

# Diabetic Retinopathy Awareness and Practices in a Low-income Suburban Population in Karachi, Pakistan

Rubina Hakeem, Zahid Awan<sup>1</sup>, Saleh Memon<sup>2</sup>, Munazza Gillani<sup>3</sup>, Sikandar Ali Shaikh<sup>3</sup>, Muhammad Adil Sheikh<sup>4</sup>, Sidra Ilyas<sup>4</sup>

Department of Food and Nutrition, Raana Liaquat Ali Khan College of Home Economics, <sup>1</sup>Prevention and Control of Blindness Program, Civil Hospital, Health Department Government of Sindh, <sup>2</sup>Director Projects, Community Based Projects, <sup>3</sup>Country Office for Pakistan, Sightsavers International, Al Ibrahim Eye Hospital, Karachi, Pakistan, <sup>4</sup>Department of Internal Medicine, Detroit Medical Center, Wayne State University, Detroit, MI, USA

## Abstract

**Purpose:** This study presents observations about knowledge, attitude and practices of people with diabetes living in Chanesar Goth, which is a suburban area of Karachi. **Methodology:** Data were collected by trained lady health workers during their home visits of the families. The responses in most cases were open ended and later categorised according to themes and purpose for asking specific questions. **Results:** The sample consisted of 59 (31.6%) males and 128 (68.4%) females. The mean age of males and females was 56 years and 49 years, respectively. The mean duration of diabetes for females and males was 6.8 years and 8.34 years, respectively. Frequency of correct answers to question about treatment of diabetes-related eye disease was relatively low (24% male, 20% female). Proportion of patients having good awareness was significantly higher among those who had diabetes for 10 or more years (60%) as compared to those who had diabetes for shorter duration (42%,  $P < 0.026$ ). Only half of the patients had a firm belief that diabetes is preventable and about one-third had belief that diabetes is treatable. Patients' eye testing practices were associated strongly with their attitude towards eye testing and their knowledge about the relation of eye problems to diabetes. Proportion of patients who had got their eyes checked more than twice since the diagnosis of diabetes was highest among patients with both knowledge and belief about eye testing (35.3%), followed by those who only had a firm belief (19.7%) and was lowest than among those who neither had belief nor knowledge (9.1%) ( $P = 0.008$ ). The level of awareness was higher among females and those who had diabetes for a longer duration. **Conclusion:** Educational interventions should focus on inculcating positive attitudes and firm belief in the importance of self-care.

**Keywords:** Awareness, diabetes, diabetic retinopathy

## INTRODUCTION

There were over 7 million cases of diabetes in Pakistan in 2015<sup>[1]</sup> and this figure is continually increasing. It is estimated that, if the rates of diabetes remain unchecked, by the year 2030, Pakistan would rank fourth in relation to the highest number of diabetic in a country. Diabetic retinopathy (DR) is a disabling complication of diabetes, and visual impairment or blindness caused by DR leads to serious socioeconomic burden resulting particularly in the working age group. It is an eye abnormality in which the human retina is affected due to an increasing amount of insulin in blood. The early detection and diagnosis of DR is essential to save the vision of diabetic patients.<sup>[2]</sup>

Early screening for ocular changes can prevent blindness and it requires motivating patients to contact appropriate healthcare facilities early in the process of disease and adhere to regular monitoring regimens suggested by ophthalmologists.

Early screening can help in the prevention and control of retinopathy.<sup>[3,4]</sup> Unawareness is observed to be associated with poorer control of DR risk factors and highlights room for improvement in DR prevention through better patient education and screening.<sup>[5,6]</sup> While the awareness of DR is variable, specific knowledge about DR is low such that many patients have already experienced vision loss by the time they are screened.<sup>[6]</sup>

In several countries where studies have been conducted to assess the level of patients' awareness about DR, it is observed

**Address for correspondence:** Dr. Rubina Hakeem, Department of Food and Nutrition, Raana Liaquat Ali Khan College of Home Economics, Karachi, Pakistan.  
E-mail: [rubina.hakeem@gmail.com](mailto:rubina.hakeem@gmail.com)

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that there is considerable room for improvement. For example, in a study conducted among Hispanics, less than one-third knew that strict control could prevent eye problems, less than half knew that dilated eye examinations were important and a total of 30% of diabetic participants had had an eye examination in the previous year. Another study conducted in Brazil demonstrated that 81% of the diabetic patients present some knowledge about diabetes ocular changes, but they do not have precise information.<sup>[7]</sup> In Kathmandu, it was observed that 21% of the diabetic patients on treatment had various grades of DR and 50% of the diabetic patients were not aware of DR.<sup>[8]</sup> In a study conducted among diabetics in rural India, 49.9% had knowledge of DM and 37.1% had knowledge of DR. Compared with those who had no knowledge of DR ( $n = 1220$ ), significant percentages of individuals with knowledge had the right attitude to go for regular eye examinations.<sup>[9]</sup> Patients who participated in the educational intervention demonstrated an increase in knowledge across time. Patients may benefit from education, emphasising the importance of dilated eye examinations in the absence of ocular symptoms.<sup>[10]</sup>

Several researchers have explored rates of DR in Pakistan, reporting rates ranging from around 15% to 26% in various settings<sup>[11-14]</sup> to as high as 33% among diabetics admitted in a teaching hospital of Lahore<sup>[15]</sup> and 43% among the Diabetic Association of Pakistan's outpatient department.<sup>[16]</sup> There are yet no reports of any assessment of preventive and control measures taken by diabetes patients or their level of awareness about DR. Given the high rate of diabetes in Pakistan and socioeconomic burden of DR, assessing and enhancing people's knowledge about diabetes, DR and other diabetic complications is required.

Responding to this need, and to combat DR-related blindness, Al-Ibrahim Eye Hospital, Karachi, in collaboration with the Sight Savers International Foundation, launched a major DR awareness and screening programme in a suburban area of Karachi, Pakistan. The objectives were to create awareness among the population of DR with emphasis on early detection through utilisation of available services. Prior to the launching of awareness programme, diabetes and DR-related knowledge, attitude and practices (KAP) of local population were assessed. This paper presents the observations about the KAP of diabetics living in Chanesar Goth which is a suburban area of Karachi.

### Objectives for the knowledge, attitude and practice study

- To assess the knowledge of respondents on diabetes and DR
- To measure and verify the prevailing attitudes, beliefs and misconceptions in the population about diabetic treatment
- To assess the practices of the population with diabetes and DR
- To assess knowledge about the availability of treatment facility in their neighbourhood
- To assess the attitude of the community towards the use of these facilities.

## METHODOLOGY

Prevention and control of diabetes-related blindness is planned to be carried out in one union council of Jamshed town during a 3-year project for the screening of diabetes and DR among the screened diabetics. Preproject KAP survey was conducted to explore the existing KAP of the diabetics aged 30 or above living in this community.

### Study design

This is a cross-sectional exploratory study in one union council (Chanesar Goth, Jamshed town). The selection of locality was purposive i.e., chosen to represent a low-income community where data collection was convenient. Within the locality, houses were selected by systematic sampling, for example, every 10<sup>th</sup> house was selected.

### Data collection

Data were collected by trained lady health workers during their home visits of the families. Patients' interviews were conducted with the help of questionnaire and responses were recorded on the questionnaires. The responses in most cases were open ended and later categorised according to themes and purpose for asking specific questions.

### Data collection tool

To assess the level of awareness about diabetes and diabetes-related eyes problems, the following five questions were asked:

1. What diseases are common these days?
2. Have you ever heard about sugar (diabetes)?
3. Do you have any idea what effects sugar has on body?
4. On which part of the body, the impact of sugar is greater?
5. What do you know about diabetes-related eye problems?
6. What do you know about the treatment of diabetes-related eye problems?

To explore attitudes towards diabetes and diabetes-related eye problems, agreement of particular statements was explored.

7. 'Diabetes is preventable'
8. 'Diabetes is treatable'
9. 'Diabetes is caused by eating too much sugar'
10. 'Person with diabetes is more prone to eye problems'
11. 'Person with diabetes should get his/her eyes checked at least once in a year'

To explore practices, the following questions were asked:

12. If you have diabetes, when (and how) did you come to know that you have diabetes?
13. If you have diabetes, how did you come to know that you have diabetes?
14. From whom you are getting treatment?
15. How do you treat diabetes?
16. Since having diabetes, how many times have you got your eyes checked?
17. What do you know about diabetes-related eye problem?
18. Sharing diabetes-related experiences

19. Where do you think information about ‘diabetes-related eye-lens-problem’ is available?
20. What advice would you give to your diabetic relative?
21. How do you help your diabetic relative?
22. Would you suggest the diabetic to get eyes checked frequently?
23. Do you think there is anything that they should do and they are not doing?
24. What treatment does your diabetic patient gets?

## RESULTS

### Characteristics of the patients

The sample consisted of 59 (31.6%) males and 128 (68.4%) females. Age ranged from 20 to 85 years for females and 26 to 80 years for males. The mean age of males and females was 56 years and 49 years, respectively. The duration of diabetes ranged from <1 to 51 years for females and <1 to 40 years for males. The mean duration of diabetes for females and males was 6.8 years and 8.34 years, respectively.

Fifty-four percentage of the patients had any diabetic in their family.

### Patients’ awareness about diabetes and diabetic retinopathy

Nearly all (96.3%) but surprisingly not 100% of the patients mentioned that they had heard about diabetes.

Patients’ awareness about diabetes and DR was assessed by finding their identification of diabetes as a common disease, effects of diabetes on body and eyes and treatment options for diabetes-related eye problems. The details of responses received to such questions are summarised in Table 1. Majority of males (77%) and females (81%) were aware that diabetes is a common disease. Only a small proportion of patients (9%) mentioned the effect on eye sight as an effect of diabetes. However, when it was directly asked that what effect diabetes has on eyesight, a vast majority (around 70%) mentioned short-sightedness as an effect. When the same question was asked as ‘what do you know about diabetes-related eye problem?’, only 6% mentioned short-sightedness. Only 25% considered eyes to be the main area of body affected by diabetes whereas a higher proportion considered kidney (34%) and legs as the main area of body affected by diabetes. Frequency of correct answers to question about treatment of diabetes-related eye disease was relatively low (24% male, 20% female). Frequency of at least one correct answer to the above questions was higher among females for most of the questions.

### Duration of Diabetes and gender-related difference in awareness about diabetes and diabetic retinopathy

Responses to the above-mentioned questions were categorised as correct, partially correct and irrelevant or wrong. The percentage of patients who gave at least one correct answer to a particular question is depicted in Figure 1. Patients who

gave at least one correct answer were titled as having good awareness and others as having poor awareness. Level of awareness was compared between younger and older groups and male and females. Chi-square test was performed to estimate statistical significance of differences. The proportion of patients having good awareness was significantly higher among females (53.1%) as compared to males (35.8%,  $P < 0.019$ ) [Figure 2]. The proportion of patients having good awareness was significantly higher among those who had diabetes for 10 or more years (60%) as compared to those who had diabetes for shorter duration (42%,  $P < 0.026$ ) [Figure 3].

### Patients’ attitudes towards diabetes and diabetic retinopathy

#### Views about diabetes and related eye problems

Only half of the patients had a firm belief that diabetes is preventable and about one-third had belief that diabetes is treatable. Nearly two-thirds were sure that diabetes is caused by eating too much sugar and a vast majority (>80%) had

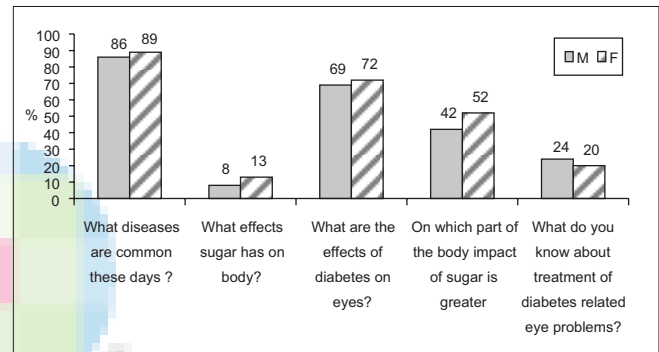


Figure 1: Percentage of males and females who gave at least one correct answer to various questions

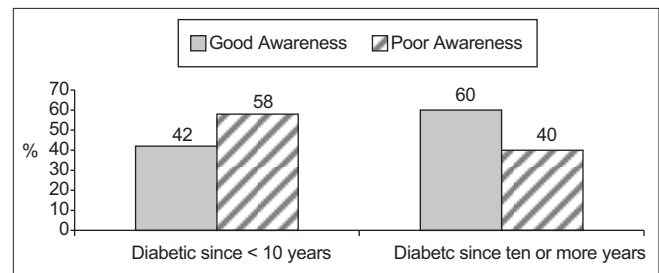


Figure 2: Level of awareness according to the duration of diabetes ( $P = 0.026$ )

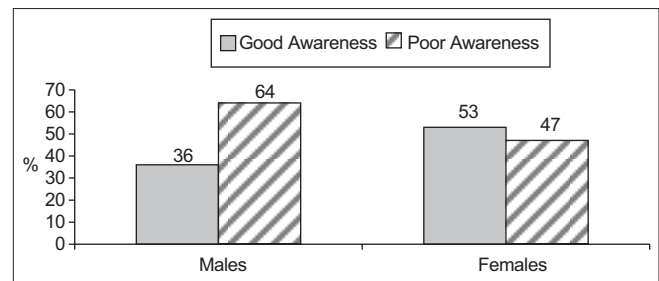
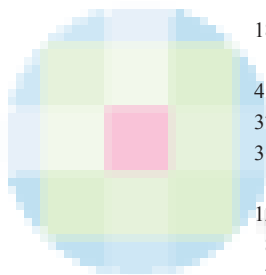


Figure 3: Level of awareness according to gender ( $P = 0.019$ )

**Table 1: Respondents' answers to question related to knowledge**

	Sex		Total, n (%)
	Female, n (%)	Male, n (%)	
What diseases are common these days?			
Diabetes	99 (77.3)	48 (81.4)	147 (78.6)
Blood pressure	74 (57.8)	33 (55.9)	107 (57.2)
Heart diseases	30 (23.4)	19 (32.2)	49 (26.2)
Jaundice	28 (21.9)	7 (11.9)	35 (18.7)
Tuberculosis	24 (18.8)	4 (6.8)	28 (15.0)
Fever/headache	19 (14.8)	8 (13.6)	27 (14.4)
Hepatitis	12 (9.4)	9 (15.3)	21 (11.2)
Diarrhoea	11 (8.6)	8 (13.6)	19 (10.2)
Do you have any idea what effects sugar has on body?			
Weakness	40 (31)	21 (36)	61 (33)
Urine problem	23 (18)	13 (22)	36 (19)
Rheumatism	12 (9)	10 (17)	22 (12)
Acidity	13 (10)	8 (14)	21 (11)
Short sight	10 (8)	7 (12)	17 (9)
Skin diseases	8 (6)	4 (7)	12 (6)
Kidney problem	5 (4)	4 (7)	9 (5)
Laziness	6 (5)	4 (7)	10 (5)
What are the effects of diabetes on eyes?			
Short sightedness	89 (70)	43 (73)	132 (71)
Blindness	1 (1)	0	1 (1)
Cataract	18 (14)	10 (17)	28 (15)
On which part of the body, the impact of sugar is greater?			
Kidney	41 (32)	22 (37)	63 (34)
Legs	37 (29)	19 (32)	56 (30)
Eyes	31 (24)	15 (25)	46 (25)
What do you know about diabetes-related eye problems?			
Cataract	13 (12)	7 (12)	20 (14)
Blindness	8 (7)	1 (2)	9 (7)
Short-sightedness	7 (7)	3 (5)	10 (6)
Blurred vision	2 (2)	3 (5)	5 (3)
Eye lens problem	2 (2)	2 (4)	4 (3)
Eye problem	3 (2)	2 (4)	4 (3)
Watery eyes	1 (1)	0	1 (1)
What do you know about the treatment of diabetes-related eye problems?			
Doctor can tell	9 (7)	4 (7)	13 (8)
Eye test needed	5 (5)	3 (5)	8 (6)
Eye specialist	3 (2)	2 (3)	5 (3)
Treatment needed if eye sight problem occurs	1 (1)	0	1 (1)
Treatment is difficult	1 (1)	1 (2)	2 (1)
Medicine needed	0	1 (2)	1 (1)
Laser	1 (1)	0	1 (1)
Getting treatment	1 (1)	0	1 (1)



no doubt that people with diabetes are more prone to eye problems and should get his/her eyes checked at least once in a year [Table 2].

**Patients' behaviour and practices regarding diabetes and diabetic retinopathy**

Those who responded about the time of knowing about their diabetes (i.e., 13%), the period mentioned ranged from 1 to 30 years. Most of the patients came to know about their diabetes through medical checkup done for a variety of reasons.

Other reasons that led to diagnosis were urine problem and weakness [Table 3].

One hundred and sixty-three patients (87%, female, 88%, male) reported that they were getting some form of treatment for diabetes. Amongst those getting treatment, all the men and most of the women (97%) were getting treatment from a doctor. Other got treatment either from a traditional physician called 'hakeem' or both from 'hakeem' and doctor [Table 3].

Most of the patients reported (71%) treating their diabetes with medicine and around one-third by sugar-free diet. A vast majority (71%) have had their eyes checked at least once since having diabetes. Seventy-four percentage of patients (70% females and 81% males) reported having shared their diabetes-related experiences with their friends and family. About 53% (55% females and 49% males) had some ideas about place from where information about ‘diabetes-related eye-lens-problem’ is available. Amongst those who had any ideas, majority (around 90%) thought that information is available in the hospital and a small proportion (10%) considered that the information is available with the doctor [Table 3].

### Association of knowledge and attitude with practices

Patients’ eye testing practices were associated more with their attitude towards eye testing and their knowledge about the relation of eye problems to diabetes. All the patients who identified eye problems as an effect of diabetes ( $n = 18$ ) had a firm belief in need for annual eye checkups, but not all of

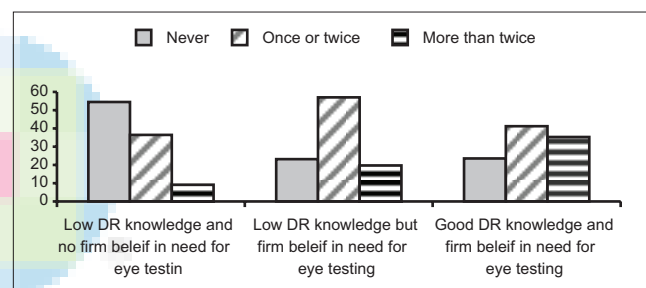
them were getting their eyes checked regularly. Four of them had never got eye test done. The frequency of eye testing was statistically significantly higher ( $P = 0.008$ ) among patients who had better awareness as well as a firm belief in need for annual eye checkups. Among those who had low awareness and lacked firm belief, 53% never got their eyes checked, while among those who had a firm belief alone or firm belief with good awareness, only 23% never got their eyes checked. The proportion of patients who had got their eyes checked more than twice since the diagnosis of diabetes was highest among patients with both knowledge and belief about eye testing (35.3%), followed by those who only had a firm belief (19.7%) and was lowest than among those who neither had belief nor knowledge (9.1%) [Figure 4].

### Patients’ advice to their diabetic relative

The most frequent advice given by the patients to their diabetic relative was to follow diet restrictions (70%). Other suggestions were to get checkup done and consult a doctor. The most frequently reported method of helping diabetic relative was advising about self-care (39%). Other methods of helping included suggestion for going to hospital and following diet restrictions.

**Table 2: Attitude towards diabetes and related eye problems (proportion of patients who completely agreed to particular statement)**

	Female, n (%)	Male, n (%)	Total, n (%)
Do you think that diabetes is preventable?	60 (46.9)	33 (55.9)	93 (49.7)
Do you think that diabetes is treatable?	50 (39.1)	20 (33.9)	70 (37.4)
Do you think that diabetes is caused by eating too much sugar?	89 (69.5)	31 (52.5)	120 (64.2)
Do you think that person with diabetes is more prone to eye problems?	104 (81.3)	50 (84.7)	154 (82.4)
Do you think that person with diabetes should get his/her eyes checked at least once in a year?	111 (86.7)	52 (88.1)	163 (87.2)



**Figure 4:** Frequency of eye testing according to the knowledge of diabetic retinopathy and belief in need for annual eye checkups ( $\chi^2 = 12.337$ ,  $P = 0.015$ )

**Table 3: Respondents’ answers to question related to practices**

	Sex		Total, n (%)
	Female, n (%)	Male, n (%)	
How patients did come to know their diabetes?			
Through medical checkup	107 (84)	52 (88)	159 (85)
Urine problem	11 (9)	8 (14)	19 (10)
Weakness	9 (7)	3 (5)	12 (6)
Practices regarding the treatment of diabetes?			
Medicine	91.0 (71.1)	43.0 (72.9)	134.0 (71.7)
Sugar-free diet	48.0 (37.5)	16.0 (27.1)	64.0 (34.2)
Injection	8.0 (6.3)	4.0 (6.8)	12.0 (6.4)
Test	1.0 (0.8)	2.0 (3.4)	3.0 (1.6)
Since having diabetes, how many times have you got your eyes checked?			
No	32 (25)	17 (29)	49 (26)
Yes	12 (9)	7 (12)	19 (10)
1	34 (27)	15 (25)	48 (26)
2	20 (16)	6 (10)	26 (14)
3	15 (12)	7 (12)	22 (12)
4 or more	5 (4)	2 (3)	7 (4)

The most frequently reported required activities that the patients thought that their diabetic relative was not doing were: 'not following diet restrictions', 'not going to a doctor' and 'not taking medicine'. Amongst all the patients, taking medicine was the treatment that was being taken by the diabetic relatives of the patients (35%).

## DISCUSSION

This study has explored the various aspects of diabetes and DR-related KAP of a selected group of diabetics living in Karachi.

This study had a small sample size and was limited to one locality; however, because of data collection by local lady health workers, there was a good assurance of validity of data. Larger studies can definitely provide more detailed information nonetheless the observations made in this study provide advocacy and guideline for awareness campaigns and further research.

As observed in another study in Turkey,<sup>[17]</sup> we also found that, as compared to knowledge about the effect of diabetes on eye health, level of awareness about the prevention and management of DR was less. We observed that patients look towards healthcare centres as their main source of information, thus employing trained diabetes educators to provide comprehensive diabetes education including education about the prevention of retinopathy can increase the level of awareness about care practices.

As noted in other studies from South Asia,<sup>[5]</sup> we also observed that women had better awareness of diabetes and DR; however, men were more likely to believe that diabetes is preventable and less likely to take alternative medicine. These gender differences in awareness and belief could be used in determining areas to be focused while educating men and women.

Level of awareness was higher among those who had diabetes for a longer duration. The association of duration of diabetes with level of awareness has been reported by others also.<sup>[17]</sup> This indicates the possibility of success for peer-support diabetes education programmes.

Educational interventions should focus on inculcating positive attitudes and firm belief in the importance of self-care and seeking appropriate and timely treatment as well as on options available in relation to the treatment of diabetes-related eye problems. Reason for lack of regular eye testing in spite of being aware of its need should be explored. It has been identified by other researchers also that the main barriers to receiving adequate screening were lack of knowledge regarding the need for ocular examination.<sup>[18]</sup>

Another area of improving self-care includes creating better awareness about diet and nutrition. It has been known since a long time that, by integrating nutritional strategies, the risk of developing DR can be reduced substantially.<sup>[19]</sup> However,

in this study, patients were mainly aware of avoiding sugar and diet restrictions and not about the role of nutritious diet.

While an earlier review about DR in developing countries concluded that the awareness was not translated into a positive practice,<sup>[6]</sup> our observation evidenced significant positive association between the level of awareness and belief and frequency of eye testing. This observation provides hope that, by providing good-quality diabetes education, we can convince patients to take better preventive care and the rates of DR-related loss could be reduced. It has been concluded by other researchers also that, although the reasons for low adherence involved social, emotional, cultural and economic factors, the key issue was the lack of awareness and knowledge of DR.<sup>[20]</sup>

## CONCLUSION

The level of awareness and belief in association between diabetes and eye problems influences patients' care practices, and investing in evidence-based culture-specific diabetes education programmes could control the rates of DR-related blindness. Women and people with the experience of managing their own diabetes are good within community resources that can be utilised for developing local diabetes education programmes.

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## Conflicts of interest

There are no conflicts of interest.

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