Journal of Diabetes & Metabolic Disorders
https://doi.org/10.1007/s40200-020-00575-4

RESEARCH ARTICLE

Diabetic retinopathy screening barriers among Palestinian primary health care patients: a qualitative study

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Received: 14 March 2020 / Accepted: 19 June 2020

Abstract

Purpose Diabetic Retinopathy (DR) screening among Palestinian diabetic patients is limited. To improve the care of our patients, we explored the barriers to DR screening with a qualitative study.

Methods Three focus groups were conducted in the northern West Bank. Patients noncompliant with DR screening were recruited from Primary Health Care clinics. Questions were adapted from similar published studies. Informed consent was obtained and group discussions were audio recorded, transcribed, and analyzed for themes by three researchers.

Results Most patients reported financial barriers including the costs of the exam and additional treatments, and transportation to the referral clinic. System related issues were the difficulty of getting appointments and long wait times due to inadequate numbers of ophthalmologists or screening facilities, and physicians failing to recommend screening. Personal concerns related to patients having other priorities, fears about the results, and the negative experiences of family members. Finally, cultural aspects included the stigma of wearing glasses and not doing a test for a condition without symptoms.

Conclusions Barriers to completing retinopathy screening are multidimensional with financial, personal, educational, health system, and cultural factors. These should be taken into consideration by policy makers in order to increase the uptake and quality of service.

Keywords Barriers · Diabetic retinopathy screening · Primary health care

Introduction

Diabetes mellitus (DM) is one of the most common chronic disorders worldwide [1]. The global prevalence of DM for adults aged over eighteen years was 8.5% in 2014 [2], and is predicted to increase to 10% by 2030 [3]. Diabetic retinopathy(DR) is the leading cause of vision loss among adults aged 20 to74 years, [4] and a preventable micro-vascular complications. [5] It is predicted that up to 84.5% of diabetic patients who have had DM for more than 20 years will develop DR. [6]. According to the American Academy of Ophthalmology the global prevalence of DR was77.3% in DM Type1 and 25.1% in DM Type 2 in 2016 [7].

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Published online: 29 June 2020

In Palestine the prevalence of DM was 15.3% in 2010 and it is predicted to increase to 20.8% and 23.4% in the years 2020 and 2030, respectively [8]. According to 2017Palestinian Annual Health Report, DR ranks second (9.2%) in DM complications after Neuropathy (16.4%) [9]. Early stages of DR, are often asymptomatic and it progresses unnoticed, until vision is affected with flashes, and visual fluctuations with dark spots or poor night vision [5]. Screening is defined as the presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations or procedures which can be done rapidly [10]. Early detection of DR protects patients' vision [11]. Diabetic Retinopathy Screening (DRS) in patients with DM Type 1 should begin after five years of the onset of their illness then annually. While patients with DM Type 2 should have an initial comprehensive eye examination and dilation at the time of diagnosis, followed by at least annual exam [10]. DRS uptake percentage varies from country to another. In developed countries like Ireland, US, Turkey, UK, and the Netherlands it is55%–95% [12–15]. While in developing countries the situation is much worse; a study conducted in Jordan showed that 33% of diabetic patients had never undergone DRS [16], while in Saudi Arabia more than a third (36%) of diabetic patients were not compliant with DRS guidelines [17].

Several studies identified barriers to DRS that when removed resulted in increased screening uptake [12, 18–21]. Generally, three barrier categories have been identified: patients, culture, and system-related factors. Patient factors included lack of awareness, fear about the DRS results, having other priorities and economic problems [12, 18, 19]. Cultural factors related to experience with other family members who had DM complications, trust of health care providers, lack of access to eye care, and lack of family support [19–21]. System factors included the difficulty of getting appointments, the long waiting times, lack of patient education, and difficulties with insurance coverage [12, 19, 22].

All Palestinians have health insurance through the Ministry of Health (MOH). As a result, patients have access to ambulatory and hospital care, primary and specialist physicians, procedures and medications as they are available. MOH has an essential drug list. Patients can purchase private insurance which gives them access to private physicians and additional medications not on the MOH list, or they can pay out of pocket if they are able [23].

To date, there are no data about the screening uptake among Palestinian diabetic patients. However, as primary health care (PHC) physicians, we noticed that many patients do not routinely follow through with retinal screening referrals. To find out why patients are not adhering to DRS recommendations, and with the goal of improving care, this study seeks to understand the factors affecting DM patients' nonadherence with DRS.

Subjects, materials and methods

We conducted three focus groups in northern Palestine, selecting clinics in different sized communities where family physicians provide care in MOH clinics. Focus groups were thought to be the best way to explore patients' experiences and understanding about DRS. We recruited diabetics who were delinquent with their DRS, defined as more than 18 months since the last exam or never having done it based on procedures in other studies [20]. Patients were contacted by phone or in person by their family physician. We explained the study as 'seeking their opinions about barriers to DRS accompanied by a short lecture about diabetic retinopathy.' At the conclusion of the session, they were offered a referral to a MOH ophthalmology clinic and a meal in appreciation for their time. We emphasized that not participating in the study would not affect the care they received. If they agreed to participate, we contacted them later with the date and location of the focus group.

Three focus groups were conducted with either TY or AH as facilitators or note takers. Twenty-four diabetic patients participated in the focus groups with group sizes of 11, 7 and 6.More than half (14) were female. Most (22) were diagnosed with DM Type 2 and the mean duration of the diagnosis was 10.5 years, range (<1–35 years); half used insulin. Many (18) had other chronic diseases and more than fourth (7) had never received retinal screening. See Table 1 for additional participant characteristics.

Sessions were audio recorded. Researchers secured verbal consent and collected demographic details from each participant in private before the session began. Discussions were conducted in Arabic and lasted about ninety minutes. Study procedures were approved by the An-Najah National University research ethics committee.

Conceptual framework

We used the Ecological Framework Model to guide the development of interview questions [24], as well as similar studies [19, 25]. This model describes the complex interactions between people, groups, and their environments. The questions explored patients' awareness of DR, knowledge about DRS and barriers to completing the exam. Questions were piloted in two practice focus group sessions with colleagues before finalizing the guides. See Table 2 for the interview guide.

Data analysis and coding

Audio recordings were transcribed in Arabic and then translated into English. Four researchers (TY, AH, AAF, SB) read and reread the transcriptions then coded and organized them into themes following qualitative analysis techniques outlined

Table 1 Characteristics of study participants ($n = 24$)

Variables	Frequency (%)
Gender	
Male	10 (41.7%)
Female	14 (58.3%)
Age in years	
30–45 years	5 (20.8%)
45–60 years	8 (33.4%)
≥ 60 years	11 (45.8%)
Duration of DM in years	
< 5 years	4 (16.7%)
5–10 years	9 (37.5%)
≥ 10 years	11 (45.8%)
Level of education	
Less than secondary level	12 (50%)
Completed secondary level	8 (33.3%)
College level or more	4 (16.7%)
Average income (USD per month)	
Less than 431 USD	13 (54.2%)
431–862 USD	8 (33.3%)
≥862 USD	3 (12.5%)
Marital status	
Single	4(16.7%)
Married	20 (83.3%)
HbA1C %Mean (range)	8.36% (5–14)
Eye diseases	
Yes	6 (25%)
No	18 (75%)
Other chronic diseases such as Hypertension, hyperlipidemia, COPD	
Yes	18 (75%)
No	6 (25%)
Currently employed	
Yes	10(41.7%)
No	14 (58.3%)
Residence	
City	19 (79.2%)
Refugee Camp	1 (4.2%)
Village	4 (16.7%)
Insulin prescription	
Yes	12(50%)
No	12 (50%)
Last time for DR screening	
More than 18 months	17 (70.8%)
Never done	7 (29.2%)

by Creswell [26].Researchers discussed their codes, and agreed on final themes and appropriate quotations. Disagreements were discussed until consensus was reached. The results were shared with two family physicians who specialize in diabetes to ensure rigor and check the accuracy of our findings.

Table 2 Interview guide used in focus groups

1-Topic - Where do you usually go for seeking medical care when you fall ill?
Probe - When do you decide to seek medical advice?
2- Topic - Tell me about your condition (diabetes)?
3- Topic - How did you get to know that you have this condition?
4- Topic - How do you get treatment for your condition (diabetes)?
5- Topic - What do you know about conditions (complications) that may be associated with long standing diabetes?
Probe - How do you acquire any information or knowledge about those conditions?
6- Topic - Tell me about the things you have seen, heard or read about the complications of diabetes? Probe - How would you like to acquire this type of information (? through a poster displays at clinics / leaflets/ through newspaper / radio / television / video / from your doctor)
7- Topic - Tell me about the things that you know about your condition and associations with your eyes /sight?
8- Topic - Tell me about the things that you do about the diabetic eye conditions?
Probe - Have you seen an eye doctor / optician regarding this last few years
9- Topic - Tell me about the things which may have prevented some patients from seeing an eye doctor with regard to undergoing an eye examination due to diabetes?
Probe - Was it due to you were not told? You did not have time? Did not have money to go? Did not like the hospital staff?
10- Topic - What is your opinion about need for checking your eyes as you have diabetes?
Probe - Can you tell me how would you like to check your eyes (method of screening)?
If you have done so, how was the experience at that eye care facility?
11- Topic - What is your opinion about check your eyes (for diabetic eye problems) if a doctor suggests it to do regularly?
Topic - How frequent would you like to visit your eye doctor?

Results

Five categories of barriers to completing the DRS were identified: financial issues, personal concerns, educational issues, health system problems, and cultural issues. Examples of quotes related to each barrier are presented in Table 3. We will discuss each area.

Financial issue

Financial issues were mentioned most often. Despite government health insurance, patients incurred additional costs when referrals are made. Ophthalmological units are not available in some MOH hospitals and screening services are not provided in some MOH PHC clinics. Hence, patients are either referred to a nearby MOH clinic, often located in another city, or to

Table 3 Examples of quotations for each barrier

Barrier	Quotes examples
Financial	"Besides the cost of doctor's visits, drugs and treatments, I also have to pay for the transport or taxi, because the health care center or clinic are far away from my living area".
Personal issues	
-Other priorities	"I have two babies,they need care and there is no time for the test." "The time factor plays a role, I am working and I have to leave my job to go to an appointment. When I go to the exam, I wait a long time. It is hard to leave my job and then spend so much time waiting."
-Fear	"My psychology might be affected, and I am afraid of surprises. So don't let me know so my mind is not affected. [I won't have to worry.]
-Need a companion	"When I have to travel to Nablus one of my sons has to take me and he bears the cost. This is a problem."
Educational issues	
-Uneducated patients	"Awareness is necessary before and after examination. The patient must be guided and educated about the protocol and steps of the procedure, the complications that might happen, where to go, and who he should ask for help."
-Inadequately educated physicians	"The Ministry of Health should provide an instructor next to the diabetes doctor, to guide the patients, also to help and support the doctor, because sometimes there is a crowd [of waiting patients] that prevents the doctor from following the patient as well as he should."
Systemic-level factors	
-Limited cameras and eye specialists	"This test is special and only available in the ophthalmologist clinic, It should be available in the primary health care centers, and it should be forfree".
-Long waiting times	"The distance to the [eye] clinic is too far, and takes a lot of time". "Somedays it's crowded at the clinic, so you have to stand in a long queue and wait for your turn to come, this is time consuming, and I don't have the whole day!"
-Long time waiting for appointments	"it's hard to make an appointment with the doctor at the clinic".
-MOH responsibility for well-trained physicians	"In our health directorate, there is no diabetes specialist, So, there is no curriculum or schedules for the continuity of diabetic patients' followers".
Cultural issues	
-Stigma	"I am afraid of wearing glasses, even though I need them to read, because my kids would make fun of them, and keep saying: mom is ugly with glasses".
-Community habits carelessness and laziness	"I don't think the economical factor is a good excuse, I'm sure that most of the patients are just lazy and careless to go and check their health status.

private clinics which offer DRS services. Due to the long waiting times for appointments in MOH settings, some patients chose to pay out of pocket to go to a private clinic. Some MOH PHC clinics use a digital retinal camera to perform DRS by non-ophthalmologic technicians, and then make referrals if abnormalities are found. Because many patients are on fixed incomes, additional out of pocket costs compete with other obligations. Participants reported fixed monthly incomes (less than $430 USD). In addition to the costs at the private clinic, there are the costs of gas or a taxi to another clinic. Prescribed medications or treatments are not typically covered by government health insurance. One eye injection for treatment costs around $10USD.

Many participants prioritized the needs of their families, they prefer to spend money on most important things other than screening. A male participant said, "*I save the money for more important [family] stuff*." Another complained: "*I don't feel eye pain or problems so why should I take the time to get an eye exam? Why spend the money?*" This quotation also underlines the lack of awareness about the importance of the exam before symptoms occur. Educational barriers are addressed in more detail later. Older participants, who had had

diabetes for a while, appeared to be the most worried about the cost as one suggested that health care centers should provide the diabetic tests, treatment, drugs, and free retina examination for patients who are older than sixty.

Personal concerns

Personal concerns were also mentioned. These included: fear about the findings and how to handle what the DRS revealed, other priorities taking precedent as suggested above, and prior negative experiences with the DRS. Fear of the results was a frequent concern. A male participant said, "*People are afraid of knowing the truth if it is bad.*" A woman said: *"I don't like going to the doctors because I am afraid of the result.*" Others described concern about their emotional state if they learned they had problems with their eyes.

Most of the participants (70%) had had DRS before and described prior experiences with their exams, or experiences of family members as reasons not to have another screen. One was annoyed and surprised by the effects of the eye drops, "*The eye drop caused blurred vision, I could not see anything. The blurred vision lasted two hours, and this annoyed me.*" This participant hints at the fact that he was not educated about what to expect during the exam. Several participants reported needing someone to accompany them likely due to the side effects of the eye drops, but also because of the distance. In summary, fear of bad results, other priorities, prior negative experiences with DRS, and needing assistance were personal barriers to completing the DRS. (See Table 3 for participants' quotes).

Educational issues

Several participants stressed the importance of understanding why the DRS is indicated, what the exam entails, and complained about the lack of education provided by their referring physicians as well as the absence of explanations during the exam. A participant pointed out how she was never referred for DRS. "*For 5 years I have been suffering from diabetes, and I never once had a doctor advise me to have a retinal examination.*"

Health system related problems

As suggested above, many of the barriers described could be rectified by improvements in the MOH clinics and procedures. The lack of screening digital retinal cameras in some MOH PHC clinics, and the lack of providers available to do the DRS in other clinics caused additional time, hassle, and waiting for patients. Participants reported long waiting times for appointments and in the waiting room. Older patients described forgetting about the examination because they had to wait so long for an appointment. Participants blamed MOH for the doctors being too busy and not using diabetic guidelines. Newly diagnosed diabetics and those who had lived with the diagnosis for only a few years seemed most troubled by the systemic problems at MOH. Other complaints included not seeing the same doctor each time, and different doctors making different recommendations about treatment. In addition, the fact those medical records were often incomplete with missing data troubled patients. As a result, some Patients reported frustration and losing faith in their doctors. One said, "*The doctor in our PHC clinic does not guide me, he frustrates me. Once, there was a misunderstanding with him.*"

Cultural issues

Culture played a role as well, especially in the smaller communities. Participants from these tight knit areas seemed more concerned about what people would say about them. Individuals worried about the way society and family members perceived them. In addition, some patients just do not bother to do the examination, even if they have no good excuse. Some insisted that without symptoms, there was no need for the examination. Others felt all was in the hands of Allah.

One patient said, "*My sister had diabetic retinopathy and doctors told her that she needed a laser. And she lost her eye [Lost her vision after the treatment]. So I am afraid, what is from Allah is good."* This participant's sister had a bad outcome from the treatment, which caused the participant to distrust physicians. She concluded that screening was unnecessary regardless of the outcome, bad or good, because all is good when it comes from Allah.

Discussion

Barriers to completing the DRS in northern Palestine are multidimensional with economic, personal, educational, health system and cultural factors. A study in rural US communities also found multiple levels of barriers to DRS and categorized them according to the Ecological Model of Health; environmental, social, and individual issues [19]. Other studies reported similar factors to those we identified. Financial barriers were mentioned most frequently among our participants and other studies, even in developed countries, reported cost as an important barrier [12, 19, 21, 25]. The personal concerns described by our patients were similar to those reported in both the US and UK [20]. While other countries described system-related barriers similar to ours, as a lower-middle income country according to the World Bank, the financial challenges in Palestine may make it impossible to provide —the one stop shopping for diabetics in every MOH PHC clinic that patients requested. While this may be possible in England [15], it is likely unrealistic in Palestine. However, Sri Lanka, classified an upper middle income country, found institutional factors

similar to ours with long waiting times and limited time for consultations. Researchers recommended providing examination locations close to patients and suggested mobile clinics to examine patients in their workplaces [25]. That may or may not be possible in Palestine, but nevertheless creative solutions are needed given the economic and geographic constraints.

The educational issues noted by our participants may be easier to address. Health awareness is imperative and other studies also identified lack of awareness or knowledge about DR by physicians and patients as an important reason for not attending early and/or annual screening [27]. Public health education efforts such as World Sight Day, held annually in October and sponsored by the International Agency for the Prevention of Blindness in cooperation with WHO, is an effort MOH might promote. The VISION 2020 Global Initiative raises awareness on vision impairment and blindness and how to prevent the avoidable causes of blindness [28]. It provides media campaigns that could be promoted locally. Another study recommended sending reminder messages that explain the DR and remind diabetics to have DRS [29]. Finally, education of doctors about diabetes guidelines is an effort MOH might undertake or may be an initiative the Palestinian Medical Board addresses with their members.

Cultural barriers, defined as individual behaviors that are the product of and in reaction to the expectations of society [30], were identified in both the Sri Lank and Saudi Arabia studies. Sri Lanka reported family responsibilities and gender norms, where women don't want to be a burden on anyone, even for health preserving issues [25]. In Saudi Arabia the lack of gender specific screening professionals limits DRS uptake, pointing to the impact of cultural and religious beliefs [31].

Fear was the second most frequently cited reason for not adhering with DRS screening referrals in our study. While we categorized fear as a personal factor, there may be some cultural overlay. Other studies discussed fear as a barrier as well [16, 19, 20]. Women appeared to have more fear than men. This may be due to the culture in Palestine where many women are dependent on men and report many fears: fear of the future, illness, and what might happen to her family, especially given the daily uncertainties of the Occupation.

While our study presents data not available in the literature to date, there are some limitations. Our sample was limited to northern Palestine so our results may not be generalizable to the entire the West Bank or Gaza. However, the barriers we identified were similar to those reported in other countries, both developed and developing. Our sample size is acceptable for qualitative work and we reached theoretical saturation [32].While focus groups allow participants to discuss issues, cultural norms may have made it difficult for women to be completely honest. Given the increasing prevalence of diabetes among Palestinians as well as the serious consequences of eye complications, it is imperative that MOH, physicians, and public health do all they can to raise awareness and provide high quality care to our diabetic patients.

Conclusion

There are many barriers to completing the DRS in northern Palestine for patients served by the government system. These are multidimensional and include economic, health system, cultural, educational and personal factors. It is out hope that the study's results provide evidence on the inadequacies of the current service and considered and acted on by policy makers. If the goal is to provide high quality care to diabetics in Palestine, physicians, especially primary care physicians, need training on the use and implementation of international clinical practice guidelines for diabetes. The Ministry of Health should implement a strategic plan to provide eye examinations in all PHC clinics, and work toward providing sufficient number of ophthalmologists to reduce the problem of long waiting appointments. This may include collaboration with the private sector and looking at ways to limit out of pocket costs to patients. Cultural issues are likely best addressed by public health and health awareness campaigns such World Sight Day [28].

Acknowledgements We would like to thank the team of Family and Community Medicine Department at AL–Najah National University (ANU) for this opportunity to conduct this study, and for their assistance. Researchers are grateful to Ministry of Health and ANU for support and facilitation our access to primary health care centers. A special thank for those who facilitated our fieldwork, and data collection, specially our colleague Dr. Layali Qaddoumi for her support in the second focus group conduction at Nablus, the research participants for cooperation, encouragement, and kindly welcome.

Authors' contributions ZN conceived of the presented idea, all authors contributed to study design, data analysis, data interpretation, the writing and revision of the abstract, and developed the manuscript drafting. TY, AA and A AF contributed to data collection. All authors have seen and approved the final version of the abstract for submission.

Funding information This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Data Availability Data, transcripts (in Arabic language) are available for sharing upon a request to the corresponding author ZN.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval Ethics approval was obtained from the Institutional Review Board of An-Najah National University, Nablus, Palestine.

Consent to participate Verbal informed consent was obtained from all participants after explaining the aims of the study, including the use of audio recording.

Consent for publication Not applicable.

Code availability Not applicable

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