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ORIGINAL RESEARCH

Late Diagnosis of Sight-Threatening Diabetic Retinopathy: Knowledge, Attitudes, and Practices in Western India

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ABSTRACT

Purpose: To identify the reasons for delayed presentation among patients with sight-threatening diabetic retinopathy (STDR) and to assess their knowledge, attitude, and practice (KAP) patterns in the context of diabetes mellitus (DM) and diabetic retinopathy (DR). **Methods:** Single-center, cross-sectional, questionnaire-based KAP survey. All consecutive cases of STDR who presented to our tertiary eye care facility from August 2023 to July 2023were recruited. The KAP scoring survey tool was incorporated into the questionnaire to help evaluate and represent the patient's disease. **Results:** 200 patients with STDR were enrolled in the study. The mean age of patients was 54 ± 9.3 years; 128 patients were between 41 and 60 years; 152 patients had DM for more than 5 years. The STDR changes were more prevalent in patients with an educational qualification of high school or less (n = 168). Sixty patients had been informed regarding the detrimental effect of diabetes on the eyes and were recommended to consult an ophthalmologist by the treating physician. Of these, 28 patients were educated about retinal changes due to diabetes. One hundred patients in our study had good knowledge about DM; 15 patients had good knowledge about DR. For patients not compliant with follow-ups with the treating physician, the use of "home glucometers for self-monitoring/SMBG" (n = 70) was the most prevalent reason. The main reason for poor compliance for undergoing a dilated fundus examination by the ophthalmologist was "Had good vision, so didn't feel the need" in 180 patients. **Conclusion:** The absence of visual complaints, lack of knowledge, and failure to undergo a dilated fundus examination in the past were prevalent risk factors in patients presenting with STDR. Knowledge and practice regarding DR were poor among the patients with STDR. The treating physicians and ophthalmologists were the most common sources for patient education.

Keywords: Diabetes mellitus, Diabetic retinopathy, Dilated fundus examination, Knowledge-attitude-practice, Patient compliance, Sight-threatening diabetic retinopathy, Tertiary eye care.

INTRODUCTION

Diabetes mellitus (DM) remains a major global concern due to its increasing prevalence and association with high morbidity. India is home to 69.2 million diabetics, a figure projected to rise to 123.5 million by 2040, positioning India as the diabetic capital of the world in the near future. [1, 2]

Diabetic retinopathy (DR) is the leading cause of visual disability in diabetics, resulting from progressive damage to the retinal microvasculature. The reported prevalence of DR in India ranges between 17.6% and 28.2%, with central India reporting a prevalence of 12.3%. [3-5]

Raising awareness about DR among diabetics is crucial to ensure prompt diagnosis, prevent vision loss due to sight-threatening retinopathy, and reduce the eventual financial burden. Maintaining good metabolic control and undergoing periodic screening are essential in preventing sight-threatening DR (STDR). However, several investigators have expressed concerns about the prevalent knowledge gap among patients and their treating physicians regarding the importance and implications of screening methods for early detection of DR. [6-11]

In the absence of a state-run screening program for DR and its related complications, early identification of DR relies solely on the health-seeking behavior of the population and their knowledge and attitude toward the disease.Limited resources and the unequal distribution of health care facilities, with the majority clustered around urban areas, combined with higher illiteracy rates, deprive the rural population of basic health care services. Insight into the prevalent knowledge-attitude-practice (KAP) parameters

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regarding retinopathy awareness among diabetic patients is still insufficient. While many cross-sectional studies have evaluated the KAP scores among DR patients to understand patient compliance issues better, the factors responsible for delayed first presentations in patients with STDR remain unclear. Understanding the existing limitations from the patient's perspective can aid in strengthening strategies and improving existing programs to decrease the burden of DR-related blindness. [12-16]

The aim of our study was to identify the reasons for delayed presentation among patients with STDR and to assess their knowledge, attitude, and practice patterns in the context of DM and DR.

METHODS

We conducted a single-center, cross-sectional, questionnaire-based Knowledge, Attitude, and Practice (KAP) survey to understand the prevalent reasons for the delayed presentation of newly diagnosed cases of sight-threatening diabetic retinopathy (STDR). The study population included all consecutive cases of STDR who presented to our tertiary eye care facility from August 2023 to July 2023. The KAP scoring survey tool was incorporated into the questionnaire to evaluate and represent the patients' understanding of diabetic retinopathy (DR) and diabetes mellitus (DM). The study was approved by our institutional review board.

The study protocol was approved by the Institutional Review Board and Informed consent was obtained from all participants before enrolling them in the study. All treatment-naive patients presenting with STDR during the study period were included. Patients were classified as having STDR if they had one or more of the following in the worst affected eye: proliferative diabetic retinopathy (PDR), vitreous hemorrhage, tractional retinal detachment, and neovascular glaucoma. Those with visual loss due to other ocular comorbidities like advanced glaucoma, mature cataract, or other retinal pathologies like macular degeneration, retinal vein occlusion, and anterior ischemic optic neuropathy were excluded.A KAP scoring questionnaire was provided to all cases diagnosed with STDR. Following the administration of the questionnaire, patients were counseled to undergo mandatory patient education and awareness sessions, where they were informed about the need for metabolic control and the systemic implications of DM.Best-corrected visual acuity (BCVA) was assessed using a Snellen chart, with values converted to LogMAR for statistical analysis. The clinical grading of retinopathy for enrolled patients was performed by two vitreo-retina specialists. Evaluation for systemic control included fasting blood sugar (FBS), post-prandial blood sugar (PPBS), glycosylated hemoglobin (HbA1c), and hemoglobin levels.The questionnaire used by existing studies on DR-related KAP scoring in Indian populations was reviewed and compiled to formulate a customized questionnaire. The compiled questionnaire was tested and validated through a pilot study on ten subjects. The questionnaire was translated into Gujarati and Hindi, the major dialect used in the region. The questions were read to the patient by one designated vitreo-retina fellow in the presence of the patient's attendant, and the patient's responses were noted for each question. [17, 18]

To understand the distribution of scoring across the patients' knowledge, attitude, and practice patterns, the questionnaire was divided into three segments. Section 1 consisted of 14 questions regarding the demography and metabolic status of the patients. Section 2 had 10 questions to assess the role of physicians and general ophthalmologists in spreading awareness about DR. Section 3 had 46 questions to test the knowledge, attitude, and practice patterns about DM and DR in these patients. Each segment of the questionnaire consisted of two sets of questions: 1) those used for scoring KAP (italicized) and 2) those used to determine the causes of poor KAP responses. Correct responses were decided based on questionnaires from parent studies . Answers were then scored according to the option chosen and tallied for each section. Based on their responses, patients were categorized as having good or poor knowledge, good or poor practices, and positive or negative attitudes toward DM and DR. A correct "attitude" response was defined as an opinion that corresponded with the pre-decided correct responses, while an incorrect "attitude" response did not. Scores were then tallied for individual sections of DM and DR, and the patient was deemed to have a "positive attitude" if their overall score favored the correct responses, and a "negative attitude" if the overall score did not.At the end of the questionnaire, the diagnosis and visual status of the patient were noted. The worst eye from each patient was chosen for statistical analysis.

Statistical Analysis

In India, the prevalence of DR is reported to be 12.3%.[5] With a prevalence rate of 12.3% and a precision error of 5%, the sample size of 166 was calculated. Data were analyzed using SPSS (IBM SPSS Statistics for Windows, Version 29.0, IBM Corp).

RESULTS

Two hundred patients with STDR were enrolled in the study. The mean age of patients was 54 ± 9.3 years. The demographic details of the patients are listed in Table 1. The majority of the patients (n = 128) were between the ages of 41 and 60 years. A total of 152 patients had DM for more than 5 years. Details regarding the duration of DM and treatment taken are demonstrated in Table 2. Among the 200 patients, 168had an educational qualification of high school or less. In our cohort, 90 patients had PDR with macular edema, 30 patients had PDR without diabetic macular edema, 60 patientshad vitreous hemorrhage, 20

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patients had tractional retinal detachment, and 4 patients had neovascular glaucoma.

The mean BCVA of the patients was LogMAR 1.89 ± 1.41 (Range: LogMAR 0.00 to LogMAR 2.8). A total of 110 patients had a BCVA between PL and 3/60, 70 patients had a BCVA between 4/60 and 6/18, and 20 patients had a BCVA better than 6/18. The mean FBS was 192.47 ± 91.65 mg/dl. The mean PPBS was 258 ± 79.00 mg/dl. Mean HbA1c was 9.13 ± 2.61. Eighty-nine patients also suffered from coexisting hypertension.

Role of Physicians and Ophthalmologists

All patients had been to physicians for the treatment of DM. Sixty patients had been informed about the detrimental effect of diabetes on the eyes and were recommended to consult an ophthalmologist by the treating physician. Of these 60 patients, 28were educated about retinal changes due to diabetes. None of the patients had undergone dilated fundus examination for screening and grading of background retinopathy by the physician at the diagnosis of DM.A total of 136 patients had visited a general ophthalmologist at some point after the diagnosis of DM. Among them, 60 patients were informed about the effect of diabetes on sight by the concerned ophthalmologist. Out of these 60 patients, 30 were informed about the importance of regular eye check-ups in DM. Out of the 136 patients, 40 patients underwent a dilated fundus examination. Fifty patients underwent a fundus examination only (37%) after a recent onset of deterioration of vision (within 2 months of visiting us).

Knowledge Attainment, Patient Attitude, and Practice (KAP) Pattern Regarding DM and DR

There were 100 patients in our study who had good knowledge about DM, whereas only 15 had good knowledge specifically about DR. In our cohort, 156 patients knew that kidneys are affected in DM, and 125 were aware that eyes, in general, are affected in DM. One hundred eighty patients had not gone for regular eye check-ups. Of the 125 patients who received some form of patient education regarding DR, only 42 were aware/recalled the need for regular eye check-ups. Of the 125 patients who were aware of DR, the physicians were the source of information and patient education in 55cases, ophthalmologists were responsible in 40 cases , 25 patients got the information through family and friends, while 5 patients gathered this information through self-reading/learning via available literature in the media and books.

A positive attitude toward DM and DR was present in 120 and 110 patients, respectively. Good practice for DM was present in 80patients, while good practice for DR was present in 15 patients. In our study, 180 patients were aware that life-long treatment is required for DM, 12 did not know how long the treatment should be taken, and 8 believed that medications should be taken until the sugar levels were controlled.

While evaluating treatment compliance practices for DM, our study found that 170 patients took diabetic medications regularly, 50 exercised, 120 followed dietary control, and 80 went for regular physician follow-ups.

For patients not compliant with follow-ups with the treating physician, the use of “home glucometers for self-monitoring” (n = 70) was the most prevalent reason. Other reasons for poor follow-up with the treating physician were financial restraints (n = 30), lazy attitude (n = 10), lack of family support (n = 10), unawareness and lack of insight into the importance of follow-up (n = 10), and other preoccupations in 5 patients.

The reason for poor compliance in undergoing examination by the ophthalmologist was “Had good vision, so didn’t feel the need” in 180 patients, “Lazy attitude” in 10 patients, “Financial problem” in 4 patients, “Long distance from the hospital” in 4 patients, and “Poor family support” in 2 patients. A total of 140 patients stated that they were having their first dilated eye examination on the day they visited our hospital.

Table 1: Distribution of Cases According to Demography

Factor	Number (Percentage)
Age	
21-40 years	20 (10.0%)
41-60 years	130 (65.0%)
>61 years	50 (25.0%)
Gender	
Male	140 (70.0%)
Female	60 (30.0%)
Residence	
Rural	96 (48.0%)
Urban	104 (52.0%)
Literacy	
Illiterate	32 (16.0%)
Primary school	8 (4.0%)
Middle school	46 (23.0%)

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High school	82 (41.0%)
Graduate	20 (10.0%)
Postgraduate	10 (5.0%)
Professional degree	2 (1.0%)
Socioeconomic status (modified Kuppuswamy scale)	
Upper	6 (3.0%)
Upper middle	48 (24.0%)
Lower middle	70 (35.0%)
Upper lower	72 (36.0%)
Lower	4 (2.0%)

Table 2: Distribution of Cases According to the Duration of Diabetes Mellitus and Treatment Taken

Duration	**Number of Patients**	**Percentage**
>10 years	118	59.0%
6-10 years	36	18.0%
<5 years	46	23.0%
Treatment Taken	**Number of Patients**	**Percentage**
Oral hypoglycemics	156	78.0%
Insulin injection	14	7.0%
Combination of oral hypoglycemics and insulin injection	30	15.0%

DISCUSSION

This hospital-based study aimed to investigate factors contributing to delayed presentation among 200 patients diagnosed with sight-threatening diabetic retinopathy (STDR), emphasizing the critical role of early detection and management in improving outcomes.

The demographic distribution revealed a predominant age group of 41 to 60 years with a notable male predominance, reflecting a typical profile of diabetic patients at risk for developing STDR. There was no significant disparity noted between urban and rural populations, underscoring the widespread prevalence of diabetes-related complications across different socioeconomic backgrounds. A substantial proportion of patients had been living with diabetes mellitus (DM) for more than five years, with a majority having educational qualifications at high school level or lower, factors which are known to influence health literacy and disease management.Duration of diabetes and poor metabolic control are established risk factors for the progression of DR, which was also noted in our study.[13] We observed that a majority of patients had educational qualifications less than high school and belonged to lower socioeconomic groups, which aligns with findings from previous KAP studies that highlight education as a major determinant for knowledge acquisition and application.[19,20] This lack of education necessitates repeated counseling to reinforce the importance and significance of the information provided. Similar results were found by Hamzeh et al.[12], where most patients had low socioeconomic status, low educational levels, and a quarter were illiterate.

Disease-specific knowledge can be transferred to patients through medical literature, treating physicians, and public educational programs disseminated via mass media. Despite all patients being under treatment, only a third were counseled about DR, and only half of those were informed about the need for ophthalmic examinations. About two-thirds consulted an ophthalmologist, but only a third underwent a dilated fundus examination, highlighting a failure in primary prevention and screening.

A significant observation was that while many patients had good knowledge of DM, only 7.6% had good knowledge of DR, emphasizing the need for better public awareness programs. Physicians and ophthalmologists were the primary sources of DR awareness, but media and books contributed minimally, indicating an area for improvement in public information dissemination. Positive attitudes toward DM were common, but good practice patterns for DR were lacking. Most patients managed DM well but did not prioritize ophthalmic screenings, often consulting an ophthalmologist only when vision deteriorated. This misconception needs to be addressed through patient education to ensure early detection of retinopathy changes before STDR develops.

Previous KAP studies have shown a strong concordance between patients' knowledge and their practice patterns regarding disease management.[14,15,16,17,21] We recommend a three-step approach for diabetic patients: "screen all, educate all, motivate all," to achieve primary prevention goals and modify disease progression. Nonmydriatic cameras for fundus imaging can be efficiently used by physicians for early DR screening.[22] Health education should be disseminated at all healthcare levels through mass media, pamphlets, and posters, especially targeting lower educational and socioeconomic groups. Paramedical personnel can also help spread awareness about DR.

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Proliferative diabetic retinopathy (PDR) emerged as the most common primary cause of STDR among our cohort, with patients presenting at a mean visual acuity of LogMAR 1.89 ± 1.41, indicative of significant visual impairment at diagnosis. The study highlighted that primary care physicians were the primary source of information regarding the ocular manifestations of diabetes in one-third of cases, with only half of these patients being informed about the secondary retinal changes associated with DM. Despite the initial education received from physicians, a substantial number of patients did not undergo timely ophthalmic evaluations, with only a third undergoing dilated fundus examinations following DM diagnosis.

Knowledge, attitudes, and practices (KAP) regarding DM and diabetic retinopathy (DR) varied widely among the patient population. While 50% of patients demonstrated good knowledge of DM, fewer than 10% possessed adequate understanding of DR, highlighting a significant gap in awareness specifically related to diabetic eye disease. This disparity underscores the critical need for comprehensive patient education initiatives focusing on the early signs and management of DR.

The study also noted that while a positive attitude toward DM management was prevalent among more than half of the patients, there was a lack of corresponding good practice patterns concerning DR, particularly in terms of regular ophthalmic screenings. This discrepancy suggests a need for targeted interventions to enhance patient adherence to recommended screening protocols, irrespective of perceived visual acuity.

The findings underscored the impact of socioeconomic factors and educational levels on disease awareness and management. Patients with lower educational qualifications and socioeconomic status demonstrated poorer knowledge retention and adherence to recommended practices, reinforcing the need for tailored educational strategies aimed at improving health literacy and promoting proactive healthcare behaviors.

The study's limitations included recall bias among patients and the inherent challenges associated with questionnaire-based research methodologies. Efforts were made to mitigate these biases through a comprehensive questionnaire validation process and careful consideration of question order.

CONCLUSION

In conclusion, this study highlights significant deficiencies in knowledge and practice related to diabetic retinopathy among patients presenting with sight-threatening complications. Enhancing patient education through collaborative efforts between physicians, ophthalmologists, and community health initiatives is crucial for improving early detection and management of DR. Implementing routine dilated fundus examinations for all diabetic patients, regardless of visual acuity, is essential for detecting and managing retinopathy at its earliest stages.A comprehensive approach incorporating technological advancements in screening tools and targeted health education campaigns is necessary to bridge existing gaps in patient awareness and healthcare delivery. By addressing these challenges, healthcare providers can effectively reduce the burden of diabetic retinopathy and improve visual outcomes for diabetic patients across diverse socioeconomic backgrounds.This study underscores the urgency of integrated healthcare strategies that encompass screening, education, and patient motivation to achieve effective primary prevention and management of diabetic retinopathy in clinical practice.

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