Awareness and knowledge of diabetic retinopathy in diabetics and non-diabetics: A descriptive cross-sectional study

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Background and Aims. Early diagnosis and management of the ever-increasing global consequences of diabetes is of concern to all nations. The populations of developing countries in particular, account for about 75% of the estimated total number of those afflicted. The Middle East and North Africa Region have around 35.4 (24.3–47.4) million diabetics with a prevalence of around 10.5% in the Middle East. A high proportion of these are undiagnosed. The aim of this study was to assess the awareness of and knowledge about the ocular impacts of diabetes as diabetic retinopathy (DR) in Jordanians by comparing those with and those without diabetes.

Methods. In this cross-sectional study, diabetic and non-diabetic patients attending different clinics at the National Center for Diabetes, Endocrinology and Genetics (NCDEG) were interviewed face-to-face using a questionnaire, to assess the level of knowledge about diabetic retinopathy (DR). The questionnaire was assessed beforehand by ophthalmologists from the School of Medicine, the University of Jordan, in Amman

Results. A total of 214 subjects participated in this study (108 males:106 females). The mean age was 58.2 ± 10.6 years; (28 to 88 years) ~70% were diabetic. More than 98% were aware that diabetes can have ocular consequences. Only 17.3% however, had an adequate knowledge of DR. Around 40% did not know the treatment options although 75.7% of the diabetics carried out regular blood sugar checks in <6 months, and 73.4% had their last eye checkups in <one year. The main source of information about DR was the media (33.6%) though healthcare personnel made a minor contribution to raising the knowledge level (5.6%).

Conclusions. The participants in this study had good awareness of DR but their knowledge of this ocular condition and treatment options is limited. Health-education programs and awareness campaigns should be initiated at health and eye care centers. Enrichment of social media and internet websites with evidence-based information by medical professionals are promising options for upgrading knowledge about this common global cause of blindness.

Awareness and Knowledge about Diabetic Retinopathy among Diabetic and non-Diabetic Subjects

Background:
Diabetes mellitus (DM) is a common metabolic and systemic disease globally.
About three quarters of the estimated total number of affected patients are from developing countries.
The Middle East and North Africa Region have around 35.4 (24.3–47.4) million diabetic patients.
The prevalence of DM is around 10.5% in the Middle East.
Diabetic retinopathy (DR) affects more than 60% of Jordanian diabetic patients.

Aim:
To assess the awareness and knowledge levels of DR among diabetic and non-diabetic Jordanian subjects and the factors that may affect it.

Methodology:
A cross-sectional study that included diabetic and non-diabetic subjects attending different clinics of the National Center for Diabetes, Endocrinology and Genetics was performed.
Participants were interviewed face-to-face to collect their socio-demographic data and information about DR.

Main outcomes:
More than 98% of subjects were aware that diabetes can affect eyes but, only 17.3% had a high knowledge level of DR.
The main source of information about DR was media while healthcare professionals had a minor contribution in educating people about DR (5.6%).

1. **The awareness level of DR among Jordanians is high but knowledge level is average.**
2. **More health-education programs and campaigns should be activated at health and eye care services.**

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INTRODUCTION

Diabetes mellitus (DM) is a common metabolic and systemic disease globally. The populations of developing countries account for 75% of the estimated total number of DM patients worldwide[1]. The Middle East and North Africa Region have around 35.4 (24.3–47.4) million diabetic patients with a prevalence of around 10.5% in the Middle East[1]. A high proportion (more than 40.6%) of diabetic patients in the Middle East and North Africa Region are undiagnosed[2]. The prevalence of DM in Jordan is 13.1% according to the WHO website[3]. Previous studies found that DM patients who were unaware of DM complications had a four-fold higher risk of DM complications compared with those who were aware[4]. As a complication of DM, DR is a major health problem that can result in visual impairment and can hugely influence the life style of the affected individual. It affects more than 60% of Jordanian diabetic patients[5]. This figure is relatively high compared with international studies. Due to the systemic complications that DM causes in different organs and cell types of affected individuals, it is a global burden on healthcare systems[6]. The characteristic chronic hyperglycemia is the main cause of these complications in diabetic patients such as, cardiovascular disease, neuropathy, nephropathy, and diabetic retinopathy (DR) (ref.[7-8]). More than one third of diabetic patients have signs of DR; it is a key cause of blindness in middle-aged and elderly people[9]. Loss of vision interferes with daily life and constitutes an economical burden[10]. The size of the burden was estimated to range from $3 trillion in 2010 to about $3.6 trillion in 2020 (ref.[10]).

Regular eye checkup is fundamental for early diagnosis and efficient treatment[11,12]. To encourage this routine practice, diabetic patients, as well as other community members, need to be aware of and knowledgeable about these complications. Even though the awareness of DR is an essential factor that encourages patients to go for regular eye examination, DR awareness among diabetic patients and their families still needs attention[13]. Other barriers may also impede routine checkups, such as the absence of insurance coverage and the unaffordable cost of treatment.

This study aims to assess the awareness and knowledge of diabetic patients as well as non-diabetics about DR. Unique to most studies in the Jordanian community, this study is the first to include non-diabetics in the assessment of DR awareness. Unaffected subjects may have an essential role in raising awareness about DM. Additionally, they are prone to DM in the future due to the high prevalence of this disease in Jordan as well as in other communities. Moreover, many of them might be taking care of a diabetic relative, which is a common finding in our social communities.

MATERIALS AND METHODS

Study design and subject recruitment

In this descriptive, cross-sectional study, an ad hoc sample of non-diabetics and diabetics with or without DR was recruited to assess the level of awareness and knowledge about DR. Study participants were recruited from adults who attended different clinics at the National Center of Diabetes, Endocrinology and Genetics (NCDEG), Amman, Jordan. The main focus was diabetic patients; non-diabetic participants were recruited for comparison. Healthy subjects were attending the NCDEG with their relatives or visiting the center for other reasons. The NCDEG Institutional Review Board (IRB) approved this study, approval number 10/671/9/MS. Subjects were asked to participate voluntarily, and they signed an informed consent before starting the interview by field researchers and after explaining study aims to them. Anonymity was maintained throughout the study and manuscript preparation.

Surveys and interviews

This study was approved by the NCDEG and was conducted in accordance with the latest Declaration of Helsinki on Ethical Principles for Medical Research Involving Humans. Participants were interviewed face-to-face by field researchers at the outpatient clinics of NCDEG. DR awareness was defined as knowing that DM can affect the eyes, whereas DR knowledge indicated the level of understanding of this diabetic complication. The questionnaire content was assessed by ophthalmologists from the School of Medicine, the University of Jordan, Amman, Jordan. Before actual data collection, we conducted a pilot study that involved responses from 30 subjects to validate our questionnaire and to assess its ability to collect accurate and meaningful data. Accordingly, minor changes were made before the final version was used on a large scale. Data from the pilot test were not included in the final analysis. Questions were both open-ended and close-ended adopted from published manuscripts on awareness and knowledge about DR in other populations[14-16]. The questionnaire included two sections; the first section handled demographic data such as sex, age, marital status, and nationality; and socio-economic data including occupation, and educational level. The second part included questions about retinopathy and diabetes including disease duration, effect of DM on vision, consequences, treatments, preventive measures, their habits in performing regular checkups for blood sugar and eyes and sources of information and barriers that interfere with eye screening. Subjects were interviewed and asked questions for approximately 5 min. This way, illiterate patients would have no problem to participate in the study. Additionally,

interviews would allow participants to answer questions based on what they know rather than guessing answers of multiple-choice questions. Survey data were collected on paper and then entered into Microsoft Excel. This manuscript is in line with the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals.

Statistical Analysis

Data were analyzed using SPSS software version 16 (IBM Corp., New York, NY, USA). Descriptive analysis including derivation of proportions, means and standard deviations was performed. Chi-square test was applied to find significant differences in categorical variables, while analysis of variance (ANOVA) was performed to assess the presence of significant variations in quantitative variables. $P<0.05$ was considered statistically significant. Blooms Taxonomy was applied to analyze the level of knowledge.

RESULTS

A total of 214 subjects were involved in this study (males 108, 50.5%; females 106, 49.5%). The male/female ratio was close to one with no significant difference based on sex, Table 1. The average age was 58.2 ± 10.6 years. The participants were grouped into three groups; diabetic with DR, diabetic without DR and healthy controls. For diabetics, the mean duration of DM was 8.2 ± 4.5 years, with a maximum of 15 years and a minimum of one year. The demographic and clinical characteristics of the participating subjects were shown in Table 1.

Table 2 presented the questions that dealt with knowledge and awareness of DR, in addition to those related to

Table 1. Demographic and Clinical Characteristics of the Study Population (n=214)

Parameter	Mean +SD or n (%)	*P*
Age	58.2±10.6	–
Sex (M:F)	108:106 (50.5:49.5)	0.891
History of DM	143 (66.8)	0.000
History of DR	52 (24.3)	0.001
Duration of diabetes	8.2±4.5	–
Diabetes treated by		0.000
– General Physician	5 (3.5)	
– Family medicine physician	2 (1.4)	
– Endocrinologist	136 (95.1)	
Family history of DM	161 (75.2)	0.000
Family history of DR	72 (33.6)	0.000

DR, diabetic retinopathy; DM, diabetes mellitus; M:F, male: female; n, number; SD, standard deviation
Qualitative data was represented as counts and (percentages)
Quantitative data was represented as mean ± standard deviation
P value less than 0.05 was considered significant

Table 2. Subjects' Awareness of Diabetic Retinopathy and Compliance to Regular Sugar and Eye Assessment

Question	Answers		
Part 1: Awareness to diabetic eye disease: (Yes/No) Questions	Yes n (%)	No n (%)	*P*
1. Do you think that diabetes can affect eyes?	210 (98.1)	4 (1.9)	0.000
2. Do you think that controlling blood sugar can help preserve your vision?	204 (95.3)	10 (4.7)	0.000
3. Do you think that diabetes can lead to blindness?	207 (96.7)	7 (3.3)	0.000
Part 2: Awareness to diabetic eye disease: Informative Questions and Compliance to Preventive measures and treatments	n (%)		*P*
1. What the treatments available for diabetic retinopathy are?			0.000
Good control of diabetes only	52 (24.3)		
Laser treatments	23 (10.7)		
Surgery	14 (6.5)		
Combination of more than one treatment	41 (19.2)		
Do not know	84 (39.3)		
2. What are the reasons that make you undergo first eye screening?			0.000
Doctor's referral	80 (37.4)		
Self-awareness	82 (38.3)		
Eye symptoms	21 (9.8)		
3. How often do you visit your doctor to check blood sugar?			0.000
≤6 months	162 (75.7)		
> 6 months or irregular	52 (24.3)		
4. When was the last time your eyes were evaluated by an ophthalmologist?			0.000
≤6 months	20 (9.3)		
7–12 months	157 (73.4)		
>1 year	13 (6.1)		
Never	24 (11.2)		

DM, diabetes mellitus; DR, diabetic retinopathy; n, number
Data was represented as counts and (percentages)
P value less than 0.05 was considered significant

compliance towards preventive measures, with the number and percentage of subjects based on their answers. The awareness of DR was defined as being able to understand that DM can affect the eyes. The level of awareness was high (98.2%) as shown in Table 2.

The level of knowledge was assessed by categorizing subjects based on the percentage of correct answers for all questions related to information about DR. Subjects who achieved less than 50% correct answers were considered with a low knowledge level, whereas those with 50–70% correct answers achieved a fair level of knowledge. Achieving more than 70% right answers was set as a threshold of high level of knowledge, Table 3.

Sex-based analysis was performed to investigate any differences in several parameters or characteristics based on sex as shown in Table S1. Several significant differences were found between males and females, Table S1.

We also compared the differences in several variables between diabetic patients in our samples versus non-diabetic participants as presented in Table 4. We found a surprisingly high and statistically significant percentage of non-diabetic subjects had a good level of knowledge about DR compared to diabetic patients, Table 4. In addition, non-diabetics had regular eye examinations every 6 months more than diabetic patients, Table 4.

The source of information about DR was also investigated and the different sources with their relative importance in proving information about DR were shown in Fig. 1.

We also evaluated habits such as monitoring blood sugar and adhering to visiting an ophthalmologist as an important factor in early detection and diagnosis of DR as shown in Table S2.

Table 3. Subjects' Level of Knowledge about DM and DR

Knowledge Level	n (%)	*P*
Low (<50% correct answers)	9 (4.2)	
Fair (50–70% correct answers)	168 (78.5)	
High (>70% correct answers)	37 (17.3)	
Total	214 (100)	0.000
Undetermined	0 (0)	

DM, diabetes mellitus; DR, diabetic retinopathy; n, number
Data was represented as counts and (percentages)
P value less than 0.05 was considered significant

In addition, we assessed whether certain factors were correlated with low level of knowledge in our sample, Table S3.

DISCUSSION

For any health issue, lack of awareness and knowledge can have negative consequences for early diagnosis and proper management. In our study, we evaluated the level of awareness and knowledge of DR in a sample of Jordanian diabetic patients and healthy controls. We defined DR awareness as knowing that DM can affect vision, while DR knowledge was related to the level of understanding of this diabetic complication. Former studies from Jordan reported that 88.2% and 98.3% of patients were aware of the effect of diabetes on the eyes[16,17]. Previous studies from other populations showed similar results, however the awareness level was higher among our subjects (98.2%). For example, around 83% of Saudi patients knew that DM could affect the eyes[18] while only 66.1% of South African subjects knew this[19]. Liu and Chen also reported that only 36.6% of subjects with DM were aware of DR as a diabetic complication that could lead to loss of vision, whereas, Wang et al study showed that 76.7% of subjects were aware of the effect of DM on the eyes[20,21]. Nonetheless, only 49.4% thought that regular eye check-up was necessary[21]. When compared to other communities, the level of awareness of DR reported by Jordanian subjects was much higher than that reported in the populations of other countries such as Turkey and Baltimore, USA (ref.[22,23]). The high level of awareness detected in our study sample might be attributed to the established national eye-healthcare program and referral guidelines for DM and DR management from primary care clinics. At the time of DM diagnosis, patients are referred for an eye examination. However, vision loss due to diabetes is common in Jordanian adults[24,25]. Another key reason behind the increased awareness to DM and DR was the level of education as shown by previous studies[16,22,26-28]. More focus should be given to raise awareness about early detection by screening and timely management of DR especially between non-diabetic individuals[29-31]. This would allow early diagnosis of DM and its complications. Successful experience from Iceland and the UK had shown this[32,33]. With the increasing number of diabetic patients, self-seeking behavior and awareness

Table 4. DR Knowledge Level, Compliance and Other Information Based on DM History

Characteristic	Diabetic (n=143)	Non-Diabetic (n=71)	*P*
Age	60.7±7.8	53.3±13.5	0.000
High knowledge level	17 (11.9)	20 (28.2)	0.011
Regular eye checkup (<6 months)	3 (2.1)	17 (23.9)	0.000
Regular blood sugar checkup	140 (97.9)	22 (31.0)	0.000

DM, diabetes mellitus; DR, diabetic retinopathy; n, number
Qualitative data was represented as counts and (percentages)
Quantitative data was represented as means+standard deviation
P value less than 0.05 was considered significant

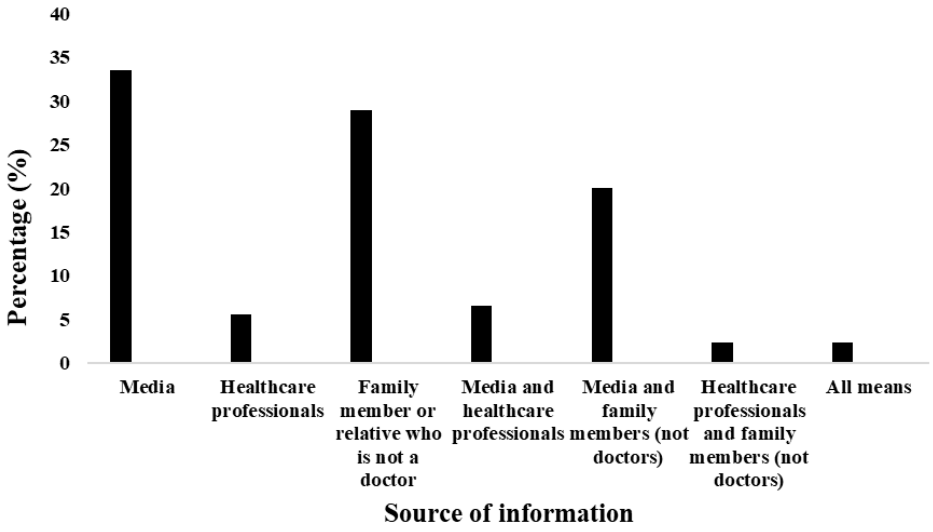

Fig. 1. Participants' Source of Information about DM and DR. Results were represented as percentages. DM, diabetes mellitus; DR, diabetic retinopathy

may play an essential role in the prevention and timely treatment of this complication.

Although the awareness level was high among our sample, knowledge level about DR was mostly intermediate with specific deficits in knowledge about the available treatment and prevention options for DR (only 19.2% knew). In our study, the compliance with performing regular examinations was high while a Swiss study reported that a significant proportion of people did not go for annual eye examinations although their awareness level of DR was high[34]. This is a very important factor in prevention and early management of DR, however, DR is the main cause of blindness among Jordanian diabetics[24,25,35]. This indicates the need for more awareness of regular blood sugar testing for an early diagnosis of DM and early detection of its consequences.

The main reasons for the first eye screening of our sample subjects was referral from doctors (38.3%) and self-awareness (37.4%), whereas it was doctor referral 74.8% in a Saudi study[15]. Although about 40% of our subjects were referred by doctors, healthcare personnel were not the main source of information about DR. This may imply that doctors just refer patients for eye screening without explaining the reason for that or discussing diabetic complications or their treatments with the patient.

Regarding the source of information among the participants in our study, the most reported source was the media (33.6%), but healthcare personnel including doctors and ophthalmologists had a minor contribution to spread knowledge among subjects. DR awareness could be obtained from different sources, but a healthcare provider's recommendation might be the key source that should be strengthened particularly, about this common disease and its complication as a major cause of vision loss in our society[36]. The reason behind their minor contribution should be further investigated. Previous Jordanian studies showed that general practitioners were the main source of knowledge about DR (ref.[16,17]). In several Saudi studies, physicians, family members and media were the main sources of information about DR (ref.[15,18]). A study from Pakistan reported that doctors were the key source of information about DR (ref.[27]).

Concerning the treatment of DR, we showed that more than 60% of subjects were able to identify one or more treatment or prevention strategy for DR, however, less than 20% knew all treatment or prevention options for DR.

To the best of our knowledge, our study is the only one that involved healthy individuals with no known history of diabetes in addition to diabetic patients. Including non-diabetic individuals is an advantage due to the role they would perform in increasing awareness and knowledge about DR in the community in addition to taking care of their diabetic parents or relatives, particularly illiterates or those with a low educational level. Additionally, their awareness of DR may encourage them to perform regular checks of blood sugar to avoid late diagnosis of DM and its complications. In this study, trained field researchers interviewed participants rather than handed them the questionnaire, hence, our data acquire more credibility in obtaining answers from subjects. This type of study would have a significant role in community health planning, particularly with regards to DM and its complications, such as DR, that are common in our society as well as the global community.

The majority of the diabetic patients in this study were being treated by endocrinologists, however, this might be because the sampling was at the NCDEG. This may indicate the need to focus more on the role of primary care providers in raising awareness and increasing knowledge level about DR as it was emphasized in a former Irish study[37]. The follow-up frequency of the majority was 7–12 months suggesting a good level of awareness of preventive measures of DR. This is also consistent with the high percentage that regularly check-up the level of blood sugar every 6 months. Additionally, the majority of the

participants in this study are covered by medical insurance that covers ophthalmology clinic services, this may improve diabetic patient compliance to visit ophthalmologists and perform eye examinations, and exclude the lack of insurance or financial reasons from acting as barriers that would interfere with receiving a regular and appropriate eye care. The limitations of this study include sample size, especially of healthy individuals. Another limitation is the generalisability of the results to subjects with DM throughout the country, however, patients and attendants to the NCDEG come from all regions of the country, and healthy controls together with patients with type 2 DM, with or without DR were included in this study. Another limitation of this study is that the questionnaire mostly led to descriptive findings and did not produce scores, however, questions related to information about DR were scored to categorize participants according to the level of knowledge. Our findings represent patients' perspectives without stakeholders' perspectives. Despite these limitations and difficulties, our study has provided a general picture of the situation and highlighted the need to encourage primary healthcare providers to play a bigger role in raising awareness and increasing knowledge about common diseases and health conditions in our society and to spread the culture of regular check-up.

CONCLUSION

DR awareness level among Jordanians is high, however, knowledge level is average. Detailed and targeted health-education programs and awareness campaigns should be performed at health and eye care services to uplift the level of knowledge about this common thief of sight among Jordanians and other populations.

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Availability of data and materials: The dataset supporting the conclusions of this article can be provided on request from the corresponding author

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SUPPLEMENTARY DATA

Table S1. DR knowledge level, compliance and other information based on sex.

Characteristic	Male	Female	*P*
Age	57.6±11.2	59.0±10.1	0.333
Diabetic patients	62 (57.4)	81 (76.4)	0.003
Family history of DM	80 (74.1)	81 (76.4)	0.692
Family history of DR	39 (36.1)	33 (31.1)	0.441
DR patients	26 (24.1)	26 (24.5)	0.938
High knowledge level	21 (19.4)	16 (15.1)	0.649
Regular eye checkup	10 (9.3)	10 (9.4)	0.718
Regular sugar checkup	74 (68.5)	88 (83.0)	0.013
DM Duration	9.5±4.9	7.3±3.9	0.003

DM, diabetes mellitus; DR, diabetic retinopathy
Qualitative data was represented as counts and (percentages)
Quantitative data was represented as means+standard deviation
P value less than 0.05 was considered significant

Table S2. Subjects' compliance of visiting an ophthalmologist.

Parameter	Choice	n (%)	*P*
Performance of eye screening	Yes	183 (85.5)	0.000
Reasons for first eye screening[a]			0.000
	– Doctor's referral	80 (43.7)	
	– Self-awareness	82 (44.8)	
	– Symptomatic eyes	21 (11.5)	
Blood sugar check frequency			0.000
	– ≤6 months	162 (75.3)	
	– > 6 months or irregular	53 (24.7)	
Last evaluation by an ophthalmologist			0.000
	– ≤6 months	20 (9.3)	
	– 7 to 12 months	158 (73.5)	
	– >1 year	13 (6.0)	
	– Never	24 (11.2)	

n, number
Data was represented as counts and (percentages)
[a] Percentages were calculated relative to the number of participants who performed eye screening
P value less than 0.05 was considered significant

Table S3. Factors that affect knowledge level about diabetic retinopathy.

Factor	n with low level of knowledge (%)	*P*
Age	63.3±11.6	0.003
Sex, M:F	5 (4.6):4 (3.8)	0.649
Diabetic patients	7 (4.9)	0.011
Family history of DM	7 (4.3)	0.275
DR patients	3 (4.2)	0.838
Family history of DR	3 (5.8)	0.810
Regular eye checkup	0 (0)	0.000
Regular sugar checkup	7 (4.3)	0.013
DM Duration	8.6±6.1	0.019

DM, diabetes mellitus; DR, diabetic retinopathy; F, female; M, male; n, number
Qualitative data was represented as counts and (percentages)
Quantitative data was represented as mean+standard deviation
P value less than 0.05 was considered significant