Factors influencing the understanding of diabetic retinopathy complications amongindividuals with type 2diabetes mellitus: A qualitative study

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Abstract

Background: Theincidence of diabetes mellitus continues to rise steadily over the years, contributing to a significant increase in the risk of developing eye-related complications. The escalating burden of vision-related complications urge the early prevention measuresfor type 2diabetes mellituspopulation.
Purpose: Explore factors influencing the understanding of diabetic retinopathy among participants with type 2 diabetes mellitus who attended a diabetic clinic in a tertiary teaching hospital in Malaysia.
Methods: This study employed a descriptive qualitative design using purposive sampling. From March to April 2021, three focus group discussions ranging in length from 30 minutes to an hour were performed utilising a semi-structured interview guide conducted with nine participants (five women and four men) aged 35 to 65 visited the diabetic clinic. Participants included in the study were who had type 2 diabetes mellitus diagnosed after six months or more. Data retrieved was thematically analysed using ATLAS/ti software, following the qualitative data analysis stages.
Results:. Two themes emerged: challenges in practicing self-care and facilitating factors for health education. Subthemes within the challenges of practicing self-care included lack of knowledge about eye anatomy, changes in vision quality, concerns about medication intake, issues with glucose monitoring, challenges in nutritional management, and alternative practices. Subtheme for facilitating factors for health education included team work for giving health education, elements in diabetic retinopathy health education and teaching aid.
Conclusions: Despite the availability of health education materials in the clinical context, participants identified a need for greater depth in diabetic retinopathy implications. Future studies and efforts include developing educational programs.

Keywords: diabetes mellitus, type 2; diabetic retinopathy; focus groups; health education

Introduction

The rising prevalence of diabetic retinopathy (DR), a condition expected to affect an estimated 245 million people worldwide by 2045, underscores its significant potential to progress into sight-threatening diabetic retinopathy (STDR) (Burton et al., 2021). This advanced stage of the disease can lead to severe visual loss, profoundly diminishing an individual's quality of life and overall well-being. The projected increase from 162 million cases in 2019 to 245 million by 2045 not only highlights the growing public health

burden but also reinforces the critical importance of prioritizing eye health as a cornerstone for achieving the Sustainable Development Goals (SDGs).

Visual impairment, particularly blindness, is associated with numerous adverse outcomes, including reduced independence, heightened safety risks, and a marked decline in quality of life. These factors collectively contribute to frailty, decreased productivity, and increased mortality rates. Among this group, the leading causes of distance vision impairment and blindness include cataract (94 million cases), uncorrected refractive error (88.4 million), age-related macular degeneration (8 million), glaucoma (7.7 million), and diabetic retinopathy (3.9 million). The most significant cause of near vision impairment is presbyopia, affecting approximately 826 million people (World Health Organization, 2023). These staggering statistics illustrate the urgent need for comprehensive public health interventions and sustainable policies to address the escalating burden of vision-related complications, particularly those stemming from DR.

The prevalence of diabetes mellitus (DM) in Southeast Asia is projected to double by 2025, highlighting the urgent need for targeted healthcare strategies (Internation Diabetes Federation Atlas, 2022). However, national data on diabetic retinopathy (DR) remains limited due to the absence of large-scale, population-based studies, which impedes comprehensive understanding and policy development. Asia, home to 60% of the global diabetic population, faces a staggering burden, with 22 million individuals suffering from blindness and 67 million experiencing low vision, much of which is preventable with early intervention (Wong et al., 2019).

In Malaysia, the prevalence of DR and sight-threatening diabetic retinopathy (STDR) is alarmingly high, further emphasizing the critical need for effective blindness prevention initiatives (Chew et al., 2018; Goh et al., 2010). Despite this provision of information regarding the macrovascular and microvascular complications of diabetes mellitus, there is a paucity of research examining the in-depth understanding of diabetic retinopathy toward the eye health among individuals with type 2 diabetes mellitus. This gap underscores the importance of exploring these aspects to inform the development of targeted strategies aimed at reducing DR risks, improving early detection, and preserving eye health on a national scale.

Objectives

This study sought to investigate existing knowledge and practices among this population, laying the foundation for evidence-based interventions to combat the rising burden of diabetes-related visual impairment.

Materials and Methods

Design

This study uses a qualitative design for need assessment for web-based health education. Focus Group Discussions (FGDs) were utilized as a qualitative research method to gather in-depth insights into participants' experiences, opinions, and perceptions (Creswell & Poth, 2018). This approach involves guided discussions among small groups of individuals, facilitated by a moderator to ensure a focused yet open exchange of ideas. FGDs are particularly effective in exploring complex issues as they allow participants to interact, build on each other's responses, and provide nuanced data reflecting collective and individual perspectives. In this study, FGDs served to bridge participants' experiences with scientific inquiry, generating rich, contextual qualitative data. This method aligns with contemporary practices in qualitative research, which emphasize understanding participant perceptions in their social and cultural contexts. The discussions were carefully planned and structured using a semi-structured guide, ensuring the inclusion of relevant themes while leaving room for emergent topics of interest (Nyumba et al., 2018).

Participants and Setting

This study was conducted at a tertiary teaching hospital located in Kuala Lumpur, Malaysia. Participants were recruited using purposive sampling technique. The inclusion criteria were participants living with type 2 diabetes mellitus (T2DM) at least six months diagnosed at the time of screening which conducted based on the stages of the diabetic retinopathy, while those with severe NPDR and proliferative diabetic retinopathy were excluded.

Three FGDs were conducted, each of it comprises of three participants. The FGD was conducted about 30 to one hour per session moderated by the researcher and assisted by the nurses to ensure smooth flow of the discussions and addressed any participants' concerns during the sessions. A semi-structured interview guide was used to facilitate the data collection process. The FGD sessions were audio-recorded.

Ethical consideration

This research was conducted when ethical approval obtained from the ethics committee, under the reference number 202068-8726.. In addition, formal permission was sought and granted from the Nursing Department to ensure compliance with institutional policies and to facilitate the smooth execution of the study. This dual approval process underscores the commitment to maintaining ethical integrity and adhering to established guidelines throughout the research.

Data collection

The study involved three focus groups, each with three participants, conducted by the researcher (female, nurse graduated with master degree) and assisted with two diabetic educators during focus group discussions. These sessions, lasting 30 minutes to an hour, provided in-depth insights into participants' experiences and perceptions prompted by an semi-guided interview guide using Malay language. The focus group discussions (FGDs) included brief personal remarks from participants before concluding (Nyumba et al., 2018; Braun and Clarke, 2019). Sessions were recorded and meticulously transcribed, capturing not just the verbal dialogue but also contextual elements like the environment, nonverbal cues, tone of voice, body language, and facial expressions, ensuring a comprehensive understanding of the participants' experiences. Data collected stop until reached data saturation. Table 1 provides the details of study participants. All FGDs were conducted by the PI between March 2021 and April 2021. The following inclusion and exclusion criteria were utilized:

Inclusion criteria

Participants living with type 2 diabetes mellitus diagnosed with Non-Proliferative Diabetic Retinopathy (NPDR) to mild NPDR with cognitive capability. The assessment process guided by the staging of diabetic retinopathy clinical practice guideline from Ministry of Health Malaysia and diagnosis given by ophthalmologist based on patient registry system.

Exclusion criteria

Participants living with type 2 diabetes mellitus who have blindness, bedridden and dementia with cognitive impairment.

Themes, patterns, and key concepts begin to repeat across different interviews or data sources. Once data saturation is reached, researchers halted data collection process.

Data analysis

All FGDs were recorded, transcribed, and translated into English from Malay language. The thematic analysis during the qualitative data analysis process was utilized (Lincoln and Guba, 2013), including (a) reading and re-reading the transcriptions for familiarization with the depth and breadth of the data; (b) data coding to generate initial codes; (c) developing the theme and subthemes based on descriptions; (d) reviewing the theme and subthemes; (e) defining and naming the theme and subthemes; and (f) writing the report.

The researcher used Microsoft Word to create the codebook and Atlas-ti software to organize the data and to create the coding framework to ensure accuracy in the coding process. In addition, the researcher and two more researchers (CMC, LWL) independently coded two transcriptions to enhance coding consistency. The transcripts were return to participants for cross checking the information before finalizing the theme.

Trustworthiness

The study's trustworthiness was ensured by considering credibility, transferability, confirmability, and dependability (O'Connor and Joffe, 2020; Lincoln and Guba, 2013). Credibility was achieved through the researcher's expertise and cultural understanding, with initial coding verified by the research team, including experienced coauthors. Transferability was ensured by collecting data from participants with varying diabetes mellitus diagnoses. To maintain confirmability, the researcher practiced reflexivity, conducting interviews in comfortable settings without influencing participants' responses. Dependability was ensured through rigorous, ongoing assessments by the research team. The study's two-step coding process, using both manual methods and Atlas-ti, and adherence to the Consolidated Criteria for Reporting Qualitative Research, support its replicability (O'connor and Joffe, 2020). The study followed COREQ guidelines, ensuring transparent reporting, rigorous analysis, and participant-centred insights through ethical, reflexive practices.

Results

The study's results identified two primary themes: Challenges in Practicing Self-Care and Facilitating Factors for Diabetic Retinopathy (DR) Health Education. Pseudonyms applied to ensure participants' privacy. This section presents a comprehensive summary of the main themes along with their corresponding subthemes, offering a clear and organized overview of the findings.

Theme: Challenges in the practice self-care

There are a few challenges in practicing self-care that elaborated in the subthemes.

Subtheme 1: Lack of information on eye anatomy

A few participants only had minimal knowledge of the outer structure of the eyes but not the inner structure and pathophysiology of the eyes.

"I know a bit about it but not sure the detail.." (PT1)

"I am not sure about it...I just know our outer structure only...might need more information on this..." (PT2)

"I am not sure about the inner structure, just know the outer layer of our eye structures..., I am not sure about it...the doctor explains to me but it's hard for me to digest... (giggling)" (PT4)

When the participants were asked about the changes in the inner anatomy of the eyes through the

disease process, the participants looked confused. The excerpts below describe the statement.

"I know outer part but uncertain regarding inner issue..oo I see..there are difference..(mumbling and staring at fundus photo.."(PT3)

"Am not sure what it is..is it related to diabetes complication?...I think you should add on more on how the glucose affect the eye structure..also how I could take care more.." (PT4)

Generally, the participants were quite familiar with checking their vision using the vision chart. However, certain terms such as visual field and fundus camera procedure were unfamiliar to them. They might have undergone the procedure but are unfamiliar with the terms of the procedure.

" I am not sure..what is visual field? I usually read the alphabet..and then the nurses snap my both.." (PT3)

"...hmm. I am not sure...maybe just want to see my eyes problem...I don't really know about it. also I don't know the fundus photo on that board" (PT6)

"I am not sure about that..I know about eye screening.. checking my power for spectacle..like that la" (PT1)

Hence, the emphasis is to improve their knowledge and prevent confusion due to the difference between the layman and scientific terms of the procedure or instrument included in health education.

Subtheme 2: Altered quality of vision issues

Participants reported altered vision quality due to diabetes, affecting daily activities. They faced difficulties with reading small text, watching TV, and driving at night, reflecting significant impairments in visual health. These issues underscore the need for effective diabetes management and regular eye care to maintain quality of life.

"For reading, I have to wear glasses especially small letters and reading subtitles on the television… Sometimes, I experienced black line in my visual field..but it faded away.." (PT2)

"I am far-sighted person..so I need to wear spectacles while driving and traveling" (PT1)

"I think now I must change my spectacle... because you know, my power keeps changing. I have to wear my glasses while reading.. , Sometimes I can see the big letters but small letters quite difficult without glasses.."(PT5)

The issue of being short-sighted or near-sighted was commonly recognized among the participants , and they understood that wearing glasses was a typical solution. Consequently, they were conscious of the need to reassess their prescription strength when they noticed a decline in their vision quality. The following excerpts illustrate their concerns regarding this matter.

"But I need to wear glasses to read small letters. Now I feel no changes in my power, no problem driving during day but some difficulty during night" (PT6)

"I wear spectacles for long time ago for driving but it needs rechecking on my power" (PT4)

However, there was a participant diagnosed with type 2 diabetes mellitus on top of the migraine problem. This makes the participant situation worsen with the glaring issue.

" I have glare issue and diagnosed with diabetes mellitus..and also have migraine issue under neuro-medicine.." (PT6)

Thus, the visual-related changes become a liability for most of the participants .

Subtheme 3: Medication consumption issues

Most of the participants were compliance with medication regime but some of the participants forgot to take the medication on time. These excerpts detail on the participants' experience,

"I have diagnosed with diabetes for 7 years ago.. so now I am taking oral medication..but sometime I forgot.." (PT2)

"I am taking tablet medication as ordered." (PT1)

"I take oral mediation regularly for the time being..sometimes, I forgot to eat the medication.." (PT6)

However, one participant blatantly revealed that he modified by reduce the dosage of his medication because of the side effect which affect the effectiveness of the drug.

"After take two tablets, I felt nauseated...so I took half half only as advice by my daughter..." (PT5)

Hence, medication intake should become a routine to participants living with type 2 diabetes mellitus to enhance their health quality.

Subtheme 4: Glucose monitoring issue

While exploring the glucose monitoring issue among the participants, a few participants own a blood monitoring device and they self-monitor their glucose level at least once a week at home.

"...monitor my glucose at home...last week only" (PT5)

"Check my blood glucose level once a week" (PT3)

Most of the participants monitor their blood glucose levels during the routine checkup and at the nearest pharmacy. However, during the pandemic phase, they seldomly monitor their blood glucose level due to the COVID restrictions.

"No, I did not have it..I just go to nearby pharmacy to check my glucose level.." (PT2)

"No I don't have at home..sometimes, I check at pharmacy sometimes..but due to covid I rarely check i…I checked last night 9.0 but this morning 7 I think..why aa my glucose quite high at night?.. Yes sometimes..but I am not sure is it normal or not" (PT1)

"I seldomly check my blood glucose..usually the reading between 6 to 9.." (PT6)

Although there are many challenges in monitoring blood glucose levels, most of the participants are aware that they must check their blood glucose level at least weekly and adhere to their regular hospital

follow-ups to maintain optimal glucose levels.

Subtheme 5: Dietary management issues

A range of diverse dietary patterns were observed among the participants. Some of the participants honestly admitted to eating rice, bread, and drinking tea, while others followed the dietitian's advice to control their glucose levels.

"During my breakfast, I do eat rice, bread with tea..during lunch depends, sometimes I ate rice.. I just took plain milo at night la..sometimes three times per day I just took milo..but doctor asked… They asked me to take goat milk..so I just started it" (PT5)

"Currently, I have no appetite...I just took my breakfast but delay in taking my lunch and dinner" (PT3)

However, some participants control their rice intake as low as twice monthly. They also reported having appetite loss especially sugary-based food.

"Rice contains high sugar, so I took twice monthly..I don't like to eat roti canai dan teh Tarik.. but sometimes I ate less because no appetite" (PT6)

"I did not eat sugary food..even my friend persuade me to eat ice cream, I also refuse..i am very careful.." (PT7)

The participants actively applied knowledge from dietitian consultations and medical advice to maintain a balanced diet, demonstrating an understanding of their condition and a commitment to adhering to dietary guidelines.

Subtheme 6: Alternative practices

For alternative practices, some participants take vitamin supplements and herbal treatments to enhance their healing process.

" I take vitamin supplement to boost my energy.. (PT4)

"Sometimes, I asked by my friends to try *traditional supplement such as 'root (akar kayu)' and herbal treatment.."* (PT3)

Furthermore, the participants engaged in activities like brisk walking and yoga to alleviate stress. Many of the female participants chose to do household chores as a form of daily exercise to stay active. However, one participant mentioned that a spinal degeneration condition had interrupted her regular exercise regimen.

"..but sometimes I did perform yoga to release my stress.." (PT4)

" For the time being, I just perform yoga" (PT2)

" I rarely do my exercise because of my spinal degeneration long time ago, so it was painful if I do.."(PT3)

Therefore, the incorporation of contemporary and alternative methods to divert the attention from the disease process motivated them to tune in to new activities.

Theme: Facilitating factors for health education

Several enabling factors for health education were identified during the FGDs, including teamwork, components of diabetic retinopathy education, and the usage of teaching aids.

Subtheme 1: Team work for giving health education

The participants consistently attended their clinic appointments, adhering as closely as possible to the doctor's recommendations and guidance. In these sessions, the doctor discussed their current health status and outlined the treatment plans.

"Yes I follow what doctor prescribed..I take before meal.." (PT4)

"..just follow whatever doctor said to me" (PT8)

However, some participants expressed difficulty in understanding the explanations provided. They mentioned awaiting further clarification during consultations with doctors and dietitians.

"I am not sure about it..the doctor explain to me but it's hard for me to digest.."(PT9)

As a result, to encourage the implementation of best practices and provide information to participants , healthcare professionals must support them.

Subtheme 2: Elements in diabetic retinopathy health education

Participants suggested several key elements for inclusion in diabetic retinopathy (DR) health education. These include a detailed explanation of the eye's internal structure, an understanding of how glucose levels impact eye health, and a focus on interpreting fundus images. These aspects should be emphasized during educational sessions.

" I think you should add on more on how the glucose affect the eye structure.."(PT9)

"Yes sure, it might help me to improve my knowledge about my eye health" (PT4)

I know outer part but uncertain regarding inner issue..oo I see..there are difference..(mumbling and staring at fundus photo..).. (PT5)

These components must be included in the health education materials that were given to the participants.

Subtheme 3: Teaching aid

Multiple educational aids were recognized as helpful in providing information to participants, including brochures, videos, and eye models. The usage of graphical presentations, featuring vivid colours and straightforward layouts, was particularly effective in helping participants understand and retain the information.

"Yes, I got brochure sometimes..what I love is the graphical information that I can benefit from it. It captures my sight if the colour is bright and simple layout to see the information.." (PT1)

" It captures my sight if the colour is bright and simple layout to see the information"(PT4)

Diabetes mellitus information and ophthalmology procedures such as laser video being shared in the television during the waiting time indirectly helps the participants to understand the disease and

procedures.

"We have video playing in the laser room and in the waiting area.. so that the participants will look at.."(PT6)

Besides, the eye model with additional information and the image from the computer eases the explanation process during the doctor's consultation session.

"..during consultation with the doctor, he show me the eye model..I could understand that.. . images also shown in the computer allow me to show all the image.." (PT1)

Discussion

Theme 1: Challenges in Practicing Self-Care

This study's findings indicate that participants face challenges in practising diabetes self-care, yet they demonstrate awareness of diabetic ocular complications. According to American Association of Diabetes Educators (2020), effective self-care management includes adherence to prescribed medication, exploration of alternative treatment methods, dietary improvement through appropriate food choices, recognition of the importance of regular exercise, vigilance towards diabetes symptoms, effective stress management, and acceptance of available support systems. This study in line with the Meng et al. (2016) and Stewart and Shamdasani (2014) which stated that participants' perceptions of the benefits derived from diabetes-related self-care activities significantly influence their dedication to self-care (Stewart and Shamdasani, 2014). Perceived benefits, central to the Health Belief Model, motivate lifestyle changes by highlighting positive outcomes of adopting healthier behaviours. In addition, people with diabetes learn based on their capacity and relate beliefs relying on subjective measurement (Huang et al., 2015).

The finding from Moura et al. (2019) indicate that the people living with type 2 diabetes mellitus possess a moderate understanding of diabetes, diet, and physical activity. Notably, one-fifth of diabetic participants exhibited poor level of knowledge, with female participants generally less informed than their male counterparts. Additionally, a significant positive correlation was observed between participants' attitudes and their quality of life scores. Moreover, a moderate level of health-related quality of life was reported among the participants.

Hence, modifying lifestyle factors such as self-care management education, nutrition interventions to healthy eating, increasing physical activity, periodic screening of participants and determining the main modifiable risk factors of chronic diseases can be considered efficient approaches to achieving the goals (Zarkogianni et al., 2015).

Theme 2: Facilitating Factors for Diabetic Retinopathy (DR) Health Education

The participants consult physicians regularly and undergo annual eye examinations. This is influenced by the participants' diabetic education. This was supported by Murray et al. (2019) stated that attending education program was associated with increased visits to the ophthalmologist. The patients become empowered because of clear insights into eye health through fundus photography (Moinul et al., 2020, Moura et al., 2019, Khalaf et al., 2019). This was supported by Li et al. (2020) found that 20% of participants that undergo fundus examination requested more information on serious effects of type 2 diabetes mellitus.

Additionally, participants valued free online education for diabetes self-management, especially as diabetic retinopathy is often overlooked by healthcare providers. The use of internet-based resources enhances patient support and engagement. Thus, the access to information and healthcare services, effective communication with healthcare professionals, and engaging in activities to manage the disease are crucial (FItzpatrick, 2023).

Besides, family support plays a vital role in enhancing participants' understanding and management of their condition. In the cultural context, family support strengthens shared responsibility, aligns with communal values, and promotes learning, decision-making, and action in diabetes care (Ligita et al., 2020). This can be enhanced by sharing stories or experiences and information related to diabetes with each others and their caregivers via electronic mediums such as social media (Zarkogianni et al., 2015) and mobile application (American Association of Diabetes Educators, 2020).

Strength of the study

This study serves as a foundation for investigating the diabetic retinopathy issue through the knowledge and practice of eye care among individuals living with type 2 diabetes mellitus.

Nursing Implication

This study identifies key factors affecting how individuals with Type 2 Diabetes Mellitus understand diabetic retinopathy complications. It reveals significant barriers to effective self-management and early intervention, such as gaps in knowledge and misconceptions. The findings highlight the need for customized educational strategies and improved communication between healthcare providers including nurses and patients. Addressing these issues can increase patient awareness, encourage timely treatment, and potentially reduce the risk of severe diabetic retinopathy. Overall, the research provides valuable insights for developing targeted interventions to better support patients in managing their condition and preventing vision-related complications.

Limitation of the study

The data was limited to single setting, potentially

affecting the generalization of the findings. Another limitation was the limited interaction time with participants during clinic sessions, restricted to just an hour. However, the rapport maintain through online interaction.

Conclusions

In conclusion, the study emphasizes the need for tailored diabetic retinopathy education for type 2 diabetes patients, focusing on effective communication, regular eye exams, and proper diabetes management. Leveraging digital tools and adapting to cultural needs is essential. Continuous program evaluation and institutional care procedures are vital for improving patient outcomes and eye health. Future research should explore diverse locations and participants to identify therapy effectiveness across different groups. In Malaysia, studies on diabetic eye conditions, hypertension, viral eye diseases, and AI-based diagnostics are needed. Retrospective hospital data analysis and research on eye health in children and young adults should also be conducted

Declaration of Interest

No potential conflict of interest was reported by the author(s).

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Data Availability

The datasets generated and analysed during this study are not publicly available due to confidentiality agreements with participants and ethical restrictions. However, they are available from the corresponding author upon reasonable request and with approval from the relevant ethics committee.

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