowledged, primarily related to the self-report nature of much of the data used in the analyses and the recruitment of at-risk persons in an urban oral healthcare location, thereby possibly limiting the generalizability of study findings.

Implications for Diabetes Educators

With diabetes educators – whether nurses, dietitians, pharmacists, exercise physiologists, physicians, or mental health professionals - increasingly addressing the needs of at-risk patients,²⁵ the findings of this study demonstrate the importance of their providing these patients with diabetes education and correcting their diabetes-related misconceptions. Exercise physiologists, dietitians and other diabetes educators can especially educate at-risk patients about the importance of a healthy diet and an active lifestyle, thereby helping them guard against weight gain and potentially high BMI that might precipitate progression to diabetes.

In addition, increasing diabetes incidence and prevalence²⁶ has demonstrated the importance of additional opportunities for prediabetes and diabetes screening. As was the case in the current research, patients may therefore be identified with prediabetes in alternate settings, such as at oral healthcare sites.^{27,28} Whatever the location of this identification, study findings indicate that diabetes educators should also be aware that some diabetes illness perceptions among those at risk for diabetes or with prediabetes may be different from those with frank diabetes. This may especially be the case when specific diabetes risk factors are taken into account. When working one-on-one with an at-risk patient, it would be best to administer a short, psychometrically robust instrument such as the Brief IPQ - Diabetes to determine the patient's specific illness perceptions. Then, education and counseling can be tailored to the patient's specific perceptions and needs. Fortunately, unhelpful and inaccurate illness representations can be modified through effective communication between a patient and provider.²⁹ When working with a group of patients who share a common diabetes risk characteristic, study findings suggest that diabetes educators maintain a particular focus for their education and counseling. For example, when the group of at-risk patients is predominantly of Latino ethnicity, diabetes educators need to recognize that the possibility of having diabetes has a greater emotional effect on Latinos than non-Latinos, and that they will need to deliver their support accordingly.

Conclusions

Despite its limitations, this study provides important information regarding the diabetes illness perceptions among a group of persons at risk for contracting it, highlighting differences based on their specific risk factors. This suggests the importance of having diabetes educators and other healthcare providers focus their diabetes-related communication and education to at-risk persons' specific needs and vulnerabilities.

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Table 1

Illness Perceptions about Diabetes among Adults At-Risk (mean, s.d.)^{*}

		Consequences ^a	Timeline ^b	Personal Control ^c	Treatment Control ^d	Identity ^e	Concern ^f	Understanding ^g	Emotional Response ^h
Entire sample		7.2 (2.7)	6.9 (3.3)	7.3 (2.6)	8.5 (2.1)	2.0 (2.2)	4.1 (3.4)	5.2 (2.8)	5.3 (3.3)
BMI 25kg/m ²	no	6.6 (2.9)	6.7 (3.6)	7.3 (2.7)	8.3 (2.4)	1.8 (2.1)	3.8 (3.4)	4.8 (3.1)	4.9 (3.3)
	yes	7.4 (2.6)	7.0 (3.2)	7.2 (2.6)	8.6 (2.0)	2.1 (2.2)	4.1 (3.3)	5.4 (2.6)	5.5 (3.2)
Little/no exercise	no	7.3 (2.7)	6.8 (3.4)	7.2 (2.5)	8.4 (2.2)	2.0 (2.2)	3.7 (3.1)	5.0 (2.8)	5.0 (2.8)
	yes	7.2 (2.7)	7.0 (3.3)	7.3 (2.7)	8.6 (2.1)	2.1 (2.2)	4.3 (3.5)	5.4 (2.8)	4.6 (2.8)
Latino	no	7.0 (2.7)	6.9 (3.4)	7.3 (2.6)	8.5 (2.0)	1.9 (2.1)	3.8 (3.3)	5.0 (2.8)	4.9 (3.2)
	yes	7.6 (2.8)	7.0 (3.3)	7.1 (2.6)	8.5 (2.2)	2.3 (2.4)	4.8 (3.6)	5.7 (2.8)	6.2 (3.1)
Age	18–44	7.6 (2.6)	6.9 (3.2)	7.5 (2.4)	8.8 (1.8)	2.5 (2.3)	4.7 (3.4)	5.4 (2.4)	5.7 (3.3)
	45	7.0 (2.7)	6.9 (3.4)	7.1 (2.7)	8.4 (2.2)	1.9 (2.2)	3.8 (3.3)	5.1 (2.9)	5.1 (3.3)
Parent/ sibling with diabetes	no	7.2 (2.6)	6.7 (3.4)	7.2 (2.6)	8.5 (2.0)	1.9 (2.0)	3.7 (3.3)	4.9 (2.6)	4.9 (3.2)
	yes	7.3 (2.9)	7.2 (3.3)	7.4 (2.7)	8.5 (2.3)	2.3 (2.4)	4.6 (3.5)	5.6 (3.0)	5.9 (3.3)
At-risk race	no	7.1 (2.8)	7.2 (3.2)	6.9 (2.6)	8.3 (2.1)	2.1 (2.2)	3.9 (3.2)	4.9 (2.7)	5.4 (3.2)
	yes	7.3 (2.6)	6.3 (3.5)	7.9 (2.6)	8.9 (2.0)	1.9 (2.2)	4.2 (3.6)	5.7 (2.8)	5.0 (3.4)

^{*} Statistically significant differences (<.05) are in bold type^a How much do you think that diabetes would affect your life? (0=no effect at all ... 10=a severe effect on my life)^b If you had diabetes, how long do you think your illness would continue? (0=a very short time ... 10=forever)^c If you had diabetes, how much control do you think you would have over it? (0=absolutely no control ... 10=extreme amount of control)^d If you had diabetes, how much do you think treatment could help your illness? (0=not at all ... 10=extremely helpful)^e Do you have symptoms that make you think you have diabetes? (0=no symptoms at all ... 10=many severe symptoms)^f How concerned are you that you might have diabetes? (0=not at all concerned ... 10=extremely concerned)^g How well do you feel you understand diabetes? (0=don't understand at all ... understand very clearly)

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How much does the possibility of your having diabetes affect you emotionally? (0=not at all affected emotionally ... 10=extremely affected emotionally)

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