

# Diabetes and Diabetic Retinopathy: Knowledge, Attitude, Practice (KAP) among Diabetic Patients in A Tertiary Eye Care Centre

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## ABSTRACT

**Introduction:** Diabetic retinopathy is becoming an increasingly important cause of visual impairment in India. Many diabetic patients who come to our centre have undetected, advanced diabetic retinopathy. If diabetic retinopathy had been detected earlier in these patients, irreversible visual impairment could have been prevented.

**Aim:** To document Knowledge, Attitude and Practice (KAP) patterns of diabetic patients regarding diabetes and diabetic retinopathy, to determine association between them, and to identify barriers to compliance with follow up and treatment regimes.

**Materials and Methods:** This was a hospital-based, cross-sectional study, conducted at the Department of Ophthalmology at Christian Medical College, Vellore, Tamil Nadu, India, over a six-month period from June 2013 to November 2013. Two hundred and eighty eight diabetic patients, who fulfilled the eligibility criteria, were included in the study. KAP of patients was assessed using a 45-point, verbally administered questionnaire. Patients were placed in different categories, such as, 'good/poor' knowledge, 'positive/negative' attitude and 'good/poor' practice. Data were analysed using Chi-square test and binary

logistic regression, as appropriate. The proportion of patients with 'good/poor' knowledge, 'positive/negative' attitude and 'good/poor' practice, and the association between KAP were studied. Barriers to compliance with follow up/treatment regimes were identified.

**Results:** Out of the 288 patients in the study, 42% had good knowledge about diabetes, but only 4.5% had good knowledge about retinopathy. Good knowledge about diabetes was significantly associated with positive attitude towards diabetes and good practice patterns regarding retinopathy; awareness of retinopathy was also significantly associated with good practice. A total of 61.1% of patients did not have periodic eye examination; most common barrier identified was lack of awareness about the necessity for this (38.5%).

**Conclusion:** Good knowledge about the disease was significantly associated with positive attitude and good practice patterns. Knowledge about diabetic retinopathy was poor among the patients in our study. Lack of awareness concerning the need for screening for retinopathy was a major barrier to regular screening. There is an urgent need to educate diabetic patients about this potentially blinding complication of diabetes.

**Keywords:** Blindness, Diabetes mellitus, Visual impairment

## INTRODUCTION

Diabetes has been termed one of the largest health emergencies of the 21<sup>st</sup> century [1]. In 2015, there were 415 million people with diabetes living in the world. This number is expected to increase to 642 million in 2040. With an overall global prevalence of 34.6% [2], diabetic retinopathy accounts for 4.8% of the cases of blindness throughout the world [3]. Diabetic retinopathy is a leading cause of new-onset blindness in populations of working age in industrialized countries, and an increasingly frequent cause of blindness in middle income countries.

India is already home to 69.2 million people with diabetes, and it is estimated that 123.5 million people will have diabetes in India by the year 2040 [1]. Diabetic retinopathy is becoming an increasingly important cause of visual impairment in India due to the increase in the diabetic population, as all diabetics will develop some form of retinopathy within 20 years of onset of the disease [4]. The reported prevalence of diabetic retinopathy from various studies done in India ranges from 7.3% to 25% [5-10].

We find that many diabetic patients who come to the outpatient clinics and inpatient wards of our hospital, a tertiary eye care centre in South India, have advanced diabetic retinopathy, and have not undergone screening, treatment or follow up for retinopathy according to the standard recommendations. If diabetic retinopathy

had been detected in these patients at an early stage, irreversible visual impairment could have been prevented. Several investigators from India as well as from other parts of the globe, have expressed similar concerns, regarding the lacunae in knowledge about the disease, and 'less than effective' screening methods for early detection of this silently blinding disease [11-13].

We conducted this study to document the Knowledge, Attitude and Practice (KAP) patterns of diabetic patients regarding diabetes and diabetic retinopathy, to determine the association between KAP patterns, and to identify barriers to compliance with follow up and treatment regimes for diabetes and diabetic retinopathy.

## MATERIALS AND METHODS

This was a hospital-based, cross-sectional study, which included diabetic patients on treatment with oral hypoglycaemic agents or insulin, in the outpatient clinics or inpatient wards of our hospital, a tertiary eye care centre in South India. The study was conducted from June 2013 to November 2013. Children (age less than 18 years), patients who did not speak or understand English, Tamil or Hindi, mentally challenged patients who were unable to give informed consent or respond meaningfully to the questions administered, patients with hazy media in both eyes precluding adequate visualization of the fundus for grading of diabetic retinopathy, and

patients with retinal vein occlusion or ocular ischemic syndrome in one or both eyes were excluded from the study.

Diabetic patients, who met the eligibility criteria of the study, were enrolled after obtaining informed consent. The study was started after obtaining the approval of the Institutional Review Board. Data were collected using a clinical research form. The socioeconomic and educational status of each patient was graded using Modified Kuppuswamy classification [14]. The presence and level of diabetic retinopathy were assessed by dilated fundus examination using slit lamp binocular indirect ophthalmoscopy. Diabetic retinopathy was classified according to the Modified Airlie House Classification (Early Treatment Diabetic Retinopathy Study) [15].

Data regarding KAP patterns, and barriers to compliance with follow up and treatment regimes for diabetes and diabetic retinopathy were collected using a 45-point, verbally administered questionnaire in the clinical research form [Appendix-1].

The questionnaire was formulated by the investigators after conducting a thorough literature search. To minimize bias due to 'leading' questions, most of the questions in the knowledge and practice sections of the questionnaire were constructed as open-ended questions. The questions in the attitude section were framed as statements, and the patient was asked whether he or she agreed or disagreed with the statement, or was undecided. The questionnaire was reviewed for adequacy, appropriateness and relevance of content by five subject matter experts. It was then translated to Tamil and Hindi. To ensure uniformity of administration, the questionnaire was administered in all cases by one of two investigators; both investigators were trained to administer the questionnaire in a standard manner. A pilot study was then conducted to familiarize the investigators with the questionnaire, and to identify practical problems with its administration. The questionnaire was further refined, based on the lessons learned from the pilot study. A final 45-point questionnaire was thus formulated, with 13 questions in the knowledge section, 8 questions in the attitude section, and 24 questions in the practice section. This questionnaire (in English, Tamil or Hindi) was verbally administered to the patient to assess his or her knowledge, attitude and practice patterns regarding diabetes and diabetic retinopathy.

The answers to the questions were scored. The total score achieved by the patient in each section was calculated. On the basis of the number of correct responses to 'must know' questions in the knowledge section of the questionnaire and 'must do' questions in the practice section, each patient in the study was categorized as having 'good' or 'poor' knowledge, and 'good' or 'poor' practice pattern. In the attitude section of the questionnaire, the responses best indicative of a positive attitude were scored, and the patients were categorized as having 'positive' or 'negative' attitude.

## STATISTICAL ANALYSIS

Data were analysed using SPSS, Version 22.0. Chi-square/Fisher-exact test was done to check the association for categorical variables. Binary logistic regression was done with statistically significant variables at 25% level of significance for univariate analysis, and 5% for multivariate analysis. Duration of diabetes, gender, educational status, socio-economic status and presence of diabetic retinopathy were identified as potential confounders. Information regarding these potential confounders was meticulously documented using the clinical research form. Potential confounders were addressed by using multiple logistic regression analysis.

## RESULTS

Two hundred and eighty eight patients who fulfilled the eligibility criteria were recruited into the study. The demographic characteristics and retinopathy status of the study population are given in [Table/Fig-1]. Of the 288 patients recruited, 121 (42.0%) had good knowledge of diabetes, while only 84 (29.2%) had positive attitude towards

Factor	Number (percentage)
<b>Age (years)</b>	
25-35	11 (3.82)
36-45	46 (15.97)
46-55	99 (34.38)
56-65	96 (33.33)
66-75	30 (10.42)
76-85	5 (1.74)
86-95	1 (0.34)
<b>Gender</b>	
Male	160 (56)
Female	128 (44)
<b>Place of residence</b>	
Tamil Nadu	215 (75)
Other states	73 (25)
<b>Educational qualification (Modified Kuppuswamy Classification) [3]</b>	
Profession or honours	2 (0.7)
Graduate or postgraduate	48 (16.7)
Intermediate or post high school diploma	23 (8.0)
High school certificate	57 (19.8)
Middle school certificate	40 (13.9)
Primary school certificate	51 (17.7)
Illiterate	67 (23.3)
<b>Socioeconomic status (Modified Kuppuswamy Classification) [3]</b>	
Upper	7 (2.4)
Upper middle	29 (10.1)
Lower middle	90 (31.2)
Upper lower	125 (43.4)
Lower	37 (12.8)
<b>Retinopathy status</b>	
Presence of retinopathy	108 (37)
Absence of retinopathy	180 (63)
Mild- Moderate NPDR	58 (53.7)
Severe NPDR- PDR	50 (46.3)

**[Table/Fig-1]:** Demographic characteristics and retinopathy status of the study population.

diabetes; 158 patients (54.9%) were found to have good practice patterns [Table/Fig-2].

Among the 288 patients in our study, 207 (71.9%) were 'aware' that eyes could be affected by diabetes, but only 49 patients (17.01%) were 'aware' of diabetic retinopathy as an ocular complication of diabetes. The questions to assess knowledge of diabetic retinopathy were administered only to the 49 patients who were aware of retinopathy. Among these 49 patients, five had not had an eye check up prior to the study visit, and therefore, had never come into contact with an eye doctor or an eye health care system. As the questions to assess attitude towards diabetic retinopathy were designed and follow up guidelines prescribed by their eye doctor, that could not be administered to these five patients. Therefore, attitude towards diabetic retinopathy was assessed only in 44 patients in the study. All the patients in the study (n=288) were administered questions regarding practice patterns, based on their retinopathy status [Table/Fig-3]. Patients with good knowledge of retinopathy constituted only 4.51% of the total number of patients in the study (n=288), while positive attitude towards retinopathy was found in 9.38% of the total number of patients in the study.

Among the 121 patients with good knowledge of diabetes, only 12 (9.9%) had good knowledge of retinopathy; 79 out of these 121 patients (65.3%) were not even aware of diabetic retinopathy.

Parameters	Good	Poor
Knowledge	121 (42.0%)	167 (58.0%)
Practice	158 (54.9%)	130 (45.1%)
	<b>Positive</b>	<b>Negative</b>
Attitude	84 (29.2%)	204 (70.8%)

[Table/Fig-2]: KAP regarding diabetes (n=288).

Parameters	Good	Poor
Knowledge (n=49)	13 (26.5%)	36 (73.5%)
Attitude (n=44)	27 (61.4%)	17 (38.6%)
Practice (n=288)	60 (20.8%)	228 (79.2%)

[Table/Fig-3]: KAP regarding diabetic retinopathy.

Factors	Attitude DM		Adjusted analysis	
	Positive n(%)	Negative n(%)	OR (95%CI)	p-value
<b>Education</b>				0.88
Higher education	55 (42.31)	75 (57.69)	1.06 (0.53-2.08)	
Lower education	29 (18.35)	129 (81.65)		
<b>Socio-economic status</b>				<0.01
Upper/ Upper middle/ Lower middle	59 (46.83)	67 (53.17)	3.31 (1.73-6.35)	
Upper lower/ Lower	25 (15.43)	137 (84.57)		
<b>Duration</b>				0.62
>5.5 years	50 (34.7)	94 (65.3)	1.16 (0.65-2.08)	
<5.5 years	34 (23.6)	110 (76.4)		
<b>Gender</b>				0.64
Male	55 (34.4)	105 (65.6)	1.15 (0.63-2.10)	
Female	29 (22.7)	99 (77.3)		
<b>Knowledge DM</b>				<0.01
Good	60 (49.6)	61 (50.4)	4.15 (2.21-7.82)	
Poor	24 (14.4)	143 (85.6)		

[Table/Fig-4]: Association of knowledge of Diabetes Mellitus (DM) with attitude towards diabetes mellitus (Multivariate logistic regression).

Factors	Practice DR		Adjusted analysis	
	Good n (%)	Poor n (%)	OR (95%CI)	p-value
<b>Education</b>				0.50
Higher education	37 (28.46)	93 (71.54)	1.26 (0.64-2.48)	
Lower education	23 (14.56)	135 (85.44)		
<b>Retinopathy</b>				0.01
Present	14 (12.96)	94 (87.03)	0.34 (0.17-0.68)	
Absent	46 (25.56)	134 (74.44)		
<b>Knowledge DM</b>				<0.01
Good	40 (33.1)	81 (66.9)	3.95 (1.97-7.94)	
Poor	20 (12)	147 (88)		

[Table/Fig-5]: Association of knowledge of diabetes with practice regarding Diabetic Retinopathy (DR) (Multivariate logistic regression).

To identify the source of information about diabetic retinopathy, we asked those patients who were aware of retinopathy (n=49) about how they first came to know that diabetes could cause retinopathy. Doctors (both ophthalmologists and physicians) constituted the most important source of information (35 patients, 71.4%). Media, books, family and friends were the other sources of information for the patients in the study.

The odds of patients with good knowledge of diabetes having positive attitude towards diabetes were 4.2 (2.21-7.82) times those of patients with poor knowledge of diabetes, after adjusting for educational status, socio-economic status, duration of diabetes and gender, with p <0.01 [Table/Fig-4]. Similarly, the odds of patients in the higher socio-economic status group having positive attitude towards diabetes were 3.3 (1.73-6.35) times those of patients in the lower socio-economic status group, after adjusting for educational status, duration of diabetes, gender and knowledge of diabetes, with p <0.01 [Table/Fig-4].

Factors	Practice DR		Adjusted analysis	
	Good n (%)	Poor n (%)	OR (95%CI)	p-value
<b>Education</b>				0.17
Higher education	37 (28.46)	93 (71.54)	1.61 (0.82-3.18)	
Lower education	23 (14.56)	135 (85.44)		
<b>Retinopathy</b>				0.01
Present	14 (12.96)	94 (87.03)	0.30 (0.14-0.66)	
Absent	46 (25.56)	134 (74.44)		
<b>Awareness DR</b>				0.01
Aware	21 (42.9)	28 (57.1)	3.58 (1.67-7.69)	
Unaware	34 (21.5)	124 (78.5)		

[Table/Fig-6]: Association of awareness of Diabetic Retinopathy (DR) with practice regarding diabetic retinopathy (Multivariate logistic regression).

Barriers	Frequency
Cannot afford	7
No family support	3
Do not think it is important	9
Did not find time	16
Checking sugar levels with glucometer at home is sufficient	6
Did not know that regular follow up is necessary	3
Any other	7

[Table/Fig-7]: Diabetes - Barriers to compliance with regular follow up.

Barriers	Frequency
Poor family support	3
Long distance to hospital	9
Financial problems	11
Physically unwell	3
Did not know that periodic eye check up should be done	111
Had good vision; did not feel the need for check up	85
Any other	3

[Table/Fig-8]: Barriers to compliance with periodic eye check up.

The odds of patients with good knowledge of diabetes having good practice patterns regarding retinopathy were 3.9 (1.97-7.94) times those of patients with poor knowledge of diabetes, after adjusting for educational and retinopathy status, with p<0.01[Table/Fig-5].

The odds of patients with awareness of retinopathy having good practice patterns regarding retinopathy were 3.6 (1.67-7.69) times those of patients who were unaware of retinopathy, after adjusting for educational and retinopathy status, with p=0.01[Table/Fig-6].

Out of the 288 patients in the study, 41 (14.2%) were not compliant with regular follow up with their physicians for the management of diabetes. The barriers to compliance are listed in [Table/Fig-7].

The most common reasons that the patients gave for poor compliance were 'did not find time' and 'do not think it is important'.

One hundred and seventy six patients (61.1%) in the study did not go for a periodic eye examination.

The barriers to compliance are given in [Table/Fig-8]. The most common barrier identified was the fact that the patients did not know that they should go for a periodic eye check up (111 patients, 38.54%). The second most common reason cited was that the patients did not feel the necessity for an eye check up as they had good vision.

## DISCUSSION

This was a hospital-based, cross-sectional study, which documented the KAP patterns of diabetic patients regarding diabetes and diabetic retinopathy. The study included 215 patients from Tamil Nadu and 73 patients from different parts of India. One hundred and

twenty one patients (42%) in the study had good knowledge about diabetes. This is similar to the results of other studies conducted in South India by Hussain R et al., and Rani PK et al., who reported good knowledge in 40.7% and 49.9% respectively, of the subjects of their studies [16,17]. However, in another study done in South India by Babu N et al., only 28% of the population was 'aware' of diabetes [4]. We found that only 84 patients (29.2%) in our study had a positive attitude towards diabetes. In contrast to this, Hussain R et al., found a positive attitude towards diabetes in 53.8% of the diabetic patients in their study [16]. Good practice patterns with respect to diabetes were found in 158 patients (54.9%). In comparison, 57.6% and 48.45% respectively, of the subjects in the studies by Hussain R et al., and Rani PK et al. were reported to have good practice patterns [16,17].

The questions to assess knowledge of diabetic retinopathy in our study were designed to assess both awareness and knowledge of diabetic retinopathy. Just having heard about the disease is awareness, while having understood the disease is knowledge [18]. Among the KAP studies done on diabetes and diabetic retinopathy in India, Mahesh G et al., have also documented both knowledge and awareness of diabetic retinopathy [18]. Koshy J et al., and Dandona R et al., have reported awareness of diabetic retinopathy [19,20], while Hussain R et al., and Rani PK et al. have documented knowledge of diabetes and retinopathy [16,17]. In the study published by Babu N et al., the terms 'awareness' and 'knowledge' have been used interchangeably [4].

We felt that it was important to differentiate between awareness and knowledge of diabetic retinopathy. While awareness of the disease is important, having good knowledge of the disease is probably more important in influencing attitude and practice patterns regarding the disease. We therefore, documented both awareness and knowledge of diabetic retinopathy among our patients, and looked for the association of both awareness and knowledge of diabetic retinopathy with attitude and practice patterns regarding retinopathy.

Among the 288 patients in our study, 207 (71.9%) were aware that eyes could be affected by diabetes, but only 49 patients (17.01%) were aware of diabetic retinopathy as an ocular complication of diabetes. Babu N et al., and Dandona R et al., have also reported poor awareness of diabetic retinopathy (7% and 27% respectively) among the subjects in their studies done in South India [4,20]. However, in the study done in South India by Mahesh G et al., 36.31% felt that they were well educated about retinopathy, while 30.9% of the patients in the study done in North India by Koshy J et al., knew that diabetes could lead to retinal disease [18,19]. In our study, only thirteen out of the 49 patients (26.5%), who were aware of retinopathy, had good knowledge of retinopathy. This constituted only 4.51% of the total number of patients in the study. Das T et al., also reported poor knowledge of retinopathy among the patients in their study conducted in Eastern India [21]. In contrast to this, 37.1% had 'knowledge' of retinopathy in the study by Rani PK et al., [17].

Even among the 121 patients who had good knowledge about diabetes, only 12 (9.9%) had good knowledge of diabetic retinopathy. We also found that 65.29% of the 121 patients who had good knowledge of diabetes were not even aware of retinopathy. In spite of the fact that diabetic retinopathy is the most serious, potentially blinding complication of diabetes in the eye, the majority of the patients were completely unaware of the existence of such an entity. This indicates the poor state of patient education measures regarding diabetic retinopathy, as it was the same subgroup of patients who had good knowledge of diabetes.

Strategies to educate diabetic patients about this potentially blinding complication of diabetes should be evolved. This would have to be done at all points of patient contact with the health care system. General practitioners, physicians, endocrinologists, ophthalmologists and

optometrists should be made aware of the sad lack of knowledge about diabetic retinopathy among diabetic patients, and should all be involved in the planning and implementation of both hospital-based and community-based patient education strategies.

Health education measures should be implemented at primary, secondary and tertiary levels of health care. Health education through mass media, pamphlets, posters and diabetic retinopathy screening camps on special days like World Diabetes Day and World Sight Day would help in creating awareness of diabetic retinopathy, especially among people in the lower educational and socio-economic status groups.

We found a statistically significant association between good knowledge of diabetes and positive attitude towards diabetes. The odds of patients with good knowledge of diabetes having positive attitude towards diabetes were 4.2 (2.21-7.82) times those of patients with poor knowledge of diabetes, after adjusting for educational status, socio-economic status, duration of diabetes and gender, with  $p < 0.01$ . This shows that, as the knowledge that a patient has about his or her disease increases, the attitude towards the disease also becomes positive. Therefore, imparting knowledge about the disease to the patient is of paramount importance, and it is the duty of the treating physician to ensure that this is done. This is especially important in the Indian health care scenario. The average Indian patient may not get a lot of information about diabetes from books or mass media, and the doctor is often the only individual in the health care system that the patient comes into contact with on a regular basis. Data from our study also corroborate this surmise. Doctors (both ophthalmologists and physicians) constituted the most important source of information (35 patients, 71.4%) for the patients who were aware of retinopathy in our study.

We found that awareness of diabetic retinopathy ( $p=0.01$ ) and good knowledge of diabetes ( $p<0.01$ ) were significantly associated with good practice patterns regarding diabetic retinopathy. The odds of patients with awareness of retinopathy having good practice patterns regarding retinopathy were 3.6 (1.67-7.69) times those of patients who were unaware of retinopathy, after adjusting for educational and retinopathy status, with  $p=0.01$ . Mahesh G et al., also found a statistically significant association between awareness of retinopathy and good practice regarding retinopathy [18]. The odds of patients with good knowledge of diabetes having good practice patterns regarding retinopathy were 3.9 (1.97-7.94) times those of patients with poor knowledge of diabetes, after adjusting for educational and retinopathy status, with  $p<0.01$ . Knowledge about the disease and its complications is a powerful tool, which helps patients in developing good practice patterns that will ultimately help them in keeping the disease under good control.

Out of the 288 patients in our study, 41 (14.24%) were not compliant with regular follow up visits for the management of diabetes, with only three patients (1.04%) saying that they did not know that regular follow up for diabetes was necessary. However, 176 patients (61.1%) in the study did not go for a periodic eye examination; the most common barrier identified was the fact that the patients did not know that they should go for a periodic eye check-up (111 patients, 38.54%). Most diabetic patients seem to know that regular follow up is necessary for their systemic disease; however, the majority do not know that they need to have a periodic eye check up to look for ocular complications of diabetes. The facts that diabetic retinopathy is a silently blinding disease, and 'good vision' is not an indicator of the status of the retina in a diabetic patient need to be emphasized to the patient. It is the duty of the ophthalmologists to educate diabetic patients in their clinics about these basic facts.

## LIMITATION

Most of the questions in the questionnaire were constructed as open-ended questions to minimize bias due to 'leading' questions. However, we could not avoid a few closed-ended questions. These

may have been 'leading,' which may have resulted in falsely high scores in certain sections of the questionnaire. Among the 288 patients in our study, only 49 were aware of diabetic retinopathy. The questions to assess knowledge of diabetic retinopathy were administered only to these 49 patients. After excluding another five patients who had not had an eye check up prior to the study visit, the questions to assess attitude towards retinopathy were administered only to 44 patients in the study. Many of the associations between KAP of retinopathy may not have been statistically significant due to the small sample size for analysis of KAP of retinopathy.

## CONCLUSION

Visual impairment and blindness due to diabetic retinopathy are almost entirely preventable with early detection and timely treatment. Awareness and knowledge about diabetic retinopathy were very poor among the patients in our study. Lack of knowledge concerning the need for screening for diabetic retinopathy was found to be a major barrier to compliance with regular screening. Good knowledge about diabetes was significantly associated with positive attitude towards diabetes and good practice patterns regarding retinopathy. Awareness of diabetic retinopathy was significantly associated with good practice patterns regarding retinopathy. Therefore, there is an urgent need to evolve strategies to educate diabetic patients about this potentially blinding complication of diabetes.

## APPENDIX-1

### Questionnaire

#### Key

The questionnaire will be administered to the patient by one of two investigators, who have been trained to administer the questionnaire in a standard manner. The questionnaire will not be shown to the patient. The patient will not be given the answer options or prompted regarding the options.

- Some questions do not have a right answer and hence, are left unmarked.
- Correct answers in knowledge and practice sections are highlighted in green.
- In the Attitude section, the responses best indicative of positive attitude are highlighted in green.
- Some questions in knowledge and practice sections may have more than one correct answer.
- Each correct response is given a score of one.

#### Knowledge

**Preliminary statement:** You will be asked a few questions to test your knowledge about diabetes and its complications. These questions are asked purely to test your knowledge about diabetes. They are not aimed at finding out what you actually practice. (Do not mention anything about diabetic retinopathy at this point.)

#### 1. What are the tests done to diagnose diabetes (to find out if a person is diabetic)?

1. Blood tests
2. Urine tests
3. Any other (specify)

#### 2. How can you keep diabetes under control?

1. Medication
2. Diet
3. Exercise
4. Weight reduction
5. Going for regular check up
6. Do not know
7. Any other (specify)

#### 3. Once diabetes is diagnosed, how long should diet control/ treatment be continued?

1. Till the sugar levels get under control
2. Lifelong
3. Any other (specify)

#### 4. Which parts of the body are affected by diabetes?

1. Kidney
2. Feet
3. Eyes
4. Nerves
5. Heart

6. Do not know
7. Any other (specify)

If option 3 in Question 4 has been circled (diabetes can affect the eyes), proceed to question 5; if not, skip to Attitude section.

#### 5. What problems can patients with diabetes have in the eye?

1. Cataract
2. Retinopathy (damage to retina/nerve at the back of the eye due to diabetes)
3. Infections in the eye
4. Defective vision
5. Do not know
6. Any other (specify)

#### Total score for knowledge regarding diabetes: 17

Good knowledge: score of 9 and above

Poor knowledge: score of less than 9

If option 2 in Question 5 has been circled (patients with diabetes can have retinopathy, i.e., damage to retina/nerve at the back of the eye due to diabetes), proceed to question 6; if not, skip to Attitude section.

#### 6. How did you first find out that diabetes can cause retinopathy (damage to the retina/ nerve at the back of the eye due to diabetes)?

1. Informed by physician at local hospital
2. Informed by ophthalmologist at local hospital
3. Informed by optometrist at local optical dispensary
4. Informed by physician at CMCH
5. Informed by ophthalmologist at Eye hospital, CMCH
6. Got information from media, books (specify)
7. Got information from family/ friends
8. Any other (specify)

#### 7. How many years after diagnosis of diabetes did you find out that diabetes can cause retinopathy?

1. At the time of diagnosis
2. Any other (specify time interval in years since diagnosis of diabetes)

#### 8. Can diabetic retinopathy cause blindness?

1. Yes
2. No
3. Do not know

#### 9. What are the factors that cause progression/worsening of diabetic retinopathy?

1. Poor control of diabetes
2. Hypertension
3. Nephropathy
4. Anaemia
5. Do not know
6. Any other (specify)

#### 10. What are the treatment options available for diabetic retinopathy?

1. Spectacles
2. Laser
3. Surgery
4. Injection into the eye
5. Do not know
6. Any other (specify)

#### 11. Can a person with diabetic retinopathy have normal vision?

1. Yes
2. No
3. Do not know

#### 12. Should patients with diabetes have a periodic/regular dilated eye check up to look for diabetic retinopathy (examination of the back of the eye after instilling dilating eye drops to look for changes in the retina due to diabetes)?

1. Yes > proceed to Question 13
2. No > skip to Attitude section
3. Do not know > skip to Attitude section

#### 13. How often should patients with diabetes who have no diabetic retinopathy have a dilated eye check up?

1. Once in 6 months
2. Once a year
3. Once in 2 years
4. Once in 5 years
5. Do not know
6. Any other (specify)

#### Total score for knowledge regarding diabetic retinopathy: 11

Good knowledge: score of 5 and above

Poor knowledge: score of less than 5

### Attitude

**Preliminary statement:** These are some statements regarding your thoughts, feelings and opinions regarding diabetes and its complications. These statements are not designed to test your knowledge regarding the disease or to find out what you actually practice/ do. Please indicate whether you 'agree' or 'disagree' with these statements, or whether you are 'undecided'.

1. Eating sweets occasionally is quite alright.

1. Agree 2. Undecided 3. Disagree

2. Even if I forget to take my medicines on some days, it is alright.

1. Agree 2. Undecided 3. Disagree

3. I should go for regular check up as my doctor says, even if my sugars are under good control.

1. Agree 2. Undecided 3. Disagree

4. Even if I am not able to exercise as much as my doctor tells me to, it is alright because I get enough exercise while I am doing my daily activities.

1. Agree 2. Undecided 3. Disagree

Total score for patient's attitude towards diabetes: 4

Positive attitude: score of 3 and above

Negative attitude: score of less than 3

5. Even though eye doctors say that diabetic patients should have regular eye check up, if my diabetes is under good control, there is no real need for this.

1. Agree 2. Undecided 3. Disagree

6. I should go for regular eye check up as the eye doctor tells me even if I don't have any problem in my eyes.

1. Agree 2. Undecided 3. Disagree

For patients who have 'never heard of diabetic retinopathy', skip to Practice section; otherwise proceed to Question 7.

7. Eye doctors say that good control of diabetes prevents problems due to diabetic retinopathy; but it is not possible to keep sugars under perfect control as they say.

1. Agree 2. Undecided 3. Disagree

8. No matter what I do, my vision may become poor/may not improve. So what is the use of doing all this treatment/follow up for diabetic retinopathy?

1. Agree 2. Undecided 3. Disagree

Total score for patient's attitude towards diabetic retinopathy: 4

Positive attitude: score of 3 and above

Negative attitude: score of less than 3

### Practice

**Preliminary statement:** You will be asked a few questions to find out what you actually do regarding treatment and control of diabetes and its complications.

1. Do you take medicines for diabetes as advised by the physician?

1. Yes

2. No

2. Do you follow the diet schedule as advised by the physician?

1. Yes

2. No

3. Do you take regular exercise?

1. Yes (specify type: walking/ jogging/ cycling/ work out in gym/ any other; duration per day; how often in a week)

**Recommended exercise regime:** Regular moderate-intensity physical activity; 30-60 min daily, 5-7 days/week

2. No

4. Is your diabetes under control at present? (verify later with AC, PC, HbA1C levels)

1. Yes 2. No 3. Do not know

5. Do you go for regular follow up as advised by your physician?

1. Yes > skip to Question 7

2. No > proceed to Question 6

6. Why do you not go for regular follow up as advised by your physician?

1. Cannot afford

2. No family support

3. Do not think it is important

4. Did not find time

5. Checking sugar levels with glucometer at home is sufficient

6. Did not know that regular follow up is necessary

7. Any other (specify)

Total score for patient's practice pattern regarding diabetes: 5

Good practice pattern: score of 4 and above

Poor practice pattern: score of less than 4

7. Has anyone told you that you need to go for a periodic/regular eye

### check up?

1. Yes (specify when: time interval in years since diagnosis of diabetes, and who, and where)

2. No

8. Do you have a periodic/ regular eye check up?

1. Yes > proceed to Question 9

2. No > skip to Question 13

9. To whom do you go for your periodic/ regular eye check up?

1. Physician at local hospital

2. Optometrist at local optical dispensary

3. Ophthalmologist at local hospital

4. Ophthalmologist at Eye hospital, CMCH

5. Eye camps

6. Any other (specify)

10. Why do you go for a periodic/regular eye check up?

1. Follow up/treatment of diabetic retinopathy

2. To check power of glasses

3. Been instructed to have periodic eye check up, but do not know reason

4. Any other (specify)

11. How often do you go for a dilated eye check up?

(Key: correct option will depend on presence and level of diabetic retinopathy and treatment regime followed)

1. Once in 3 months

2. Once in 6 months

3. Once a year

4. As advised by ophthalmologist (specify)

5. Any other (specify) Score of 1 for correct answer

12. To whom do you go for your dilated eye check up?

1. Physician at local hospital

2. Optometrist at local optical dispensary

3. Ophthalmologist at local hospital

4. Ophthalmologist at Eye hospital, CMCH

5. Screening by dilated fundus photography

6. Any other (specify)

(Options 3 or 4 or 5 may be circled; score of 1 for correct practice)

> skip to Question 14

13. Why have you not gone for a periodic/ regular eye check up?

1. Do not trust the local doctor

2. Poor family support

3. Long distance from hospital (in hours of travel by the means of transport usually utilized by the patient)

4. Financial problems

5. Physically unwell (specify details of physical ailment)

6. Did not know that periodic eye check up should be done

7. Had good vision; so did not feel need for check up

8. Any other (specify)

14. Why did you come to the eye hospital today?

1. For a general eye check up

2. To check power of glasses

3. Defective vision

4. To have tests/treatment for diabetic retinopathy

5. Any other (specify)

If option 4 in Question 14 has been circled (patient came to have tests/ treatment for diabetic retinopathy), proceed to Question 15; if not, skip to Question 16.

15. Who referred you for tests/treatment for diabetic retinopathy to this hospital?

1. Physician at CMCH

2. Referred from eye camp conducted by CMCH Eye hospital

3. Physician at local hospital

4. Ophthalmologist at local hospital

5. Optometrist at local optical dispensary

6. Came on my own

7. Any other (specify)

16. How long after diagnosis of diabetes did you have your first dilated eye check up?

1. Within 3 months of diagnosis of diabetes

2. > 3 months to 1 year after diagnosis of diabetes

3. > 1 year to 5 years after diagnosis of diabetes

4. > 5 years to 10 years after diagnosis of diabetes

5. > 10 years to 15 years after diagnosis of diabetes

6. > 15 years to 20 years after diagnosis of diabetes
7. > 20 years after diagnosis of diabetes (specify number of years)
8. Any other (specify time interval in years since diagnosis of diabetes)
- 17. Why did you go for your first dilated eye check up?**
  1. Was referred by physician at local hospital (specify reason for referral)
  2. Was referred by optometrist at local optical dispensary (specify reason for referral)
  3. Was referred by physician at CMCH (specify reason for referral)
  4. Was referred from eye camp conducted by CMCH eye hospital
  5. Went on my own because I knew that diabetes can cause retinopathy
  6. Went on my own because I had problems in the eye (specify nature of problem)
  7. Any other (specify)

In a patient who has no diabetic retinopathy,

Total score for patient's practice pattern regarding diabetic retinopathy: 5

Good practice pattern: score of 4 and above

Poor practice pattern: score of less than 4

If patient has diabetic retinopathy, proceed to Question 18; otherwise, Questionnaire ends.

**18. When were you first diagnosed to have diabetic retinopathy?**

(Specify answer in years since diagnosis of diabetic retinopathy)

**19. Were you advised to undergo treatment for diabetic retinopathy?**

1. Yes (specify treatment) > proceed to Question 20
2. No > Questionnaire ends

In a patient who has diabetic retinopathy not requiring treatment,

Total score for patient's practice pattern regarding diabetic retinopathy: 5

Good practice pattern: score of 4 and above

Poor practice pattern: score of less than 4

**20. How long after diagnosis of diabetic retinopathy were you advised to undergo treatment for diabetic retinopathy?**

1. As soon as diagnosis of diabetic retinopathy was made (inference: delayed diagnosis)
2. Any other (specify time interval in years since diagnosis of diabetic retinopathy)

In a patient who has diabetic retinopathy requiring treatment, but recently diagnosed – within one month of diagnosis (not enough time for commencement of treatment) - Questionnaire ends

Total score for patient's practice pattern regarding diabetic retinopathy: 5

Good practice pattern: score of 4 and above

Poor practice pattern: score of less than 4

In a patient who has diabetic retinopathy requiring treatment (more than one month after diagnosis of retinopathy), proceed to Question 21.

**21. Have you taken treatment (laser/ intravitreal injections/ vitrectomy) for diabetic retinopathy as advised by ophthalmologist?**

1. Yes > skip to Question 23      2. No > proceed to Question 22

**22. Why have you not taken treatment for diabetic retinopathy?**

1. Was physically unwell (specify details of physical ailment)
2. Could not afford treatment
3. Did not have family support
4. Did not have any problems with vision
5. Centre with facilities for treatment is too far from home (in hours of travel by the means of transport usually utilized by the patient)
6. Could not stay on for the required period of time for treatment
7. Wanted to complete treatment for systemic disease before taking treatment for diabetic retinopathy
8. Was told that treatment could not be started without control of systemic disease
9. Any other (specify)

**23. Have you been going for follow up visits (after taking prescribed treatment for diabetic retinopathy) as advised by ophthalmologist?**

1. Yes > Questionnaire ends      2. No > proceed to Question 24

**24. Why have you not been going for follow up visits?**

1. Was physically unwell (specify details of physical ailment)
2. Could not afford to go for frequent follow up visits
3. Did not have family support
4. Did not have any problems with vision after treatment
5. Centre is too far to go for frequent follow up visits as instructed (in hours of travel by the means of transport usually utilized by the patient)
6. Was not instructed to go for follow up after treatment
7. Did not find time
8. Did not think it was important
9. Any other (specify)

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