

Explorative Research on Health Literacy and Self-care Management in Patients with Type 2 Diabetes Mellitus

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ABSTRACT

Type 2 diabetes mellitus (T2DM) is a chronic metabolic condition which is associated with high blood sugar, insulin resistance and relative lack of insulin. This qualitative research explores newly diagnosed T2DM patients' perceptions on disease knowledge and management to self-care in preventing or delaying disease progression. Eleven participants who were diagnosed for up to five years with T2DM were recruited through purposive sampling and interviewed using semi-structured interview. Interviews were transcribed verbatim and the data from the interviews were coded and categorised into themes using thematic analysis. Three key themes that motivated T2DM patients to practise self-care were identified which are 1) healthcare professionals, family and peer support, 2) self-awareness and agency and 3) fear of developing complications. With sufficient access to health services and understanding of reliable health information, patients with T2DM can be motivated or encouraged to practise self-care which consequently may help in delaying or preventing disease progression. Continuing education and support from healthcare professionals as well as support from family members is crucial as it improves the mental wellbeing of these patients as they can accept their condition and feel in control to manage their diabetes effectively.

Keywords: Type 2 diabetes, Health literacy, Self-care, Malaysia, Qualitative research

Article Info

Received 11 March 2021

Accepted 9 May 2021

Published 30 May 2021

INTRODUCTION

Diabetes mellitus is a chronic metabolic condition which is associated with high blood sugar, insulin resistance and relative lack of insulin. Type 2 diabetes mellitus (T2DM) is the most common type of diabetes and it can be caused by unhealthy diet and physical inactivity.

Diabetes has now become a major health concern not only in Malaysia, but also globally. According to the International Diabetes Federation (IDF), there are approximately 463 million adults living with diabetes and it is predicted that by 2045, the number of people diagnosed with diabetes will rise to 700 million (IIDF, 2019). The report also stated that 79% of diabetes adult population lives in low- and middle-income countries such as Malaysia (IIDF, 2019).

In Malaysia, the overall prevalence of diabetes has increased from 13.4% in 2015 to 18.3% in 2019 based on the National Health Morbidity Survey (NHMS) 2019 (Institute for Public Health, 2020). The prevalence of undiagnosed diabetes has also increased from 5.1% in 2015 to 8.9% in 2019 (Institute for Public Health, 2020). According to the survey with the increasing prevalence of diabetes and other non-communicable diseases (NCDs) such as hypertension, it is unlikely that Malaysia will be able to achieve the target of the United Nations Sustainable Development Goals of reducing premature mortality due to NCDs (Institute for Public Health, 2020).

Poor glycaemic control can lead to microvascular complications such as eye, kidney or nerve problems, and macrovascular complications such as cardiovascular disease, and this can contribute to significant rate of mortality and morbidity. The increasing complications and hospitalisation due to poor glycaemic control has also put a burden on the government and healthcare resources. Therefore, good glycaemic control is very critical to prevent the development of complications associated with diabetes.

Health literacy has an impact on the day-to-day self-care management of T2DM. According to the International of Medicine, health literacy is defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (International of Medicine, 2004). Based on this definition, individual capacities within the main components of health literacy are viewed as cultural and conceptual knowledge, listening, speaking, arithmetical, writing and reading skills (Sørensen et al., 2012). Health literacy is important as people with high health literacy skills tend to enjoy better health and wellbeing (Pillar 1 Knowledge & Health Literacy, n.d.). This allows the individual to interpret information about health, to find and use own sources of health information as well as understand when the information is poor or misleading.

An integrated conceptual model of health literacy has been developed by Sørensen et al. through an extensive systemic review of different definitions and models of health literacy. The model combines the qualities of a conceptual model outlining the four main dimensions (access, understand, appraise, and apply) of health literacy. The process of accessing, understanding, appraising and applying health related information generates knowledge and skills to enable a person to navigate the three domains of health continuity (healthcare, disease prevention and health promotion) (Sørensen et al., 2012).

Based on NHMS 2019, 35.1% of Malaysian adults possessed limited health literacy level (Institute for Public Health, 2020). The survey was conducted to determine the health literacy among Malaysian adults by using the HLS-M-Q18 questionnaire, which was compressed and adapted from the European Health Literacy Survey, HLS-EU-Q47 (Institute for Public Health, 2020). The questionnaire consisted of 18 items covering 9 sub-dimensions such as obtaining, understanding, or appraising the information and application relevant to healthcare, disease prevention and health promotion (Institute for Public Health, 2020). From the survey, it is found that 28.0% of Malaysian adults have low health literacy in managing medical issues, 32.3% have low health literacy related with disease prevention activities and 27.0% have low health literacy in health promotion and healthy lifestyle practices (Institute of Public Health Malaysia, 2019). Limited health literacy could lead to poor management of diseases such as diabetes and increased risk of developing complications (UCL Institute of Health Equity, 2015). Al Sayah et al. (2013) indicated that limited health literacy is consistently associated with poorer diabetes knowledge. Hence, assessing and managing limited health literacy is important to help patients with diabetes stay safe, informed and well controlled (Watts, Stevenson, & Adams, 2017).

A qualitative study to investigate health literacy issues among Chinese American immigrants with diabetes found that there are several issues to why they are having difficulty obtaining, processing, and understanding diabetes related information (Yee et al., 2014). From the study they found that unawareness of self-care responsibility among the patients affect their ability to obtain information, communicate with healthcare providers and their capacity to understand the choices of treatment and self-care. This is because they have the belief that patients should not be responsible for their own chronic illness care, and they did not seem to know that they should take initiatives and responsibilities for their own health maintenance (Yee et al., 2014).

With adequate or high health literacy levels, patients with diabetes are likely to be motivated to practise self-care. Self-care is defined as “the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider” (Bridgeman & Mansukhani, 2016). The International Self-care Foundation (ISF) has developed a framework for self-care which evolves around the seven ‘pillars’ as shown in Figure 1. The first pillar focuses on the knowledge and health literacy of an individual on health, disease, and self-care (Pillar 1 Knowledge & Health Literacy, n.d.).

There are seven essential self-care behaviours in people with diabetes which predict good outcomes (Shrivastava, Shrivastava, & Ramasamy, 2013). They are healthy eating, being physically active, monitoring of blood sugar, compliance with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviours (Shrivastava et al., 2013). Individuals with diabetes have been shown to make a dramatic impact on the progression and development of their disease by participating in their own care (Shrivastava et al., 2013). With strong health literacy, patients can understand information given by healthcare professionals and use the resources accordingly. Poor or limited health literacy among T2DM patients may affect self-care behaviour as they may misinterpret the information given or do not follow instructions, for example, diet plan that has been set up to help control good glycaemic level.



Figure 1: Seven Pillars of Self-Care. Adapted from International Self-care Foundation (<https://isfglobal.org/practise-self-care/the-seven-pillars-of-self-care/>).

A descriptive study investigating the self-care practices of Malaysian adults with diabetes showed that even after the recognition of the importance of self-care, the majority of the subjects continued to have problems understanding and practising appropriate self-care management (Tan & Magarey, 2008). The study recommended qualitative research should be conducted to explore patient insights on the discrepancy between the perceived importance of self-care practices and the actual behaviour of these patients. Another qualitative study which investigated the goals, beliefs, knowledge, and barriers for diabetes self-care in a multi-ethnic population in Malaysia found that the major theme of patient's goal is to obtain a better blood glucose control (Saunders, Chia, Abdullah, & Ablah, 2019). However, the exploration of what these patients are doing to achieve this goal and to understand what is important in motivating self-care practices is not thoroughly discussed.

This qualitative research explores the perceptions of newly diagnosed T2DM patients (up to 5 years post diagnoses) on disease knowledge and management in motivating self-care behaviours to prevent or delay disease progression.

METHOD

Methodological approach

The narrative approach is a systematic study of personal experience and meaning, and it is very useful for exploring people's thought about their experiences of health and illness (Anderson & Kirkpatrick, 2016). The emphasis on the story, whereby typically "what" and "how" is narrated. Using this approach, it will help researchers to better understand people's experience and behaviours (Anderson & Kirkpatrick, 2016). As Denzin (2003: xi) suggested, he said that

"We live in narrative's moment: The narrative turn in the social sciences has been taken... Everything we study is contained within a storied, or narrative representation. Indeed, as scholars we are storytellers, telling stories about other people's stories. We call our stories theories" (Holloway, 2005).

There are different types of narrative approach for example, autobiographical self-reflection, biographical data, and representative constructions. In trying to understand people's experiences of health and illness, the narrative approach has become popular. This is because when an illness strikes a person, he or she will start to make sense

of their illness in personal and social terms (Bissell, Ryan, & Morecroft, 2006). This triggers a process where the person will start to find answers to the questions about why the illness happened at the time it did, what it means to them and how it can be explained (Bissell et al., 2006). In other words, for people to make sense of their health and illness, it is clearly through their stories and narratives about the illness. The process of trying to find the true meaning of health and illness can be one of the themes of narrative approach, which is biographical data. It can be collected using conversational approach, for example, by interviewing the patients. Biographical data can be a useful way to create a record of patient experience that is as true to life as it can be at a particular point in time (Bold, 2012).

So, in this research a narrative approach through biological data enabled patients to tell their stories and perceptions about their experiences of being newly diagnosed with T2DM, and their understanding about the knowledge of the disease and its management and what motivates them to practise self-care to help in preventing or delaying disease progression.

Participants

The participants for this research were patients who were diagnosed with type 2 diabetes mellitus. The inclusion criteria included 1) Malaysian male and female who were diagnosed with T2DM up to 5 years, 2) aged 18 years and above, 3) with no known severe mental health problem e.g., patients with dementia or psychotic disorders, that could possibly affect their ability to answer questions.

Sampling

Eleven patients were recruited through purposive sampling from online platforms and a government health clinic between June 2020 and November 2020. A participant recruitment poster was disseminated through social media platforms as well as diabetes support groups. Eight patients were recruited through the postings while three participants were recruited from the government health clinic. The sample size in this study is based on the theoretical saturation and interviewing ceased when it was thought saturation was reached.

Participants recruited were from the different range of ages and states in Malaysia as shown in Table 4. They attended different healthcare facilities around Malaysia for their regular check-ups. Hence, the different recruitment methods used for this study represent the representativeness of the sampling.

DATA COLLECTION

Narrative interviewing is a method that can be used to collect people's accounts, or stories, of their experiences (Ziebland, 2013). Due to the nature of this study being an exploratory study using the narrative approach, the following research questions, using "what" and "how" were adopted to obtain rich details of peoples' views on their understanding of T2DM and its management. Using interviews, researchers are able to let the participants control the direction, content and pace of the interview (Anderson & Kirkpatrick, 2016). Hence, providing the researchers with the insights into issues about people's use of medicines and their understanding of the condition and its management within their own story (Anderson & Kirkpatrick, 2016).

The use of narrative interviews can be combined with other interview methods such as structured interviews, semi-structured interviews or unstructured interviews (Bold, 2012). In this research, narrative interview together with semi-structured interview is used to capture the people's stories and perspective. This is particularly useful if the research is designed to explore a wide range of perspectives (Ziebland, 2013). Using a semi-structured interview enabled the researcher to maintain focus, and at the same time allowing the flexibility to ask further questions when necessary to clarify certain points raised by the participants (Bold, 2012).

Due to the COVID-19 pandemic, all interviews were conducted through telephone conversations or online meeting platform, Microsoft Teams, in 2020. Once the participants agreed to be interviewed, they may choose whether to be interviewed via telephone call or Microsoft Teams. The interview was guided by a list of questions to be explored and prompting was also done when necessary. Table 1 shows the guiding questions used in the semi-structured interviews where the areas covered include the experience of being diagnosed with T2DM, health literacy and self-care. Interviews were conducted in English or Malay language and lasted for an average of 30 minutes. All interviews were audiotaped, translated as necessary and transcribed verbatim.

Table 1: Guiding questions used in the semi-structured interview

| What is your experience of the condition? |
|---|
| <ul style="list-style-type: none"> • How did you find out about having diabetes? • How was the information been passed on? • What did you feel about being diagnosed with diabetes? • What do you know about diabetes before the diagnosis? |
| How do you access, understand, or apply health information? |
| <ul style="list-style-type: none"> • Do you know how or where to find health information about diabetes? • How do you understand the information you received? • What do you do with the information you received? • If you received health information from healthcare professionals or other sources e.g. social media, friends or family, what language was used, and do you find it helpful and why? • How do you feel about having the choice to choose who you see during your visit to healthcare facilities? • What other training or guidance do you require to help in accessing or understanding health information? |
| How does your understanding of the condition and its management affect self-care? |
| <ul style="list-style-type: none"> • What motivates you to manage your diabetes? • What self-care activities have you undertaken in managing your diabetes? • What do you think is important during patient training or counselling to motivate self-care behaviours? • Do you think it is easy or hard to practise self-care? Why? |

Challenges and steps taken

Four interviews were conducted using Microsoft Teams while seven interviews were conducted through telephone conversation. Table 2 shows the challenges faced during the virtual interviews and the steps taken to overcome the challenges:

Table 2: Challenges faced during virtual interviews and steps take to overcome them

| Challenges | Steps taken to overcome challenges |
|---|---|
| Getting the right timing to conduct interview | Confirm and remind participants on the date and time of interview via text messages platforms e.g. WhatsApp messenger. |
| Poor internet connections | Inform participants beforehand that if there were internet connection disruptions, interview through telephone conversations will have to be conducted instead. |
| No eye contact and body language | Must use own judgement and immerse in the data when transcribing the data to interpret what the participants meant or felt. |
| Unsure if the patient has finished talking | Ensure participants have finish talking before asking the next question or get the participants to continue with his/her conversation if interrupted midway. |
| Building rapport with the participants | All participants were communicated via WhatsApp messenger before interviews took place to gather information from the participants as well as to explain about the study. Participants from the government health clinic spent about 10 to 15 minutes with the researcher, going through the participant information sheet and continue communicating via WhatsApp messenger. |
| Participant agreed to participate initially but withdraw afterwards | Participants have the right to withdraw from being interviewed. However, chances of not losing participants are lesser if face to face interview were to be conducted after recruitment. |

DATA ANALYSIS

In qualitative research, data collection and data analysis are closely related. Both data analysis and data collection is a part of an iterative process and cyclic in nature instead of linear, independent event (Miles, Huberman, & Saldana, 2018).

One of the challenges to analysing qualitative research data is due to its open-ended nature of the data as opposed to just numbers only. Thematic analysis (TA) is a method of identifying, analysing and reporting patterns (themes) within data (Castleberry & Nolen, 2018). It is known as descriptive method that reduces the data in a more flexible way compared to the grounded theory. It is commonly used because a wide range of research questions and topics can be addressed using this method of data analysis (Castleberry & Nolen, 2018).

The data for this research was analysed using thematic analysis using six phases of analysis outlined by Braun & Clarke, 2006 as shows in Table 3.

Table 2: Phases of thematic analysis

| Phase | Process |
|----------------------------|--|
| Get familiar with the data | Transcribe data collected, re-read the data, note down initial ideas and thoughts |
| Generate initial codes | Note down initial ideas from data and code data into small chunks of meaning |
| Search for themes | Collate initial codes into potential themes, gather all data relevant to each potential theme |
| Review the themes | Check if the themes work in relation to the coded extract and the entire data set, generate a thematic 'map' of the analysis |
| Define and name the themes | Ongoing analysis to further refine the themes and identify the essence of what each theme is about |
| Write up | Write the report |

Interviews were transcribed verbatim and then imported to NVivo@10 software. The transcribed interviews were coded line by line in NVivo@. The initial codes generated from the data was grouped together to form themes. All themes formed from the initial coding were then reviewed to check if the themes work in relation to the coded extracts and the entire data set. At the fifth phase, the emerging themes were further refined to generate a clear definitions and names for each theme.

Ethical considerations

This research has obtained ethical approval from the University of Nottingham Malaysia Ethics Committee in May 2020. This research has also been granted permission from the National Medical Research Registry (NMRR) under the Ministry of Health Malaysia in August 2020. Ethical approval has been obtained from the Malaysia Research Ethics Committee (MREC), Ministry of Health Malaysia.

FINDINGS AND DISCUSSION

Table 4 displays the demographic characteristics of the eleven participants interviewed. From the interviews conducted, three key themes were identified that motivated participants to practise self-care through sufficient access to health services as well as their understanding of the disease and its management. The themes are:

1. healthcare professionals, family, and peer support
2. self-awareness and agency
3. fear of developing complications.

3: Demographic characteristics of participants

| Variable | Number |
|--------------------------------------|---------------|
| Race | |
| Malay | 9 |
| Chinese | 2 |
| India | 0 |
| Age | |
| 20 – 29 | 1 |
| 30 – 39 | 6 |
| 40 – 49 | 2 |
| 50 – 59 | 2 |
| Gender | |
| Male | 4 |
| Female | 7 |
| State | |
| Selangor | 5 |
| Wilayah Persekutuan | 2 |
| Johor | 1 |
| Pahang | 2 |
| Sarawak | 1 |
| Years diagnosed with diabetes | |
| Less than a year | 1 |
| 1 – 2 years | 1 |
| 2 – 3 years | 4 |
| 3 – 4 years | 3 |
| 4 – 5 years | 2 |
| Medication | |
| Oral tablet only | 5 |
| Insulin only | 1 |
| Oral tablet and insulin | 4 |
| Not on any medication | 1 |

Theme 1: Healthcare professionals, family, and peer support

All participants regarded the healthcare professionals that they met during their hospital or clinic visits for example, doctor, dietitian, diabetic nurse, and pharmacist as one of the sources to obtain reliable health information.

“The other day after my check up at the hospital, I went to see the dietitian. The dietitian suggested what food is good, what time I must eat, and how to take my medication. Especially during fasting, for diabetic people is different, right?” - SA

“Every time I collect my medication, as usual they will say take this after food. That’s all. The first time I started on insulin, the pharmacist showed me how to inject the insulin.” – S

Getting to see the same healthcare professionals especially doctor, during their regular appointments encourages patient to be more disciplined to follow self-care measures such as healthy eating, exercise, and adhere to treatment regime because of the personal continuity of care. A study done to see the patients’ views on seeing the same doctor found that more than half of the patients interviewed are willing to wait to see their usual doctor due to their good or close relationship with their usual doctor, while the rest cited that it is because of the doctor’s knowledge of their condition (Freeman & Richards, 1993).

“I think... I became like this because I don't get to see the same doctor. If let's say I get to see the same doctor, I'll be more discipline. Because the doctor understands me, right? The doctor knows this and this about me.” - NA

Together with the right health information and support patients received from the healthcare professionals, patients felt reassured that they can take control of their diabetes and more determined to practise self-care.

“For example, like the doctor, the doctor told me that there's hope in diabetes, there's hope to get better if you control and all. The doctor said I can do it. Every time I go for my BSP, the doctor will say almost there. The doctor gives me support.” - ZE

“Because the doctor was like don't worry, you change your diet and then you become healthier, you lose some weight, you'll be okay. So, I felt like my doctor gave me the reassurance.” - JK

One study found that the positive interaction between patients and healthcare professionals facilitates them gaining new knowledge and developing health literacy capacity in terms of accessing and appraising health information (McKenna, Sixsmith, & Barry, 2020). The active participation of patient on their own care and supported by healthcare professionals will results in greater success of effective diabetes care (Shrivastava et al., 2013). This is because those with better knowledge will understand more of the disease and have a better impact on the progression of the disease and complications (Shrivastava et al., 2013).

Nevertheless, many patients with diabetes face multiple barriers to effective diabetes self-care, and one of it is because of the lack of support from their families and friends (Heisler, 2007). Hence, apart from getting support from healthcare professionals, support from family members and peers are also important to ensure the continuation of self-care behaviours.

“I get support from my family, like my husband and all. My mother, my siblings. They tell me, they always remind me not to eat too much, reduce my rice. Eat more vegetables and fruits. With their support, I'm trying to lose some weight. Because my doctor also told me that I must lose weight.” - ZE

One participant felt that having a group self-management programmes could help her in managing her diabetes. Having this peer support is beneficial especially for newly diagnosed patients as they are able to learn new tasks for example, insulin management, from sharing the experiences of others who have gone through the same medical tasks (Heisler, 2007).

“I feel that maybe they can invite people with experience. They can share their experience on how they get diabetes and how they manage it, especially people who have a good record, people who are well managed. Because sometimes people who are newly diagnosed, they don't know (what to do).” - SA

Therefore, having access to sufficient support on a regular basis is crucial in order to ensure effective diabetes self-care management (Heisler, 2007). Not only does it help patients to stay motivated to practise self-care, it also helps in their mental wellbeing as they are in control of their diabetes and consequently may delay or prevent the progression of diabetes complications (Pillar 2 Mental Wellbeing , Self-awareness & Agency, n.d.).

Theme 2: Self-awareness and agency

Self-awareness is the personal and practical application of a person's health knowledge to his/her own health situation whereas agency is the capacity of the person to act based on their knowledge and awareness of his/her situation or condition (Pillar 2 Mental Wellbeing , Self-awareness & Agency, n.d.).

“Now that I know I have diabetes; I start to control my diet. Only now, I start to look after my health. Because I have experience from taking care of my mother. So, I thought to myself if I get stroke, who is going to look after me.” - S

Patients having good understanding about their diabetes, for example, about the blood test results such as Hb1Ac levels or ideal body weight, were more motivated to practise self-care and aware of the areas in their health that needs improving.

“So, I try to maintain or even try to lose a little bit more day by day because my—when I was first diagnosed, I was almost 70kg, and now I am 61, 62. The doctor said I need to go to 58 or even 55. So, I’m still going because growing up I was a chubby girl. I never go, I never go any number lower than 50. So, I’m trying my best to hit that goal so, like achieving this goal, it creates the sense of satisfaction, right? So, that’s how you know, continue my self-care.” - JK

“But I can’t get my average blood sugar level down. The average level you take every three months, blood taken from my arms, you know. I only get to reduce it a few times. From 14 to 12. There’s once they took my blood twice in six months, and I got 10.2. That’s the only time. It should have come down to 7.8 or 6.8. For people with diabetes, the ideal average blood sugar level is 6.8.” - AR

Most participants interviewed practise self-care, for example, eating healthy balanced diet, doing exercise, checking their blood glucose regularly and adhering to their medications.

“For the time being, I really watch what I eat. Rice, I don’t eat normal rice. I eat brown rice, low carbohydrate. And then I eat vegetables. I eat a lot of different variety of vegetables. I use olive oil to cook now.” - SL

“Since I was diagnosed with diabetes, I never missed taking my medications.” - NL

However, some find it difficult to maintain healthy eating as well as adhering to their medication. They are aware that it is important to continue practising self-care, but they find it challenging to change their dietary habits because they have insufficient information on which food they can eat and which food they should avoid eating. For example, one participant thinks that it is difficult to practise healthy eating because the information given by the healthcare professionals is too general and wished that more information can be given to him about controlling his food intake.

“Once you have it then you’ll understand. But to implement it, it’s quite difficult because you understand but... To implement the food part is quite difficult because you do not know what is—what contains carbohydrate and sugar and everything.” - KCK

“Basically, they tell you very general knowledge. Yeah, they sort of talk to you what to eat, what not to eat. So, that’s it. But maybe more information on the food part because diabetic is food control.” - KCK

While some participants were not adherent to their medication regimens due to forgetfulness or work commitments. This is consistent with a study done previously where they found that one of the barriers to non-adherence to medication is due to forgetfulness (Al-Qazaz, Hassali, Shafie, Syed Sulaiman, & Sundram, 2011).

“You know when it comes to a stage where sometimes I feel like I’m okay, I can do it. But sometimes I’ll feel, ahh just eat whatever. And then with medications, I’ll start taking it tomorrow and then oh no, I forgot to take it. Never mind. Start again tomorrow, I’ll follow (doctor’s) instruction.” - NA

Although, we know diabetes information is readily available on the internet, some participants were not sure if the information that they obtained are reliable or not. Several information that they found especially on the internet are linked to products sold online which are claimed to be helpful in reducing blood sugar levels.

“Ahh... I don’t know. Sometimes I feel like it’s true. But we must ask the person who knows better, I think. But sometimes they said, it’s wrong. So, how? Which one is true? But for me, I will listen to the doctor’s advice. I won’t listen to Google.” - NS

“So far there’s a lot (of information on the internet) but so far, 50-50. Because some people sell products. Like in the diabetes group, there’s a lot of posting on selling products. But there is still information which is useful. Like the doctor’s group that I joined. The doctor posts a lot about diet and nutrition but the diabetes group, 50-50. Not many useful information.” - S

Due to these uncertainties, most participants will clarify the information that they have obtained with the doctors.

“I went to search about health supplements. I search for it because I think they are all under MOH (guidelines). So... I look for information and I wanted to take it, but I asked the doctor first. But because I'm on a lot of medications, the doctor didn't recommend me to take it.” - NL

“Yeah. I look at that first (internet). And then I validate with my doctor.” - JK

Lack of understanding and awareness to improve diabetes outcomes may result in the progression of diabetes complications such as eye problems and kidney damage. For example, one participant did not go for follow up appointments after being diagnosed with diabetes due to lack of self-awareness.

“I don't know (why I didn't go for follow ups). I felt lazy. Just let it be. Because my sister didn't go for follow up too after giving birth. But aa... She didn't take her medication too. So, just watch what you eat. Ha, just like that.” - NS

But after experiencing two urinary tract infections, she decided that she needed to take control of her diabetes.

“When I first went to the clinic, the doctor said it is cystitis. The doctor asked me if I have diabetes and I said, yes. So, the doctor gave me medication and then it went away. And then after one or two months later, I got it again. I went to a different clinic. The doctor only gave me medication for cystitis but no antibiotic. I thought why the doctor didn't give me antibiotic, the pain is the same. And then the doctor explained it is because my sugar is high so, he is worried that it will affect my kidneys. I then said, oh God, I must go for follow up again.” - NS

With proper individualised counselling and education from healthcare professionals, for example, having individualised advice on diet and exercise based on patient's lifestyle or job, most participants believed that they are capable of practising self-care and are motivated to continue to self-manage their diabetes successfully.

“Because if the healthcare workers have time to explain about diet, means that they have time to show me which exercise is suitable for me. Ha. It's more visible, you know. What I need to do. Based on age. I'm large, you know. They told me to exercise, but which exercise? I don't think I can run.” - NA

“I'm not talking about other people. I'm talking about my experience. The doctor said to me, I can't eat two packs of nasi lemak, I can only eat one. So, I said to him if only a pack, it's not even a handful nowadays. My job is to carry stuffs. Sometimes it weighs five, ten kg. What I mean is that it's not enough for my energy, right? How do I make sure I have enough energy (to do my job)?” - AR

Continuous counselling and education is important because the aim to conduct a counselling is to optimise diabetic patients' self-care through increase disease knowledge, skills, and self-awareness (Halkoaho, Kangasniemi, Niinimäki, & Pietilä, 2014). A study by Halkoaho et al. (2014) on the counselling content and form between nurses and diabetic patients found that counselling is more focused on medication instead of individual everyday life or health promoting and empowering aspects such as meaningfulness and manageability. Therefore more team work between different stakeholders is needed to ensure a more health-oriented counselling is provided to diabetes patients (Halkoaho et al., 2014).

Theme 3: Fear of developing complications

A study which looked at the associations between barriers to self-care and diabetes complications found that individuals with reduced self-efficacy, for example, lack of readiness to exercise, are more likely to report any complications, which are consistent to previous studies done (Sina, Graffy, & Simmons, 2018). Hence, consistent diabetes self-care is important to ensure better health outcomes in terms of good glycaemic control, fewer complications, improved quality of life and reduction in diabetes-related death risks (Adu, Malabu, Malau-Aduli, & Malau-Aduli, 2019). All the patients interviewed were fearful of developing complications, especially getting their leg amputated or losing their vision due to their diabetes.

“Because all I know about diabetes, once a person gets it, the leg will get amputated or something like that, I don't know. That's all I know.” - SL

“When I was first being diagnosed, I was like, I cried for a few days because I thought that oh, I need to be amputated and when I’m old, I need to, you know those complications. I will die because I cannot see.” - JK

“Again if I don’t want to do it, my sugar would not be good and then those complications that are coming to me, high blood pressure, blur vision, all of the thing that I’m afraid of will come to me. I’m still young. I still need to see the world so, I will need to work very hard to get my sugar very low, to get them at least to normal range so I can see the world longer.” - JK

Fear of developing complications gave them the motivation to research more about diabetes and practise self-care.

“I take it for granted at first. When I was first diagnosed, I didn’t control. I eat like normal and all. And then I started to feel like my legs, I saw black spots on my leg. It made me worried, so I did some research. Then I found out that when your legs start to get darker means that your nerves are damaged. After that I started to do my research again and start to look after what I eat until now.” - SL

“For example, like the disease, the side effects if we don’t look after what we eat. Wounds. But I don’t really get wounds, but I will take in the information because I’m scared. Like gangrene, how do you get it and all. I look for that information. Sometimes when I go to the hospital, I will take the brochures they have, and I will read them.” - S

As the participants recruited for this research were patients diagnosed with T2DM within 5 years period, more than half of the participants were less than 45 years of age. According to the study done by Hillier & Pedula (2003) on the complications in young adults (18 – 45 years old) with early-onset type 2 diabetes, they found that younger adults diagnosed with T2DM have a higher risk of developing cardiovascular disease compared to older patients. Hence, it is important to educate and motivate these younger patients on practising self-care measures so that the development of complications can be delayed or even prevented.

CONCLUSION AND RECOMMENDATIONS

In conclusion, our exploratory research indicates with sufficient access to health services and understanding of reliable health information, patients with T2DM can be motivated or encouraged to practise self-care which consequently may help in delaying or preventing disease progression. Support from healthcare professionals and family members is crucial as it improves the mental wellbeing of these patients helping them to accept the condition and feel in control to manage their diabetes effectively.

Having the skills to access information or services on diabetes care is also crucial as it helps to overcome the barriers faced by people with diabetes, for example getting insufficient information on diet or unable to see the same doctor on their regular appointments, to practise effective self-care management. Individualised counselling or education on self-care based on a patient’s lifestyle or working shift, for example, giving advice on which exercise to do for inactive patients rather than just general advice, will also help to motivate the patients.

The voices of the patients heard in this study needs to be considered by policymakers to improve the quality of diabetes care provided in the country, for example, by expanding the availability of diabetes care services to all primary healthcare facilities and increasing the number of healthcare professionals. With the increasing trend of overall diabetes prevalence in Malaysia, the enhancement of support and education for newly diagnosed T2DM is required to improve self-awareness and to prevent the progression of the condition. This can be done through the enhancement of patients’ skills in accessing information by providing training programmes or workshops to help patients to navigate and find reliable diabetes information and services. This study solely focused on patients’ perspectives therefore, it is recommended that the perspectives of healthcare professionals should be explored to identify gaps in diabetes care services in the country.

DECLARATION STATEMENT

The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

ACKNOWLEDGEMENT

The authors wish to acknowledge and express their heartfelt gratitude to the participants who agreed to participate in this study during the difficult time of COVID-19 pandemic, and also to Medical Research Ethics Committee of the university for allowing this study to be conducted in the public health clinic.

CONFLICT OF INTEREST

The authors declare no self-interest in the study conducted.

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