# Attendance To Eye Screening From The Eye of Healthcare Professionals: A Qualitative Finding

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## ABSTRACT

**Background:** Diabetes Mellitus (DM) is on a rising trend globally. In the third National and Health Morbidity Survey 2012, the number of patients who underwent proper eye screening is still far from satisfactory and the study regarding this aspect in the Malaysian setting is secluded. This study explored the current management of eye screening for diabetic patients within the Ministry of Health (MOH) setting and how it influences the attendance of patients for routine eye screening. **Method:** This descriptive qualitative study used in-depth semi-structured with ten health care provider who involved in diabetic eye screening and document analysis process. The interviews were audio-taped, transcribed and analyzed using Atlas-Ti. An iterative process of thematic analysis was used. **Results:** The factors that influence the attendance to eye screening were health care providers confidence in performing eye screening, the effectiveness of the green card system, interactive health educational session and continuous support from family members. Lack of information received by the patients on the importance of eye screening and communication issues seems to be prominent and become the reasons for patients' poor attendance to eye screening. Having a structured programme which emphasises on the importance of eye screening could be able to empower the patients and facilitate better communication strategy between patients and healthcare professionals. This simultaneously would increase the interest of the patient to follow the schedule of eye screening to achieve better health outcomes. **Conclusion:** The establishment of diabetic retinopathy–focused education materials that target multiracial and low literacy audiences, observation during data collection through more natural methods and inclusion of comorbidity aspects in future research should be considered.

**Keywords:** Diabetic Eye Screening, Diabetes Mellitus, Attendance

## INTRODUCTION

Diabetes Mellitus (DM) is on a rising trend globally. The International Diabetes Federation (IDF) predicts that the prevalence of DM in South East Asia will increase twofold by the year 2025. In Malaysia, based on the National Health and Morbidity Survey 2011, the prevalence of known and newly diagnosed diabetes has raised from 11.6% in 2006 to 15.3% in 2011 from age above 18 and 30 years old respectively (1).

Diabetic retinopathy (DR) is one of the most common diabetes complications which affected 36.8% of diabetes patients in Malaysia (1) and the incidence of visual and ocular complications increases with age and duration of disease (2). In Malaysia, the prevalence of DR from the 2007 Eye Registry was 36.8% slightly higher than the prevalence of 35% found in Singapore (3). It also reported that diabetic retinopathy was the second highest complication among diabetes patients in Malaysia (4). Diabetic retinopathy not just causes physical deterioration due to loss of vision, but also cause a devastating effect on the patients' quality of life. It includes loss of productivity and socioeconomic burden to the family through changes of daily living, roles and social interaction with others (5). Thus, eye screening is one of the measures to delay the occurrence of blindness due to DR.

In the Malaysian Clinical Practice Guideline for Diabetic Retinopathy, it is recommended that an initial fundus examination for an adult should be

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conducted after diagnosed with type II Diabetes Mellitus (DM), or within three to five years after the initial diagnosis of type I DM and before conception in pregnant women with pre-existing DM (6). Despite the devastating impacts of diabetic retinopathy to patients with diabetes, the issue of attendance to the clinic for eye screening was still unresolved.

The trend of eye screening among diabetes patients was varied. It reported that patients in their study had eye screening within the different time range where 17.4% had attended eye screening two years ago, 32,9% for the last one year and 49,7% for the last one year (7 & 8). However, this study did not highlight that whether the patients when to the screening had done the screening repeatedly or at one point in time. Therefore, the trend of patients' attendance to eye screening is still unable to be understood (8). The Malaysian National Eye Database reported that about 7701 (70.9%) from 10,929 Diabetes Mellitus patients were never done eye screening where only 998 diabetes patients undergone eye screening as suggested in the Clinical Practice Guideline (CPG) (7 & 9).

This report reflected that despite advancement in technology and fully- equipped facilities for eye screening in the Malaysian healthcare system, the number of patients who underwent proper eye screening is still far from satisfactory and the study regarding this aspect in the Malaysian setting is secluded (7 & 8). A recent study found that lack of information received by the patients on the importance of eye screening and communication issues seems to be prominent and becomes the reason for patients not attending eye screening (8). Diabetic eye screening remains an important issue to prevent sight-threatening Diabetes Retinopathy (STDR) among Diabetes Mellitus patients (10). Through quantitative studies, it is shown that some factors influencing decision needed specifically on this issue.

However, the reason why the diabetes patients were not able to follow the schedule of eye screening as stipulated in the CPG is still unclear. Thus, the questions arise whether this situation is only contributed by the patients' awareness per se or other contributing factors such as the practice of healthcare professionals, the management of the healthcare system pertinent to the provision of eye screening service for diabetes patients or other factors (10 &11). Hence, the objective of this study was to explore the current management of eye screening for diabetic patients within the Ministry of Health (MOH) setting and how it influences the attendance of patients for routine eye screening.

## METHOD

This study was conducted using a qualitative approach which employed in-depth face to face semi-structured interview with the healthcare professionals who directly involved in the management of patients with diabetes and eye screening provision and related document analysis. The in-depth interview enables the researcher to have a deeper understanding of the issues and challenges to the eye screening (12).

### *Data collection*

#### *Participant's recruitment process*

#### *(a) Semi-guided in-depth interview*

The population of this study were the Healthcare Professionals (HCP) involved in diabetic eye screening. The participants of this study were recruited using purposive sampling by selecting the participants who met the inclusion criteria and able to provide data in answering the research question (12). The healthcare professionals included in the study if they involved in diabetes management within the study settings, able to understand Malay and English and HCPs with unmet the study inclusion criteria will be excluded. Eligible HCPs were identified in several centres involved in this study. After their willingness to participate, the consent form signed and the arrangement for the individual interview session was done at the agreed place and time. All the interview sessions were recorded using an audio recorder with the agreement from the participants.

This study had involved healthcare professionals who could provide vast information regarding the topic being studied and saturation of data has been achieved. This is in line with the suggestion of six to ten participants are acceptable in describing the experience and perspective of participants on the phenomena being studied and when there is no new data identified (13). During the recruitment process, HCPs prefer to conduct interview session during working hours despite their day off because they have other commitments at home. The session has to be conducted in the designated room with limited time and few interruptions during the session from patients and their colleagues. HCP were happy to share their experience with the help the researcher with cues during the interview session to ensure the objective of the study achieved. Despite the challenge faced, 10 HCPs involved in this study.

**(b)** ***Document analysis***

In this study, the conduct of document analysis intended to find related documentation related to the management of diabetes eye screening. It was imparted from the qualitative method to provide additional information about the phenomenon of diabetic eye screening to explore the current management of eye screening within the ministry of health setting. Analyzing information obtained from relevant documents will help the researcher to gain a broad perspective of the issue being studied. This was done through elicit meaning, gaining understanding and developed empirical knowledge from the data being assessed, either in printed or electronic form (14).

***Data collection process***

***(a) Semi-guided in-depth interview***

There were two types of data collection process; semi-guided in-depth interview and document analysis. In this study, a semi-guided in-depth face -to-face interview was conducted because the researcher wanted to ask questions and record answer from only one participant at a time between one hour to two hours for each participant. An interview is a basic mode of inquiry and human histories have resided through recounting narratives of experiences represented by language (12). The interview guide was developed based on the synthesis of the literature, the research question, and the research objectives. This helped to generate an understanding of eye screening issues through engagement with the health care system, health care providers, and patients.

Open-ended questions included were 'How is the practice of eye screening in this setting, what are the factors that encourage your diabetic patients to keep their eye appointments? and what do you identify as a barrier to diabetic eye screening?'. 10 HCPs who involved in eye screening and understand Malay and English included in this study as it described the experience of the population. The sessions were recorded with permission from participants via voice recorder to help the researcher during the transcribing process.

**(b)** ***Document analysis***

The process of document analysis involved skimming, reading, and interpreting. This iterative process involves a combination of content analysis and thematic analysis. After the documents were gathered, content analysis was applied to examine the key patterns, themes, and categories from the data of the written documents (14).

In this study, the process of document analysis includes exploring the current practice in our health care system regarding diabetic eye screening in Malaysia. Document analysis in this study involved the clinical practice guideline (CPG), National Health Care Plan, pamphlets, and websites related to diabetic eye screening. The criteria assessed while carrying out the document analysis included: relevance of the document according to the problem being studied, suitable content related to the framework of study, completeness: being the comprehensive or selective and original purpose of the document.

***Data analysis***

Data were analyzed thematically. Patterns are identified through a rigorous process of data familiarization, data coding, and theme development and revision (15). One of the advantages of thematic analysis is that it's theoretically flexible. The data management and analysis involved several steps including data familiarization indexing and labelling data, sorting the data (creating a thematic chart) and summarizing the data. Each lines of the transcripts were coded accordingly based on the initial keywords. Then, the coded text was summarized and transferred to the thematic charts to look for patterns and cross-analysis between the participants. The themes then finalized during the process of data interpretation. All of the data that has been coded and summarized data have a direct link to the raw data to allow an audit trail. The process of data management and analysis was assisted by the Atlas Ti software.

The themes that emerged during the process of data analysis were divided into two main themes which are the factors perceived by the HCPs that facilitated attendance for eye screening and the challenges to the practice of eye screening. Table 1 summarized the main themes and sub-themes that emerged from the data.

| **Facilitators for eye screening** | **Challenges for eye screening** |
|---|---|
| Green card system | Facilities |
| Health education session | Communication |
| Collaborative program | Limited resources |
| Family support | HCP limitation |

Table 1: Themes and subthemes

**RESULTS**

The 10 HCPs with varied years of working experience included five nurses; three doctors, a pharmacist who involved in the education team and a medical assistant. The distribution of the participants tabulated in table 2.

| Occupation | Number of participants | Year of experience |
|---|---|---|
| Internal medicine physician | 1 | 10 years |
| Public health physician | 1 | 6 years |
| Ophthalmology physician | 1 | 8 years |
| Pharmacist | 1 | 5 years |
| Medical assistant | 1 | 4 years |
| Staff nurse | 1 | 8 years |
| Staff nurse (diabetic educator) | 3 | 10 years |
| Nurse manager | 1 | 20 years |

Table 2: Detail of participants

***Facilitators to eye screening***

There are several facilitators to eye screening highlighted by the participants include green card system, health education session, collaborative program and family support.

***a. Green card system***

A green card is the appointment card for diabetes patients in the primary health care centre on government premises. It records patients' health status (blood pressure, pulse, temperature, glucose, HbA1C, visual acuity), treatment and appointment sessions (appointment with doctor, yearly eye screening, insulin education). It functions as an identification card for diabetes patient which allows the patients to get diabetes treatment in any healthcare centre clinic nearby them. In the Clinical Practice Guideline (CPG), a patient with diabetes has to register in the National Diabetes Registry (NDR) which only accessible by authorized HCP (6). Confidential data include medical treatment, medication and other management obtained by diabetes patients during their follow up in the primary health care centre recorded in the system. Thus, the doctor could retrieve the details of the patients during the first visit or follow-up session for the management of diabetes-related complication.

Despite green card functions to remind the patients of the eye screening appointment, but many diabetes patients did not aware of the green card detail unless the date of appointment. This has been raised based on the researcher's field note.

"A patient shared that he came on the appointment date and did know about other column and notes in his green book..[she looked at the computer while having a long pause].. He also knows about his appointment based appointment date and did not know about the other column and notes for his session only, therefore, it seems to be important to emphasize the purpose of the green book during each consultation session..[voice breaks at the end of the sentences]"

In line with that, while the process of document analysis for green card, the researcher found that there was an introduction of a new tool; Framingham Risk Assessment. Few concerns were raised among the HCP regarding the usage of the tool to assess high-risk patient include lack of information on the tool itself, few sessions conducted for the implementation and the integration of the tool with current practice which affects the nurses' readiness for the implementation. This issue is line with the concept of quality which needs a continuous process of improvement must be embedded in a goal to drive the organization to quality (16).

***b. Health education session***

The provisions of information toward patients' knowledge is another aspect that thought to be able to facilitate patients' attendance for eye screening. There were styles of health education approach being practised in primary health care and tertiary healthcare setting. It includes individual consultation session, small group health education and mass information sharing. Respondent 02 stated that she delivered information in 10 minutes assisted with PowerPoint presentation and asked for feedback via a simple quiz. Meanwhile, other respondent used the flip chart and speech as her information sharing method. The sessions were divided into eight sessions during patients' appointment.

02: "We have an education session for 10 minutes every Wednesday at the patient waiting area..we hold patients first before their appointment.. Usually, we used powerpoint for the session. After that, we evaluate through a simple quiz and given some token for them"

06: "For counselling session, we have eight sessions in every appointment. We have a certain topic that will be covered such as insulin technique, medication counselling, and interaction

with other self-medication from outside. In the clinic, we explain through verbal sharing..we have a flip chart with general complications, and also pamphlet"

08: "We have two weekly patient education sessions For diabetes patients, we have divided into few sessions in a week.."

Additionally, one of the respondents who was qualified as a diabetic educator has a unique approach. She claimed that she has high courage to give patients' knowledge empowerment through sharing the root cause of disease through the physiological process of the disease using simple language assisted with video and image. The importance of diabetes eye screening and maintaining healthy condition has been emphasized in diabetes' patients. Positive encouragement provides a good medium to boost up competitions spirit to maintain a good HbA1c level. One of the respondents shared that their centre provided a token of appreciation to increase patients' motivation to maintain their HbA1c level and followed by yearly screening including eye screening. This was expressed by one respondent as follow:

03: "We give a token of appreciation..we printed our unit name on the towel and gave to them"..I prefer to share about physiology of disease with our patients..We explain in details how sugar level could be controlled..We used simple language, non -medical jargon to them..Make it easy to be understood.. It was assisted with video or image... Usually, we use their waiting time to discuss and share new information and knowledge".

Furthermore, from the content analysis of pamphlets and posters showed that general complication for diabetes was frequently emphasized. However, diabetic eye educational material per se was hardly found but if existed, the information of diabetic eye complication was imparted as small portion in these materials.

***c. Collaborative program***

Several healthcare centres had included collaborative program as part of diabetes management provision which aims to reduce or avoid diabetes complication including diabetes retinopathy (DR). One of the centres in this study had introduced a program called Cubaan Ubah Berat Badan (CUBE) program. Their main aim was to reduce body weight through exercise regularly every week and encourage participation from their patients. Another healthcare clinic provided several other programmes including the HbA1c challenge and healthy living program. These programs provided the involvement of diabetes patients to practice their knowledge and change their attitude through the support group. Few activities including cooking class, shopping while reviewing ingredient on packing, group exercise and prize ceremony for the winner after three months. The activities and the effectiveness of the programmes have been expressed by the participants below:

04: "We also have CUBE program for reducing body weight.. we have bicycle here to be used by our patients..we have exercise session for diabetic patients on Friday"

02: " For that program, we evaluate based on the target level of HbA1c below than 6.5 mmol/l for 6 months… We provide souvenir and share their achievement on board to motivate others too"..Other than that, we have a yearly program name healthy life program. We checked their baseline data, created our own WhatsApp group and have a record of their progress. Besides, they had a trip to Giant to select good food, aerobic session, cooking session also.."

This program provided a support group to improve lifestyle and reduce weight. Positive encouragement through group activities personal coaching and continuous health information sharing kept the participants' high momentum during the session. In organizing collaborative programs, the involvement and commitment of the multidisciplinary team of healthcare professionals are paramount. In a collaborative diabetes management program, the involvement of HCPs includes the physician, diabetic educator nurse, pharmacy, dietitian, laboratory technician, ophthalmologist, manager and medical assistant. Besides, the involvement of other counterparts including the medical supplier's expert who has experience doing community screening improve the effectiveness of the programme. HCPs acknowledged good teamwork while managing diabetes patients as expressed by the participant below:

05: "For diabetic management, we worked as a multidisciplinary team"

03: "We used to invite a speaker from Novartis"
This condition is consistent with the first strategic priority from Malaysia-WHO report on Country Cooperation Strategy 2016-2020. It stated that intensifying collaboration with private and non-governmental organizations through engagement and enhance multi-sectorial effort in health care

delivery (17). In short, to facilitate and execute holistic care toward diabetes patients, each health care provider should emphasize the importance of early eye screening. Thus, collaborative management could be implemented effectively within the health care system.

***d. Family support***

Family members provide the primary support and care for the participants in this study. This condition emphasized by one of the participants about the importance of family members' involvement in patients' care. It gives influence in their decision of disease management as narrated below:

04: "For the first visit, they came alone. For another visit, we asked their caregiver to come along with them. So, the information could be disseminated with the caregiver also. Because, caregiver needs to support them in terms of diet control, medication and activities."

Thus, the engagement between family members, colleagues and friends in sharing information is vital. Their advice and sharing of perception towards the management of this disease especially give influence towards patients. In all, patients' knowledge empowerment become a measure to select only positive encouragement to come for eye screening.

***Challenges for eye screening***

Despite the facilitators listed above, there were some challenges identified included facilities, communication, limited resources and HCP limitation towards patients.

***a. Facilities***

The resource is important to measure to maintain health sustainability. In Malaysia Country report, managing expensive, overutilization and underutilization of new technologies and medical advances being highlighted as one of the challenges to overcome in coming years (6). It reflected in this study as minimize utilization of equipment was discovered due to fundus photography malfunction in primary health care centres according to the following excerpt:

02: " But unfortunately, the fundus camera was malfunction for the time being..we have to wait until the machine function.."

09: "we do eye assessment only…for fundus camera, but it is not functioning now. For urgent case, we have to refer.."

10: "..our machine broken down..we have to wait until its function"

08: " Unfortunately, we don't have a fundus camera here..thus we have to do eye screening only..then, we have to refer them to another centre for fundus examination."

Maintenance of equipment is being part of the problem in handling resources. This problem causes a burden to the tertiary health centre as they received many referral and patients. Inconsistent with one of the issues that have been addressed 10th Country Planned report on the health care system's financing and cost efficiencies stated that managing very expensive medical equipment put too much strain on the nation's economy (6).

***b. Communication***

In this study, a respondent voiced out her challenges in terms of the language barrier. One of the respondents faced difficulties to communicate with her elderly Chinese patients because her patients only speak the Chinese language and could not understand Malay or English. Thus, the participation of family members during an appointment session is needed. The excerpt is enclosed below:

02: "It was a bit difficult. Sometimes, I have to learn some words that commonly used. Especially for older patients, they did not understand Malay or English that much".

Besides, communication with the patients is limited because a lot of patients need to seek consultation per day. This burden less time spends in a consultation hour. A respondent expressed her frustration for unable to spend a longer time educating her patients within consultation hour.

05: "We could not spend a long time with our patients to educate them about the disease itself. We have a lot of patients during a diabetes clinic, about 100 patients per day. We only spend 15 minutes talking and listen to our patients complained."

Documentation provides a medium of communication between Intra and inter health care centre. While exploring the documentation of patients' record, respondent 05 unsatisfied with the current situation because of incomplete documentation. Retrieval process of patients' information quite as challenging as it used the manual process with incomplete data

documentation.

01: "So far, we kept fundus image in CD but no record on diabetic eye screening per se..We will improve on that part"

05: "Actually, based on my experience the documentation of green book always incomplete. So, it is not reliable to depend on that information only, usually 50% of information we could rely on. The remainder from that we have to interview patients"

Data provided by the HCPs highlighted the limitation faced by them in managing the disease in general. However, the HCPs does not highlight the barriers that they faced in encouraging the patients to come for eye screening. Furthermore, the communication with regards to the eye complication is not thoroughly explained by the HCPs. Therefore, it could be interpreted that the issue of patients not coming for eye screening does not become the major concern as compared to the other elements of diabetes management.

***c. Limited resources***

Usage of materials provided by the Ministry of Health is a standard practice in all health care centres. There were different version of pamphlets and posters regarding diabetes complication. Also, a model such as foot and insulin simulation aid is provided but for eye model and related material is limited.

01: "We use flip chart, poster, pamphlet..usually, I use flip chart because all clinics have the same material..we teach same things using pneumonic A, B,C,D, E..we told them about our target"

In regards to educational material, unstandardized use of eye-related educational material between health care centres was discovered. Educational materials only cover general complications of diabetes, but not specific to eye-related complication per se. It is also important to include eye-related complication of diabetes due to the prevalence of this complication among diabetic patients.

01: "Regarding health education, usually we provide our materials… such as flip card, poster and our file..I always use my file on diabetic foot care.. I produce it when my post basic project we have foot model in front of room 11"

02: " We provide information pamphlet at in the waiting area..but children played with it..sometimes, our pamphlet run out of stock, so we have to indent first".." For the time being, I did not find eye-related material specifically…usually, it included in general diabetes complication pamphlet.."

08: "Our pamphlets have general information on diabetic complication only and sometimes font size is too small for elder patients"

User-friendly educational materials were hard to be found; inappropriate size, small font, and medical jargon make important information undelivered. This issue has been addressed in the Clinical Practice Guideline on the screening of diabetic retinopathy. To fully implement this guideline, some issues including establishment of a screening program, proper DR database, adequate training and privileging of screeners and graders, availability of screening tools and coordinated referral system and availability of resources for necessary treatment have to be considered (10 & 11).

**DISCUSSION**

In the early stage of the disease, the patients were still in the denial phase and default the appointment. The patients revealed that they have issues with low self-confidence and attempted to avoid engaging in the session. Unfortunately, patients came after their condition worsens as the disease progress after the late stage of the disease. This situation was found among non-attendees of eye screening as difficult to engage people as stated by health care provider (6). However, after several health education sessions on diabetes management including yearly eye screening, they realized the importance of following the designated plan of care for them (18). Negotiation skill is important among HCP to handle the situation especially in breaking news for the newly diagnosed patient.

Besides, nurses' competence in handling difficult patients indirectly relate to their knowledge, perceptions, and job satisfaction in the workplace. Age, education, gender, and geographical area have been found to have a relationship with work performance. Thus, self-perceived consequences to psychological empowerment are an increased ability to change their environments (19). The nurse-patient relationship is important to ensure trust issue for sharing any concern and problems during the health education session.

In addition, fear of uncertainty occur among diabetes patients especially those newly diagnosed because of low health literacy. Health literacy involves the numeracy and literacy skills of

participants to decide on their health based on gained information Increase patient health literacy on diabetic self-management via structured treatment and teaching programme can help to improve screening attendance which satisfies health care provider (20 -22). In the Patient and Family-Centred Care (PFCC) program, four core concepts identified; dignity and respect, information sharing about self-care, participation and collaboration in providing care to achieve optimum support from multidisciplinary team members (21-23). However, the transferability of this approach to our setting need further line of inquiry towards implementation.

Hence, the HCPs should address issues that include DABDA 5 stages of grief (Kübler-Ross model) after the doctor breaking news of the chronic disease, the application of negotiation skill and nurse-patient relationship skill is important and integration of health literacy in the provision of care. The trust issue undeniably crucial in the HCPs -patient relationship to enhance the compliance to care plan especially yearly eye screening attendance.

## CONCLUSION

Early detection is crucial to prevent diabetes-related visual impairment. Primary prevention could be undertaken to prevent the occurrence of diabetes complications by raising public awareness to avoid obesity, increase physical activity, and consume a low fat and high complex carbohydrate diet. The educational aid during a health education session is important. Thus, further consideration of the establishment of diabetic retinopathy–focused education materials that target multiracial and low literacy audiences may impact routine diabetic retinopathy screening.

Although the healthcare professionals found that many factors and challenges. influence the attendance of diabetes patients to eye screening, a further need for improvement needed. Firstly, an in -depth interview and content analysis were performed for data collection. However, the observation part was not included in this study due to time constraints. Thus, certain aspect could not be confirmed in the process of data convergence. It involved health care provider interaction with diabetes patients; the technique of communication, length of interaction, and feedback of each consultation session. However, this aspect could be improved through more natural methods of interaction between participants and the environment.

In addition, this study did not address comorbidity aspects of DM such as obesity, dyslipidaemia, chronic kidney disease, chronic vascular disease, depression, and sleep disorders. Four common tests for diabetes-monitoring tests included HbA1c levels, low-density lipoprotein, glomerular filtration rate and cholesterol levels were not included in this study. In future research, these components should be included for further integration of information.

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