Med & Health Jun 2022; 17(1): 267-281 https://doi.org/10.17576/MH.2022.1701.20

ORIGINAL ARTICLE

Initiating Activation in Diabetes Self-Management From Patients' Perspective

SYAHNAZ MH[1], IDAYU BADILLA I[2], NASRIN J[3], RAFIDAH B[4], SHALISAH S[5]

[1]Department of Family Medicine, [2]Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia
[3]Freelance Public Health Physician, Dhaka, Bangladesh
[4]Department of Psychiatry,University of Cyberjaya, Cyberjaya, Selangor, Malaysia
[5]Department of Psychiatry, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia

ABSTRAK

Peranan pesakit secara aktif adalah penting dalam menguruskan penyakit kronik seperti diabetes. Bukti semasa menunjukkan pesakit yang aktif mempunyai hasil klinikal yang lebih baik. Beberapa faktor mempengaruhi pengaktifan pesakit telah dikenalpasti tetapi kurangnya pengetahuan tentang bagaimana pesakit berjaya mula mengambil peranan dalam menguruskan diabetes. Kajian ini bertujuan untuk meneroka bagaimana pesakit mula mengaktifkan diri dalam pengurusan kendiri diabetes. Siasatan naratif diambil sebagai pendekatan metodologi kualitatif. Sepuluh peserta yang menghidap diabetes jenis dua telah diambil secara persampelan bertujuan dari satu klinik penjagaan primer awam di Malaysia. Temu bual mendalam telah dijalankan dan direkodkan. Data dianalisis dengan analisis tematik. Tiga tema dan empat subtema telah dihasilkan. Tema pertama, "Mempelajari apa yang perlu dilakukan" menerangkan proses pembelajaran daripada rangkaian sosial dan profesional penjagaan kesihatan yang membantu dalam memahami peranan mereka. Tema kedua menyerlahkan bahawa pesakit menginginkan pendekatan secara beransur-ansur dalam memulakan pengaktifan, iaitu "Mengambil satu langkah pada satu masa". Mereka bermula dengan satu tugasan kendiri yang lebih mudah dan memerlukan masa untuk mengambil peranan mereka. Tema ketiga menunjukkan bahawa apabila pesakit tidak dapat melaksanakan tugasan kendiri yang tertentu, mereka akan melibatkan orang lain untuk membantu: "Melibatkan diri dengan seseorang untuk tugasan yang mencabar". Kesimpulannya, ilmu pengetahuan kendiri diabetes adalah penting dalam membangunkan 'pengaktifan

Address for correspondence and reprint requests: Dr. Syahnaz Mohd Hashim. Department of Family Medicine, 14th floor, Preclinical Block, Faculty of Medicine & Hospital Canselor Tuanku Muhriz, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latiff, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia. Tel: +603-91456117 Email: syahnaz74@gmail.com/syahnaz@ukm.edu.my

pesakit', iaitu keupayaan pesakit untuk mengurus kendiri. Pelan pengurusan kendiri juga haruslah realistik dan sesuai dengan keadaan pesakit. Mempunyai rakan kongsi kesihatan atau rakan dalam kalangan ahli keluarga atau rakan sebaya dapat membantu apabila cuba mengamalkan tabiat pemakanan yang baik dan melakukan senaman yang kerap.

Kata kunci: diabetes, pengaktifan, pengurusan kendiri

ABSTRACT

Patients' active role is crucial in managing chronic illnesses like type 2 diabetes. Current evidence demonstrated patients who were activated had better clinical outcomes. Some factors influencing patient activation have been identified but there is little knowledge on how patients successfully start to take their role in managing diabetes. This study aimed to explore how patients begin to activate themselves in self-management. The narrative inquiry was taken as the qualitative methodological approach. Ten participants with type 2 diabetes were purposively sampled from a public primary care clinic in Malaysia. In-depth interviews were conducted and recorded. The data were analysed with thematic analysis. Three themes and four subthemes were generated. The first theme, "*Learning what to do"* describes the learning process from social networks and healthcare professionals that helped to define their role. The second theme highlighted that patients wished for a gradual approach in initiating activation, i.e. "*Taking one step at a time*". They started with a more straightforward self-management task and needed more time to take up their role. The third theme pointed out that when patients could not perform certain self-management tasks, they would engage with someone else to help: "*Engaging with someone for challenging tasks."* In conclusion, diabetes self-management education is substantial in developing 'patient activation,' i.e. patient's ability to self-manage. The self-management plan should also be realistic and suit patients' circumstances. Having a health partner or buddy among family members or peers is helpful when trying to adopt good dietary habits and perform regular exercise.

Keywords: activation, self-management, type 2 diabetes

INTRODUCTION

Type 2 diabetes mellitus has now emerged as a global pandemic, bringing an enormous threat to human health and well-being (Unnikrishnan et al. 2017). It was estimated that 1.6 million deaths were due to diabetes and this debilitating disease threatens the function of multiple organs, causing blindness, kidney failure, heart disease, stroke and leg amputation

(World Health Organisation 2016). One significant factor leading to these complications is suboptimal glycemic control, which could be contributed by patients' self-management behavior (World Health Organisation 2016). Managing these diabetes-related complications has put enormous pressure on the healthcare system and thus, more innovative efforts are needed to improve diabetes (World Health Organization 2016).

Since type 2 diabetes is a life-long illness, managing this disease largely depends on patients' active role and ability to self-manage (American Diabetes Association 2017). Considering this as an important fact, healthcare providers have proposed that patients take charge and become managers of their own health. The concept of the patient as a manager of health was proposed by Hibbard et al. (2004) is known as 'patient activation'. According to Hibbard et al. (2004), patients could only be activated if they believe they could play an active role, have the knowledge and confidence to self-manage their long term health condition. This concept is also parallel with chronic care models whereby patients need to be activated, empowered to monitor their health and perform self-management tasks (Stellefson et al. 2013; Wagner 1998). It is also in line with the evidence that activated patients had better clinical outcomes, including glycemic, blood pressure and lipid control, as well as a reduction in the cost of care (Greene et al. 2015; Greene & Hibbard 2012).

Past studies have documented that nearly half of patients with diabetes did not achieve a good activation level (Bos-touwen et al. 2015; Hendriks & Rademakers 2014). This was attributed to their negative perception towards diabetes (Bos-touwen et al. 2015; Vugt et al. 2019), depression (Ahn et al. 2015; Bos-touwen et al. 2015), inadequate knowledge (Hendriks & Rademakers 2014), low educational level (Nijman et al. 2014; Smith et al. 2016; Vugt et al. 2019) and poor literacy skills (Ledford et al. 2015; Nijman et al. 2014). In addition, other characteristics were also implicated, such as support from healthcare providers, family members or peers (Alexander et al. 2014; Bos-touwen et al. 2015; Vugt et al. 2019).

While there have been many quantitative studies on patient activation, some scholars claimed that patient activation is a dynamic process and not a static phenomenon (Johnson et al. 2016). This corresponds to the fact that when patients have chronic illnesses like diabetes, they need to develop the ability to self-manage, monitor the disease and take necessary steps to achieve good control (Aamar et al. 2015; Pikkemaat et al. 2019). However, there is currently limited information on how patients with type 2 diabetes undergo this process and successfully start to activate themselves, particularly in self-management.

Therefore, this study aimed to explore how patients start to self-manage and prepare themselves for their new roles. We hope that the current research could provide some information on patients' strategies to achieve activation in self-management, specifically for the Malaysian context. The resultant findings are pertinent in shaping a well-designed activated-based intervention programme to increase their ability to self-manage type 2 diabetes (Schliep et al. 2017).

MATERIALS AND METHODS

Study Design and Participants

A qualitative study was performed to explore the process of activation among patients with type 2 diabetes in a primary care setting from August until November 2018. This study was part of a larger project aiming to develop a suitable activated-based intervention for local patients. The narrative inquiry was taken as the methodological approach to explore patients' experiences on diabetes self-management (Liamputtong 2013). An in-depth interview was chosen as the data collection method, as it could provide a deep understanding and detailed information from the participants' personal experiences (King & Horrocks 2010).

This study was conducted in UKM primary care clinic located in an urban setting. Ten participants with a minimum one-year duration of type 2 diabetes and who were able to speak English or Malay language were recruited. They were purposively sampled to cover a maximum variation of sampling (Liamputtong 2013). Purposive sampling allows the researcher to choose the participants based on specific characteristics such as gender, age, educational level, ethnicity, duration of diabetes, level of glycaemic controls and different types of diabetes treatment ((Liamputtong 2013).

The first participant was a middle-aged man who had poor glycemic control and had diabetes for ten years. The next participant was also a male with poor glycaemic control, but he had a higher education than the previous participant. Both of them were recruited through their physician. The third participant was a middle-aged female with a long duration of diabetes and was selected from the attendees of an Enhanced Diabetes Care (EDC) clinic, a special clinic in our centre that caters for patients with very poor diabetic control (HbA1c ≥9%). All these three participants were from the Malay ethnic group. The fourth and fifth participants were from the Chinese and Indian ethnic groups. Both were also among the attendees of the EDC clinic but had different categories of age, educational background and duration of diabetes. The sixth participant was chosen because of her old age and reportedly faced difficulty managing diabetes by her doctor. The following three participants were selected from the general outpatient pool attendees and varied in terms of ethnic groups, age, and glycemic control. The last participant recruited for this qualitative study was the wife of the first participant.

The interview was open-ended, exploring patients' experience in initiating diabetes self-management (King & Horrocks 2010; Liamputtong 2013). All participants were explained about the study's objective, and informed consent was taken before the interview. The interviews took place in a private room in the clinic and were recorded with a digital voice recorder. A basic demographic and clinical profile of the participants were also obtained. The details of the methodology have also been described in a previous paper (Hashim et al. 2021).

A total of ten in-depth interviews was conducted. The principal researcher had conducted all the interviews in the presence of a research assistant. At the end of the interview, the interviewer had extracted the relevant points and invited the participants to verify them. Afterwards, a debriefing session with the research assistant was held to ensure the interviewer understood the patients' experience and avoid adding the interviewer's personal ideas (McMahon & Winch 2018). The recorded interviews were then transcribed and the transcript then was transferred to Atlas-ti.8 software, a data manager for analysis.

Data Analysis

The data were analysed with thematic analysis and was done in several steps (Braun & Clarke 2006; King & Horrocks 2010). The first step involved reading the whole transcript and performing a descriptive level of coding, which was later reviewed by the research team (King & Horrocks 2010). After two transcripts, the principal researcher then progressed to an interpretative level of coding, whereby a discussion was held and some codes needed to be re-labelled (Braun & Clarke 2006; King & Horrocks 2010). The re-coding process requires the researcher to repeatedly listen and read back the text (Braun & Clarke 2006; King & Horrocks 2010). The process of descriptive and interpretative coding continued until certain patterns could be seen. Codes that were found to have a similar meaning were grouped together, deriving themes and subthemes (Braun & Clarke 2006; King & Horrocks 2010). The themes and subthemes were sorted according to their contents and were subsequently labelled (Braun & Clarke 2006; King & Horrocks 2010).

The data collection continued until the tenth interview, where the research team noted a repetition in the participants' responses and there was no new information. The research team was satisfied that the data had reached a saturation point, in which no new themes emerged (Liamputtong 2013). Although the data analysis followed a series of steps, it was a cyclical process. The research team had continually gone back to the initial steps and kept reviewing the data (Braun & Clarke 2006; King & Horrocks 2010; Liamputtong 2013). Furthermore, the coding process, generating themes and subthemes were checked and verified by the research team. This was to ensure all the interpretations were correct, safeguarding data analysis and research findings (Cypress 2017).

Ethical Approval

This qualitative study is part of a research project and was approved by the Research and Ethical Committee of the Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre (reference number: FF-2018-235).

RESULTS

Ten patients with type 2 diabetes were interviewed. Six of them were Malay, two were Chinese, and the remaining were Indians. Their age ranged between 33 to 67 years old and varied in their educational level, diabetes treatment, duration of diabetes and glycaemic control. Table 1 shows the sociodemographic and clinical characteristics of the study participants. From the analysis, three themes and four subthemes could describe how participants start to activate themselves in diabetes self-management

Learning What to Do

When patients are ready to accept the responsibility to self-manage diabetes, they first learn about their new role.

(i) Having a role model

Some of the participants admitted that they first look upon a real-life example of managing diabetes, mainly from their relatives or peers:

"Initially, I asked myself why God gave me this illness? Why not others? But when I saw my younger sibling with diabetes continues his life as usual. It made me think that it is okay;

Table 1: Sociodemographic and clinical characteristics of the study participants

Characteristics		**Participants (n=10)**
Age groups	30-40 years old	2
	41-50 years old	2
	51-60 years old	3
	61-70 years old	3
Gender	male	3
	female	7
Ethnic groups	Malay	6
	Chinese	2
	Indian	2
Educational level	Secondary school	7
	Tertiary (college/university)	3
Marital status	Married	8
	Single/divorced/widowed	2
Employed	Yes	6
	No	4
Family History of DM	Yes	9
	No	1
Duration of DM	1 to 5 years	4
	6 to 10 years	4
	More than 10 years	2
Current treatment of DM	OHA only	5
	OHA & Insulin	5
HbA1c level (%)	7.0 - 8.0 %	4
	8.1 - 9.0 %	3
	9.1 – 10.0 %	3

Note: DM: Diabetes, OHA: Oral hypoglycaemic agents *there is the medication for diabetes."* (46 years old female, diabetic for 7 years)

Several participants mentioned that they already acquired some knowledge when they once lived with their family member who has diabetes:

"My aunt, mother and sister and even my mother-in-law have diabetes. So I pretty much know about diabetes and how to handle it. I just need to apply..(the knowledge)" (37 years old female, strong family history of diabetes)

On the contrary, the participant also claimed that learning from others could give a setback to managing diabetes. This was because their peers had persuaded them to take traditional treatment as it was thought to be effective and had lesser side effects:

"Some people told me that the pill can cause kidney problems and I was worried about it but I still took the diabetes pill because my younger brother, my father also took it" (46 years old female, strong family history of diabetes)

When deciding whether to take the advice, the participants searched for living proof. They were less convinced when they saw what happened to their peer and own blood sugar:

"My friends told me to try supplements but my blood sugar was still high after taking it, so I stopped. They also recommended other things and I tried, but I never stopped my medication even though my friends said if we take too much of this medicine, our kidneys will be affected." (53 years old female, diabetic for 25 years)

"My friends who have diabetes advise me to take natural treatment such as traditional medicine. But one of my friends who refused to take the doctor's medication ended up with a leg amputation. So I decided that even though I am taking some supplements, I should not stop the diabetes medication." (63 years old male, diabetic for 7 years)

(ii) Seeking Advice from the Experts

The participants commented that even though they knew diabetes from various sources, they still wished to know the exact manner of reducing blood sugar from the real experts.

"Actually, you got a lot of info when you google but then when you have the right doctor, and you listen to the doctor's advice, you can make a healthy life by bringing down your sugar." (33 years old female accountant, diabetic for 2 years)

They acknowledged that they believed and trusted the doctor's advice:

"Initially, I was afraid to take insulin. Some people said that when you take insulin, you will have problems with your kidneys but I asked the doctor whether this is true or not. The doctor said no. Then, I told myself, I follow what the doctor said. The doctor will know what's best." (53 years old female, diabetic for 25 years)

One participant mentioned that he needed a longer consultation time to understand his role and felt that the private medical centre could assist him:

"I also seek care in a private hospital. When they see the patient, it is usually

about half an hour but unlike, at the public clinic, maybe for only 15 minutes. Actually, in 30-40 minutes, there is a lot that we can ask." (46 years old male, diabetic for 10 years)

A participant also commented that having the same doctor-in charge would foster a better learning environment and personalised care.:

"I feel it is better that I stick to one doctor, then the doctor will know me better. I think so far, I have seen 5 or 6 different doctors and they have a different opinion. I am very confused, even on the medication wise." (60 years old female, diabetic for 12 years)

Taking one step at a time

The participants explained that initially, it was difficult to take up the role to self-manage and implement all the given tasks. Instead, they chose to start with a more straightforward task, such as taking oral medications. They admitted that it was much easier to comply with the drug compared to modifying their eating habits:

"Some people told me that I should be doing this and that..I know that I'm not doing..Probably out of 10 things that people told me about, I am only doing 2 or 3 things. I know there are rooms for improvement." (53 years old male, diabetic for 2 years)

"I don't have any problem with Metformin. I think it is difficult to control food because of my appetite" (37 years old female, diabetic for 1.5 years)

One of the reasons as to why they needed a more gradual approach to change was that they are so used to the sweet and delicious taste:

"The most challenging thing is to control the diet. If we have sweet and delicious food in front of us, we usually could not control our appetite. How is it possible when we have been so used to take that tasty food? (53 years old female, diabetic for 25 years)

For this reason, one participant felt reluctant to change his diet but he was keen to learn a healthier food menu:

"I think. I need to improve my food menu..The doctor asked me to change to brown rice but I think it is difficult. The brown rice is not tasty..it is really not nice." (46 years old male with high BMI)

Moreover, it was also during this period that a participant felt the advice given was customary, not tailored to her conditions or dietary preference:

"I think I need to know what sorts of exercise are good for me. I mean like my age is already 60 years old, you can't expect me to jog...so, what type of exercise? I also need to know what type of fruits that we can eat..I find that I'm very restricted to the fruits... I don't really know which fruit is okay and the portions that I can take." (60 years old female, diabetic for 12 years)

As such, in the beginning, healthcare providers should be more understanding as expecting total abstinence from sweet and high-calorie food was impossible for the participants. These comments also pointed out that healthcare providers should not expect an immediate adherence to self-management tasks but should have a short- and long-term plan to facilitate their patients.

On the contrary, some people have

no problem adopting it as they have already started doing so even before the diagnosis:

"Actually, because my parents have diabetes, I stop taking sugar even before. I don't take so much rice now. I have reduced my diet and I am okay with it." (60 years old female, family history of diabetes)

These remarks illustrated the significance of early awareness of good eating practices to the younger generation before diabetes set in.

Engaging with Someone for Challenging Tasks

(i) Getting assistance for technical tasks

Some participants claimed that they initially needed help in certain self-management tasks as they felt incapable of doing it alone. Several reasons might have contributed to the low level of self-efficacy: fear of needles or the task being too technical. One participant stated that she needed some time to overcome the fear and during the period, her children helped her do the insulin injection. She also admitted that the situation was tough for her when she had to master many steps:

"At first, I was afraid to do the injection and my children helped to do it but after some time, I get myself to do it. However, I still couldn't check the blood sugar on my own (with the glucometer). So when the doctor told me what to do (insulin injection), I don't understand cause there are too many things." (67 years old with a secondary level of education, diabetes for 10 years)

The participant's daughter, who was accompanying her, mentioned that her mother would not be able to learn the skill by just having her read. Upon further discussion with her on the possible education methods, she agreed that a video demonstration, together with a face to face discussion, would be the best way to teach her mother self-management skills:

"I don't think my mother will understand how to do it (insulin injection or glucometer) if by asking her to read… "Yes, I think a video will be easier but she still needs someone to sit beside her and explain step by step, according to her pace." (Daughter of the above participant)

Besides, using the glucometer and adjusting the insulin dose desired a problem-solving ability, which was indeed challenging to patients with a low literacy level:

"It is quite difficult for me to use the glucometer as I could not estimate how deep shall I prick myself. So, my husband is the one who will check my blood sugar. He will also tell me how to adjust my insulin." (46 years old with a secondary level of education, diabetes for 10 years)

This information suggests that more assistance and effort is needed to help patients with low literacy skills and family members could play a vital role.

(ii) Needing a buddy to initiate changes

Another challenging task perceived by the participant was modifying their dietary habits and performing regular exercise. Some of them were initially hesitant to make an effort, but they became more determined when seeing their close family member, spouse or peers initiate the change. They felt that they now have a buddy or health partner:

"I think I can control the diet because of my husband. I realise that he is very supportive of many things. If I don't take sugar, then he also won't.. I gain confidence from my husband and I could see the results.. He is like my partner, I have someone who can do a similar diet as I am." (33 years old female with high BMI)

"Previously, I don't have time to do exercise. I went to work early and comes back late. But now, I am following my daughter to do Zumba once a week. So at least I am trying to exercise" (67 years old female, diabetes for 3 years)

Unfortunately, when their buddy was no longer around, they were unable to continue the change:

"I know that exercise could help with the blood sugar but as for me, it is difficult. Previously, I was active in cycling but since my teammate is no longer here, I don't have anyone to exercise with me." (46 years old male with high BMI)

The above statements portrayed that having a buddy or health partner among friends or family members would help patients initiate lifestyle changes.

DISCUSSION

Malaysia is currently having a high number of diabetes cases among Asian countries, which instigated a nationwide call to improve the management of this pandemic. (Hussein et al. 2015; Rhee 2015). An important aspect worth looking into is how patients successfully start to activate themselves in diabetes self-management and this qualitative study aimed to understand it from the patients' perspectives.

When patients are ready to manage diabetes, they first learn about their role. As diabetes is highly prevalent in our society, it is easy to turn to other people for advice. For some patients, their learning process started even earlier before the diagnosis, as they had the opportunity to observe their family members or friends manage diabetes. Yet, this experiential knowledge was superficial and they did not have an in-depth understanding of how to self-manage. Therefore, they sought additional guidance from their exemplars, but some were misled and took other forms of diabetes treatment, such as traditional medicine. The use of traditional medicine is still common among Malaysians, needing a more aggressive effort to curb this issue (Ching et al. 2013; Low et al. 2016a).

It was also clear that patients were initially troubled with many differences in treating diabetes and this could interfere with their learning process and activation course (Low et al. 2016b). However, they made an effort to resolve their doubts about modern medications and realised that they needed expert advice on the best ways to treat diabetes. Hence, in the beginning, healthcare providers should start with what patients should and wish to know (Bockwoldt et al.

2016; Powers et al. 2015). The learning process should also be tailored to their needs and literacy skills as the aim is not just knowledge acquisition but building self-management ability to manage their disease (Bockwoldt et al. 2016; Fan & Sidani 2017; Powers et al. 2017). Nevertheless, this learning process failed to happen to several participants as the team of care kept changing. Furthermore, the time allocated was too short, leading some to seek private medical care that could cater to their needs.

Moreover, learning about good dietary habits and performing exercise was subdued when the participants realised that the self-management plan did not meet their conditions and preferences. For example, white rice and noodles are the staple food for most Malaysians and these types of food are affordable as well as satisfying (Sharkawi et al. 2014). Hence, it seems reasonable for the participants to be reluctant to change to brown rice or even oat because of its bland taste and higher cost. These types of diets are not within the means of those with low socio-economic income and are considered 'tasteless' (Abuelmagd et al. 2019; Aikins et al. 2015).

Another instance is when the participant is an elderly who is unable to jog or run; thus, a non-weight bearing type of exercise programme should be recommended. Our findings tie with the opinion that the "one- size-fits- all" approach for every patient with diabetes is impractical (Beck et al. 2018; Fan & Sidani 2017). This was also evident when some of our participants asked for alternative exercise plans and food menus instead of following the given advice. As such, healthcare providers should move away from 'giving instructions' and offer more suitable options and a realistic self-management plan (Rezaei et al. 2019). A realistic self-management plan would include a personal eating plan based on patients' dietary preferences, a feasible exercise programme and a suitable medication regime (Rezaei et al. 2019). This approach offers some flexibility in self-management and would help avoid feeling burdened or seeing diabetes as living with rules and restrictions (Huyard et al. 2017).

In the beginning, some patients felt overwhelmed with the need to perform multiple self-management tasks (Whittemore et al. 2019). Likewise, the study participants felt it was impossible to carry out everything immediately and they chose to start with a simple task, such as taking oral medications, which concurs with previous reports (Abuelmagd et al. 2019; Huyard et al. 2017). This finding indicates that healthcare providers (doctors and diabetic nurses) should initially focus on a specific task that patients could do and not merely a list of what they should be doing (Whittemore et al. 2019). Moreover, breaking down the tasks into smaller ones and setting short and long-term goals will also elevate their efficacy levels and motivate them (Bandura 1982). This approach is particularly useful, especially for patients who just started to exercise regularly and adopt healthier dietary habits (Huyard et al. 2017; Whittemore et al. 2019).

It is also noticeable that the

participants sought help in tasks that were too technical or required problem-solving skills such as insulin injection, using the glucometer and adjusting insulin dose. In one instance, a participant managed to overcome her needle fear with a family member's help, who was like her 'mentor'. The mentoring or buddy approach had also helped other participants overcome their inertia to change lifestyles. Their hesitancy to change could be because they neither had the experience nor the time to commit, on top of being comfortable with their current lifestyle. However, seeing their family members changing could have made them believe that they can also change. This observation consolidates the opinion by Beverly & Wray (2010) and Dailey et al. (2018), in which the quality of support is extremely crucial in helping people to change. When people feel valued and cared for, together with being pushed by their loved ones, they would be more likely to accept that they need to change (Beverly & Wray 2010; Dailey et al. 2018; Ismail et al. 2018).

Healthcare providers should be aware that utilising closed social network may be a useful approach towards helping patients in diabetes self-management. Malaysians, by and large, is a family-oriented society with members of the community mutually depending and supporting one another (Isa et al. 2019; Sumari et al. 2019). Since Malaysians highly value family ties and social relationships, it was not surprising that the participants were more willing to change when their close ones acted as their health partner or buddy. The result brought another evidence that Malaysian families have a central role in motivating and encouraging patients for behavioural change (Ismail et al. 2018). Meanwhile, one study participant mentioned that some people could easily integrate a healthier lifestyle into their lives, as they have started before the diagnosis. This information highlights that more effort should be made to instil awareness of a healthy lifestyle in the younger generation.

The current study has several limitations. The study was done in one primary care clinic and hence, it could not represent patients' views from other settings. Furthermore, the study did not include a minority of patients who could not speak English or Malay as Malaysia has a diverse cultural and ethnic group. Despite the study limitations, the present study provided some valuable insights for healthcare providers to understand better how patients could initiate activation in diabetes self-management. Several important points are worth noting. First, patients require an in-depth understanding of their role. Although they could obtain knowledge from their social network, they still wish healthcare providers to educate them and provide a realistic self-management that suit their circumstances. The second point is that when patients start to implement self-management, a more gradual approach is preferred and some patients need help with certain tasks. It is also observed that family members could play a crucial role in assisting patients with technical and problem-solving tasks. Moreover, having a health partner among family members or peers is helpful when patients try to adopt good eating practices and an active lifestyle.

CONCLUSION

In conclusion, the process of activation begins with patients' having sufficient knowledge and confidence in implementing self-management. Healthcare providers should ensure a comprehensive diabetes self-management education is being provided for their patients and tailored to their context, needs and literacy skills. This should be incorporated as a routine practice for all patients with type 2 diabetes. We also would like to recommend that further study should be done to explore how having a buddy or mentor could be incorporated as a component in an activated-based intervention in the Malaysian context.

ACKNOWLEDGEMENT

This research was supported and funded by the Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2018-235). The authors would like to thank all the patients who participated in this research.

REFERENCES

Aamar, R.O., Lamson, A.L., Smith, D. 2015. Qualitative trends in biopsychosocial-spiritual treatment for underserved patients with type 2 diabetes. *Contemp Fam Ther* **37**(1): 33-44.

Abuelmagd, W., Osman, B.B., Håkonsen, H., Jenum, A.K., Toverud, E.L. 2019. Experiences of Kurdish immigrants with the management of type 2 diabetes: a qualitative study from Norway. *Scand J Prim Health Care* **37**(3): 345-52.

Ahn, Y.H., Kim, B.J., Ham, O.K., Kim, S.H. 2015. Factors associated with patient activation for Self-management among Community Residents with Osteoarthritis in Korea. *J Korean Acad Community Health Nurs* **26**(3): 303-11.

Aikins, A.G., Awuah, R.B., Pera, T.A., Mendez, M., Ogedegbe, G. 2015. Explanatory models of diabetes in urban poor communities in Accra, Ghana. *Ethn Health* **20**(4): 391-408.

Alexander, J., Hearld, L., Mittler, J.N. 2014. Patient-physician role relationships and patient activation: The moderating effects of race and ethnicity. *Med Care Res Rev* **71**(5): 472-95.

American Diabetes Association. 2017. Standards of Medical care in diabetes - 2017. *Diabetes Care* **40**(1): 1-142.

Bandura, A. 1982. Self-efficacy Mechanism in Human Agency. *Am Psychol* **37**(2): 122-47.

Beck, J., Greenwood, D.A., Blanton, L., Bollinger, S.T., Butcher, M.K., Condon, J.E., Cypress, M., Faulkner, P., Fischi, A.H., Francis, T., Kolb, L.E., Lavin-Tompkins, J.M., MacLeod, J., Maryniuk, M., Mensing, C., Orzeck, E.A., Pope, D.D., Pulizzi, J.L., Reed, A.A. 2018. 2017 National standards for diabetes self-management education and support. *Diabetes Educ* **44**(1): 35-50.

Beverly, E.A., Wray, L.A. 2010. The role of collective efficacy in exercise adherence: A qualitative study of spousal support and Type 2 diabetes management. *Health Educ Res* **25**(2): 211-23.

Bockwoldt, D., Staffileno, B.A., Coke, L., Quinn, L. 2016. Perceptions of Insulin Treatment Among African Americans With Uncontrolled Type 2 Diabetes. *J Transcult Nurs* **27**(2): 172-80.

Bos-touwen, I., Schuurmans, M., Monninkhof, E.M., Korpershoek, Y., Spruit-Bentvelzen, L., Ertugrul-van der Graaf, I., de-Wit, N., Trappenburg, J. 2015. Patient and disease characteristics associated with activation for self- management in patients with diabetes, chronic obstructive pulmonary disease, chronic heart failure and chronic renal disease : a cross-sectional survey study. *PloS ONE* **10**(5): 1-15.

Braun, V., Clarke, V. 2006. Using thematic analysis in psychology. *Qual Res Psycho* **3**(2): 77-101.

Ching, S.M., Zakaria, A.M., Paimin, F., Jalalian, M. 2013. Complementary alternative medicine use among patients with type 2 diabetes mellitus in the primary care setting: a cross-sectional study in Malaysia. *BMC Complement Altern Med* **13**: 148.

Cypress, BS. 2017. Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimens Crit Care Nurs* **36**(4): 253-63.

Dailey, R., Romo, L., Myer, S., Thomas, C., Aggarwal, S., Nordby, K., Johnson, M., Dunn, C. 2018. The buddy benefit: increasing the effectiveness of an employee-targeted weight-loss program. *J*

Health Commun **23**(3): 272-80.

Fan, L., Sidani, S. 2017. Preferences of Persons with Type 2 Diabetes for Diabetes Self-Management Education Interventions: An Exploration. *Health* **9**: 1567-88.

Greene, J., Hibbard, J.H. 2012. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* **27**(5): 520-6.

Greene, J., Hibbard, J.H., Sacks, R., Overton, V., Parrotta, C.D. 2015. When patient activation levels change, health outcomes and costs change, too. *Health Aff* **34**(3): 431-7.

Hashim, S.M., Idris, I.B., Sharip, S., Bahari, R., Jahan, N. 2021. Understanding the Turning Point of Patients with Diabetes. *Korean J Fam Med* **42**(2): 123-31.

Hendriks, M., Rademakers, J. 2014. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. *BMC Health Serv Res* **14**(393): 1-9.

Hibbard, J.H., Stockard, J., Mahoney, E.R., Tusler, M. 2004. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* **39**(4 Pt 1): 1005-26.

Hussein, Z., Taher, S.W., Singh, H.K. G., Swee, W.C.S. 2015. Diabetes Care in Malaysia: Problems, New Models, and Solutions. *Ann. Glob. Health* **81**(6): 851-62.

Huyard, C., Derijks, L., Haak, H., Lieverse, L. 2017. Intentional nonadherence as a means to exert control. *Qual Health Res* **27**(8): 1215-24.

Isa, W.A.R.W.M., Suhaimi, A.I.H., Noordin, N., Harun, A.F., Ismail, J., Abdullah, F.I. 2019. Cultural dimensions of Malay Cultures: Performance of IT Professionals. *Int J Recent Technol Eng* **8**(2S2): 17-21.

Ismail, T.A.T., Jalil, R.A., Ishak, W.R.W, Hamid, N.F., Nik, W.S.W., Mohamed, H. J.J., Mohd, N.H., Arifin, W.N., Mohamed, W.M.I.W., Ibrahim, M.I., Ismail, R., Hassim, T.F.T., Aris, T., Muda, W.M.W. 2018. Understanding dieting and previous weight loss attempts among overweight and obese participants: Insights into my body is fit and fabulous at work program. *Korean J Fam Med* **39**(1): 15-22.

Johnson, M.L., Zimmerman, L., Welch, J.L., Hertzog, M., Pozehl, B., Plumb, T. 2016. Patient activation with knowledge, self-management and confidence in chronic kidney disease. *J Ren Care* **42**(1): 15-22.

King, N. , Horrocks, C. 2010. Interviews in Qualitative Research, hlm. 1st edition. SAGE Publications.

Ledford, C.J.W., Cafferty, L.A., Russell, T.C. 2015. The influence of health literacy and patient activation on patient information seeking and sharing. *J Health Commun* **20**(sup2): 77-82.

Liamputtong, P. 2013. Qualitative Research Methods, hlm. 4th edition. Oxford University Press.

Low, L.L., Tong, S.F., Low, W.Y. 2016a. Selection of treatment strategies among patients with type 2 diabetes mellitus in Malaysia: A Grounded Theory approach. *PloS ONE* **11**(1): e0147127.

Low, L.L., Tong, S.F., Low, W.Y. 2016b. Social influences of help-seeking behaviour among patients with type 2 diabetes mellitus in Malaysia. *Asia Pac J Public Health* **28**(1): 17S-25S.

McMahon, S.A., Winch, P.J. 2018. Systematic debriefing after qualitative encounters: an essential analysis step in applied qualitative research. *BMJ Glob Health* **3**(5): e000837.

Nijman, J., Hendriks, M., Brabers, A., Jong, J., Rademakers, J. 2014. Patient activation and health literacy as predictors of health information use in a general sample of Dutch health care consumers. *J Health Commun* **19**(8): 955-69.

Pikkemaat, M., Boström, K.B., Strandberg, E.L. 2019. "I have got diabetes!" - Interviews of patients newly diagnosed with type 2 diabetes. *BMC Endocr Disord* **19**(1): 1–12.

Powers, M.A., Bardsley, J., Cypress, M., Duker, P., Funnell, M.M., Fischl, A.H., Maryniuk, M.D., Mensing, C., Orzeck, E.A., Pope, D.D., Pulizzi, J.L., Rhinehart, A.S., Siminerio, L., Wang, J. 2015. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *Clin Diabetes* **38**: 13722-82.

Rezaei, M., Valiee, S., Tahan, M., Ebtekar, F., Gheshlagh, R.G. 2019. Barriers of medication adherence in patients with type-2 diabetes: A pilot qualitative study. *Diabetes Metab Syndr Obes* **12**: 589-99.

Rhee, E.J. 2015. Review article diabetes in Asians. *Endocrinol Metab* **30**: 263-9.

Schliep, M.E., Alonzo, C.N., Morris, M.A. 2017. Beyond RCTs: Innovations in research design and methods to advance implementation science. *Evid Based Commun Assess Interv* **11**(3–4): 82-98.

Sharkawi, I., Mohamed, Z., Rezai, G. 2014. Healthy Eating: The Preventive Factors among Malaysians. *Journal of Economics, Business and Management* **2**(4): 257-61.

Smith, S.G., Pandit, A., Rush, S.R., Wolf, M.S., Simon, C.J. 2016. The role of patient activation in preferences for shared decision making: Results from a national survey of U.S. Adults. *J Health Commun* **21**(1): 67-75.

Stellefson, M., Dipnarine, K., Stopka, C. 2013. The Chronic Care Model and Diabetes Management in US Primary Care Settings: A Systematic Review. *Prev Chronic Dis* **10**: 1–21.

Sumari, M., Baharudin, D.F., Khalid, N.M., Ibrahim, N.H., Tharbe, I.H.A. 2019. Family Functioning in a Collectivist Culture of Malaysia: A Qualitative Study. The *Family Journal* **28**(4): 396-402.

Unnikrishnan, R., Pradeepa, R., Joshi, S.R., Mohan, V. 2017. Type 2 diabetes: Demystifying the global epidemic. *Diabetes* **66**(6): 1432-42.

Vugt, H.A., Boels, A.M., Weerdt, I., Koning, E.J., Rutten, G.E. 2019. Patient activation in individuals with type 2 diabetes mellitus: Associated factors and the role of insulin. *Patient Prefer Adherence* **13**: 73-81.

Wagner, E.H. 1998. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* **1**(1): 2-4.

Whittemore, R., Vilar-Compte, M., Cerda, S.D.L., Marron, D., Conover, R., Delvy, R., Lozano-Marrufo, A., Perez-Escamilla, R. 2019. Challenges to diabetes self-management for adults with type 2 diabetes in low-resource settings in Mexico City: A qualitative descriptive study. *Int J Equity Health* **18**(133): 1-10.

World Health Organization. 2016. *Global Report on Diabetes*. *WHO Pres*.

Received: 11 Jan 2022
Accepted: 07 Mar 2022