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Illness Perceptions And Barriers To Diabetes Care:A Study From South India

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ABSTRACT

Background: Diabetes is a complex and chronic disease. The clinical management of diabetes requires diligent self-management. Research suggests that patient perceptions about the nature of diabetes and perceived barriers to treatment can influence adherence and consequently, glycemic control.

Aims: The study explores illness perceptions, perceived barriers and glycemic control amongst Indian diabetic patients.

Methods: Two hundred and sixty (n=260) consenting subjects from an Outpatient diabetic clinic were administered scales to assess illness perceptions and perceived environmental barriers to adherence to diabetes treatment advice.

Results: Subjects did not perceive their Illness to be excessively threatening, but higher scores were associated with poorer glycemic control. Although environmental barriers were only 'rarely' or 'sometimes' perceived, higher scores were associated with poorer glycemic control. Finally, personal control over the illness (amongst illness perceptions), and forgetfulness and finding time at work (amongst perceived barriers) together accounted for nearly 24% of the HbA1C variance.

Conclusions:

This study found that diabetic patients' illness perceptions are strongly associated with how environmental barriers are perceived, and they together, contribute to nearly 24% of variance in glycemic control. An important clinical implication is that an education program that encourages patients to take control over their illness by following an activity schedule that includes all elements of diabetes care could have a significant effect upon glycemic control. In practice, this could reduce the reliance on medications alone to achieve good glycemic control.

Key words: Diabetes; Illness perceptions, Environmental barriers, Glycemic control, HbA1C.

I. INTRODUCTION

The prevalence of diabetes in India has been on the rise in the past few decades. Studies indicate an overall prevalence between 12-19%, with a clear urban preponderance (1). Despite the obvious magnitude of the problem, only around 50-75% of Indians show an awareness of the condition (2,3). Knowledge and awareness is particularly low amongst diabetics from rural and illiterate urban backgrounds (1). Further, glycemic control is poor in over half of Indian diabetics (4).

Type 2 Diabetes, which affects nearly 90% of all patients with Diabetes, is often described as a chronic lifestyle disease. Both the chronicity of the illness and the salience of lifestyle factors in Diabetes render it amenable to a chronic disease management model wherein self-management plays a crucial role in achieving good clinical outcomes (5,6). Dietary modifications, regular exercise/ physical activities and weight management, together with adherence to prescribed medications and regular monitoring form the cornerstones of Diabetes self-management.

Literature suggests that environmental barriers have a significant impact upon patients' adherence to treatment recommendations(7,8). These barriers in turn, are influenced by patients' perceptions about the illness. Specifically, patients' beliefs about the nature of their diabetes, its symptoms, severity, how long it will last (its time-line), its treatability, perceived control, etc impact upon how barriers are perceived and consequent glycemic control.

In a systematic review, McSharry, et al (2011) found that patients who perceived more serious complications of diabetes (Consequences), attributed more symptoms to their diabetes (Identity), were more emotionally distressed (Emotional representations), perceived it as unpredictable and cyclical (Timeline) and were more concerned about diabetes (Concern)- had

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higher scores on measured barriers to diabetes management and higher HbA1c scores (poorer control). On the other hand, people who perceived more control over their illness had lower HbA1c scores (better glycemic control) (9).

Whilst these findings can have important therapeutic value, most of existing research on Illness perceptions and barriers has been conducted in developed economies. It is unclear whether these findings can be extrapolated to an Indian setting, particularly because of the social and cultural milieu in India is likely to be very different from Western settings. For example, acceptability of physical exercise regimes (especially amongst women), dietary norms, availability of facilities for physical activities, disruption of routines during festivals and family celebrations, professional norms regarding work-life balance are likely to be very different in an Indian context, as compared to the West (10,11). The only Indian study that looked at some of these aspects was limited by a small sample size, therefore, unlikely to be generalizable to the wider Indian population (12).

The present study aims to (i) explore illness perceptions and perceived barriers to diabetes self-management amongst Indian patients, and (ii) investigate their relationship with each other and with glycemic control.

II. METHODOLOGY

Study design

This was a cross-sectional study of patients with an existing diagnosis of Diabetes Mellitus. Participating subjects were administered a study questionnaire which elicited background socio-demographic information, illness details, most recent HbA1c, levels, Illness perceptions and perceived barriers to diabetes self-management.

Setting

The study was conducted in the city of Hyderabad, India has a population of around 6.9 million people. Telugu, Urdu and English are widely spoken, with the service industry employing nearly 90% of the workforce. Nearly 77% of men and 19% of women are employed (13).

Study subjects were drawn from amongst patients attending the outpatient clinics of the Institute of Diabetes, Endocrinology and Adiposity (IDEACLINICS). IDEACLINICS is a network of 10 specialist Diabetes and endocrinology clinics run by a multidisciplinary team of 15 qualified Diabetologists and Endocrinologists supported by dieticians, counsellors, healthcare assistants and psychologists.

Sample

The sampling frame consisted of all subjects with an established diagnosis of Diabetes Mellitus of at least 6-months duration attending one of the IDEA clinic facilities in Hyderabad. A purposive sample of 260 consenting subjects was recruited representing a range of different geographical and social backgrounds.

Eligible subjects who attended the clinic for a consultation with the diabetologist were invited to participate in the study. Inclusion criteria age over 18 years, confirmed diagnosis of Diabetes mellitus with a duration of illness greater than 6 months and ability to consent for the study. We excluded subjects that were less than 18 years of age, were diagnosed with gestational diabetes and were unable to provide consent.

Consenting subjects were interviewed by the researcher to complete the study questionnaire. Each interview took about 25-30 minutes to administer. Written informed consent was taken from all participating subjects.

Instruments

A study questionnaire elicited background social, demographic and illness related information. The latter included the type of Diabetes, illness duration, complications, and recent HbA1c values. The following scales were also administered: a) the Brief Illness Perceptions Scale (14), and b) Environmental barriers to adherence questionnaire (7). The study questionnaire and scales were translated into Telugu (the local language) and reviewed by a bilingual committee to ensure linguistic and conceptual equivalence for the purpose of the study. To ensure reliability, a guided-interview with a consenting subject was recorded (video) and rated independently by each of the 4 researchers. Any discrepancies in rating were resolved through a discussion and consensus. This was done to enhance the reliability of assessments.

Brief Illness perceptions scale

This is a 9-item scale that elicits the following illness related perceptions (14).

1. **Consequence** – the expected effects and outcome of the illness
2. **Timeline** – how long the patient believes the illness will last

3. **Personal control** – how much control the patient believes to have over the illness
4. **Treatment control** – how much the patient thinks the treatment can help
5. **Identity** – how the patient experiences/ attributes symptoms to diabetes
6. **Concern** – how much the patient worries about the illness
7. **Illness comprehensibility** – how much the patient understands about his illness
8. **Emotional distress** – how the illness affects the patient emotionally

Subjects were also asked to list out three likely causes for their illness, which were grouped into categories such as stress, lifestyle, hereditary, etc. The remaining perceptions were scored on a 10-point scale ranging from "not at all" to "extremely". An overall score was also computed as the sum of scores from items 1, 2, 5, 6 and 8 and reversed scores on items 3, 4, and 7. A higher overall score reflects a more threatening view of the illness whereas a lower overall score reflects that the illness was viewed as more benign (14).

Environmental barriers to adherence questionnaire

This is a 60 item scale whose reliability, validity and internal consistency has been well established (7). It measures perceived environmental barriers to diabetes management along 4 domains namely medications, monitoring, diet and exercise. There are 13-common items (barriers) that are measured for each of the domains, with some additional items for some domains. Each item is scored on a 5-point scale (1=never, 2=rarely, 3=sometimes, 4=often, 5=always). An overall barriers scores calculated as the sum of responses to all items. Individual scores can be calculated for the four treatment domains. Finally, 13 four-item barriers subscales can be scored by adding together the common parallel items (e.g., inconvenience) found in each of the domains.

a. STATISTICAL ANALYSIS

Based upon alpha (α 2-tailed) of 0.05, beta (β) of 0.10, and an expected correlation coefficient (used here as a measure of effect size) between variables of at least 0.200, the minimum sample size was calculated to be 259 subjects. Data was analysed using a statistical software (SPSS version 23). A multiple linear regression (stepwise) was calculated to predict HbA1C levels based upon Illness perceptions and environmental barriers that were found to be significantly associated with HbA1C levels.

The study received ethical approval from the Institutional ethics committee at the Indian School of Business, Hyderabad, India.

III. RESULTS

Two hundred and sixty subjects (n=260) participated in the study. Of these,119 were male (46%) and 141 were female (54%). The mean age was 52.8 years (SD- 12 years). The majority was literate. Nearly fourteen percent of the sample (13.6%) had completed primary school, 22.7% had completed secondary school, 13.5% had completed higher-secondary school, 27.7 were graduates, and 19.6% were postgraduates. One hundred and thirteen subjects (43.5%) were employed, 94 (36.2%) were home-makers, 45 (17.3%) were retired, 6 (2.3%) were unemployed and 2 (0.7%) were students.

Illness characteristics

The Illness characteristics of the study sample are outlined in Table 1. The majority of subjects had Type 2 Diabetes and were on oral antidiabetic medications. The mean illness duration was 9.1 years. HbA1C levels were available for 231 subjects and the mean HbA1C level was 8.2 (SD 1.9, range 4.2- 18.1, variance 3.5). There were no significant differences in HbA1c levels across gender ($p=0.96$), socio-economic status ($p=0.56$), occupation ($p=0.1$) and education ($p=0.19$) . HbA1C score was not significantly associated with illness duration ($p=0.76$) and the presence of complications ($p=0.38$). However, HbA1C had a negative correlation with age ($r=-0.141$, $p<0.05$). Subjects who were on Insulin had significantly higher HbA1C scores than those on oral antidiabetic medications (mean 8.8, SD 1.9, n=51 vs.mean 8.1, SD 1.8, n=209; $p<0.05$)

Illness Perceptions

Table 2 shows the mean Illness Perception scores for the sample. The scores (except for concern and timeline) suggest that subjects did not perceive the illness to be excessively serious or threatening. Among the illness perceptions, subjects who believed that the illness had significant consequences upon their life and affected them emotionally had poorer glycemic control. On the other hand, those who perceived their diabetes to be a chronic condition, who had a sense of personal control over the illness, who believed that treatment could help their illness and had a good understanding of their illness had better glycemic control. (Table 2).

The total Illness perception score was negatively correlated with age (r= -0.234) and years of education (r= -0.134) ($p<0.05$). There were no gender differences in Illness perception scores ($p>0.05$).The total Illness perception score was also not associated with illness duration (r=0.09, $p>0.05$)Illness perception scores didnot differ between subjects who had diabetic complications (35.8, SD 11.2) and those who did not (34.3, SD 11.7) ($p>0.05$).

The Brief Illness Perception Questionnaire also elicits the subjects' views on the causation of their diabetes. Most subjects attributed their illness to a family history of diabetes and hereditary factors (n= 164, 63%). Other causes reported were stress (n= 119, 45.8%), food habits (n=20, 7.7%) and lack of exercise (n=11, 4.2%).

Environmental Barriers to Adherence to Treatment

Table 3 shows the environmental barrier scores for each of the treatment domains (i.e., medications, monitoring, diet and exercise). Individual barrier scores ranged between 0.8 and 3.9, subjects rated most barriers as 'never' or 'rarely' or 'sometimes'. There were no significant differences in the barrier scores across males and females and across patients on insulin and oral antidiabetics ($p>0.05$). Mean scores for all environmental barriers were significantly associated with poor glycemic control ($p<0.05$).

A multiple linear regression (stepwise) was calculated to predict HbA1C levels based upon Illness perceptions and environmental barriers that were found to be significantly associated with HbA1C levels. A significant regression equation was found ($F(3,227)= 23.866$, $p<0.01$), with an R^2 of 0.24. This suggests that 24% of the variance in the HbA1C level (nearly 0.87%) was accounted for by the variables in the regression equation. Participants' predicted HbA1C is equal to 6.052 + 0.262 (personal control score) + 0.393 (forgetfulness barrier score) + 0.306 (finding time at work barrier score), where personal control and the barrier scores are scored as above. (Table 4)

IV. DISCUSSION:

The salient findings of our study are that firstly, diabetic patients' illness perceptions are strongly associated with how environmental barriers are perceived. Secondly, specific illness perceptions and barriers account for nearly 24% of the variance in HbA1C levels. An important clinical implication is that an education program that addresses how patients think about and understand their illness could in principle, have a substantial effect upon glycemic control. In practice, this reduce the pill burden of diabetic patients in the community.

The role of illness perceptions and environmental barriers in glycemic control is best conceptualised from a social cognitive perspective. Threatening or negative perceptions about diabetes predispose individuals to feel helpless, thus lower their confidence and self efficacy. This can adversely affect their perception of environmental circumstances and hinder adherence to the prescribed treatments, thus contributing to poorer glycemic control. This study sheds lights on how these factors might be related to one another.

In their study on Insulin dependent diabetic subjects, Griva, et al (2000) found higher personal control beliefs to be associated with better adherence to medications, diet and exercise and better glycemic control (15). A similar finding was reported by Broadbent, et al (2006) in their validation study of the Brief Illness perception questionnaire. On the other hand, diabetic patients who identified more symptoms with their illness (Identity) and who believed that the prescribed treatment did not substantially control their illness (treatment control) had poorer glycemic control (14,15). Other illness perceptions like consequence, timeline, concern, emotional distress and illness comprehension were not substantially associated with glycemic control in the Broadbent study. This finding is contrary to the findings from the present study. There could be a number of reasons for this. The Broadbent study had a smaller sample size, but the differences in the cultural and social backgrounds of the two studies could also be a factor.

Our results suggest that all the above threatening illness perceptions (except identity and concern) are associated with poorer glycemic control. This finding is in keeping with a more recent meta-analysis (16) with two main exceptions. A higher number of symptoms attributed to diabetes (Identity) did not correlate with glycemic control in our study. Similarly, greater concern about the illness (Concern) was also not associated with glycemic control. We would hypothesized that these findings reflect Indian patients' perception of Diabetes as a predominantly biochemical diagnosis, with few attributable physical symptoms.

With respect to the percieved environmental barriers, the results suggest that the

total and mean individual barrier scores were between 2 (rarely) and 3 (sometimes)- suggesting that the barriers measured by this scale were not commonly experienced as interfering with adherence to the treatment advice. That said, higher barrier scores were associated with poorer glycemic control, as well as higher illness perception scores. This finding is in line with the findings of Irvine et al (7). Further, subjects reported more barriers to adherence to diet and exercise than to taking medications and monitoring their glucose levels. This latter finding could reflect the local cultural landscape of the Indian population, where much emphasis is placed upon the role of medications and medical measures (including monitoring) to manage illnesses rather than lifestyle changes. This is perhaps in contrast to traditional Indian methods which were predominantly non-medical and involved home remedies- traditions that are gradually being eroded by the adoption of western ways of living. The reluctance (or inability) to adopt lifestyle changes amongst Indian subjects, as opposed to taking medications and doing blood tests has been reported by some authors (17). The lack of available facilities and resources to inculcate dietary and exercise-related changes to an urban Indian lifestyle may also be important factors that could explain these findings. Social and familial interdependence and role-demarcation of each family member in Indian society also make it very difficult for an individual person to make lifestyle changes. (10,11)

To our knowledge, this is the first study that specifically looked at the relationship of Illness perceptions and perceived environmental barriers with glycemic control in the Indian population. The study was planned so as to ensure that the findings could be extrapolated to the private healthcare seeking middle-class Indian diabetic population. Instruments used in the study were adapted for use in the local setting so as to enhance their validity and reliability. However, the study findings need to be tempered by two important limitations. Firstly, the cross-sectional nature of the study design only permits correlational inferences (rather than causality). Secondly, although the study was sufficiently powered by an adequate sample size, the subjects themselves were recruited on a purposive basis from an urban, middle-class private healthcare seeking clinic population, which could constrain generalisation of the results.

These limitations notwithstanding, the findings could have potentially significant therapeutic implications. Interventions could be designed to challenge and re-calibrate patients' diabetes related perceptions, and this could, directly and indirectly, positively impact glycemic control amongst these patients. These could form a part of a comprehensive support package of dietary advice, reminders for glucose monitoring, medication adherence and periodic lab testing. At a community level, improving availability and access to resources might encourage people to make healthy lifestyle choices. Promotion of healthy lifestyle choices through various media platforms can also have an impact. Since costs are a significant barrier, the inclusion of comprehensive diabetes care within the ambit of health insurance schemes can motivate patients to comply with dietary and lifestyle recommendations and thus, delay or prevent diabetic complications, unnecessary hospital admissions and premature deaths. Future work could focus upon studying whether these findings can be generalized to other population sets, as well as on exploring the above-mentioned interventional opportunities and their impact upon diabetic outcomes in India.

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Table: 1

Illness characteristics of the study sample

Illness characteristic		**n (%); mean (SD)**
Type of Diabetes	Type 1	3 (1%)
	Type 2	257 (99%)
Treatment	Oral antidiabetics	209 (80.4%)
	Insulin	51 (19.6%)
Mean Illness duration (years)		9.1 (SD-7.4)
Mean HbA1C		8.2% (SD-1.9)
Diabetes complications	Present	128 (49.2%)
	Absent	132 (50.8%)

Table 2

Illness Perception Scores and association with HbA1C levels

		Mean score (SD)	**Pearson's correlation coefficient with HbA1C: r (p-value)**
1	How much does your illness affect your life? (Consequence)	3.2 (3.0)	0.224 ($p<0.05$)
2	How long do you think your illness will continue? (Timeline)	8.2 (2.5)	-0.157 ($p<0.05$)
3	How much control do you feel you have over your illness? (Personal Control)	6.0 (2.3)	-0.422 ($p<0.05$)
4	How much do you think your treatment can help your illness? (Treatment Control)	7.4 (2.2)	-0.315 ($p<0.05$)

5	How much do you experience symptoms from your illness? (Identity)	3.4 (3.2)	0.126 (p=0.055)
6	How concerned are you about your illness? (Concern)	5.9 (3.1)	0.09 (p=0.894)
7	How well do you feel you understand your illness? (Illness Comprehensibility)	5.7 (2.6)	-0.220 (p<0.05)
8	How much does your illness affect you emotionally? (Emotional distress)	3.4 (3.3)	0.162 (p<0.05)

1= Not at all, 10= Extremely

Table 3
Environmental Barriers to Adherence to Treatment (n=260)

BARRIER	**MEDICATION** Mean (SD)	**EXERCISE** Mean (SD)	**MONITORING** Mean (SD)	**DIET** Mean (SD)	**Mean barrier score**
1. Finding time at work	0.8 (1.1)	1.6 (1.9)	1.0 (1.4)	1.3 (1.7)	1.6 (0.8)
2. Finding time at home	1.2 (0.7)	2.4 (1.8)	1.3 (0.8)	1.9 (1.4)	1.3 (1.1)
3. Finding a good place	1.2 (0.6)	1.5 (1.3)	1.1 (0.5)	1.9 (1.4)	1.4 (0.6)
4. The inconvenience	1.5 (1.1)	1.9 (1.7)	1.3 (0.9)	1.7 (1.3)	1.6 (0.8)
5. Problems with my health	1.2 (0.6)	2.1 (1.6)	1.2 (0.7)	1.6 (1.2)	1.5 (0.7)
6. Forgetting to take it	1.6 (1.0)	1.9 (1.5)	1.6 (1.0)	1.7 (1.2)	1.7 (0.8)
7. Feeling sick	1.3 (0.9)	2.1 (1.5)	1.4 (1.0)	1.5 (1.1)	1.6 (0.8)
8. It's too complicated	1.4 (0.9)	1.8 (1.5)	1.3 (0.9)	1.4 (1.1)	1.5 (0.7)
9. It's too painful	1.2 (1.0)	1.8 (1.5)	1.4 (0.9)	1.7 (1.2)	1.5 (0.8)
10. Being away from home	1.9 (1.4)	3.6 (1.7)	2.2 (1.5)	3.0 (1.7)	2.7 (1.1)
11. Changes in routine	1.8 (1.4)	2.8 (1.8)	1.9 (1.5)	2.5 (1.7)	2.2 (1.2)
12. The cost	1.3 (0.9)	1.1 (0.8)	1.3 (0.9)	1.2 (0.7)	1.5 (0.7)
13. Special occasions	1.8 (1.3)	3.2 (1.7)	1.9 (1.3)	3.5 (1.5)	2.5 (0.9)
14. Getting back to routine after a break		2.1 (1.6)		1.6 (1.2)	2.2 (1.2)
15. Bad weather		2.9 (1.8)			1.4 (0.8)
16. Changes in season		2.9 (1.8)			2.6 (1.2)
17. Not having right food at home				1.7 (1.3)	1.7 (1.3)
18. Having junk food at home				1.9 (1.3)	1.9 (1.3)
19. No one else				1.5 (1.1)	1.5

eats like I have to					(1.1)
20. Too few foods I like in my diet				1.8 (1.4)	1.8 (1.4)
Total barrier score (mean)	18.1 (7.8)	35.8 (14.9)	18.7 (7.7)	33.3 (14.0)	
Mean individual barrier score (total score/no of items)	1.4	2.2	1.4	1.9	

1= never, 2= rarely, 3= sometimes, 4= often, 5= always

Table 4
Multiple Regression analysis: Predictors of Glycemic control

Coefficients [a,b]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	6.961	.210		33.118	.000
	Personal control	.312	.044	.422	7.036	.000
2	(Constant)	6.260	.276		22.703	.000
	Personal control	.275	.044	.372	6.241	.000
	Forgetfulness	.524	.138	.226	3.785	.000
3	(Constant)	6.052	.293		20.659	.000
	Personal control	.262	.044	.355	5.923	.000
	Forgetfulness	.393	.152	.170	2.582	.010
	Finding time at work	.306	.153	.132	2.000	.047

[a]Dependent Variable: hba1c
[b]Excluded variables: Illness perceptions-Consequence, Timeline, Treatment control, Identity, Control, Illness comprehensibility, Emotional distress, Environmental barriers-Finding time at home, Inconvenience, Problems with health, Feeling sick, Too complicated, Too painful, Being away from home, Changes in routine, Cost, Special occasions, Getting back to routine after a break, Bad weather, Changes in season, Not having right food at home, Having junk food at home, No one else eats like I have to, Too few foods that I like in my diet.