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Mixed Feelings about the Diagnosis of Type 2 Diabetes Mellitus: A Consequence of Adjusting To Health Related Quality Of Life

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A B S T R A C T

This study aims to explore patients' reactions to the diagnosis of type 2 diabetes mellitus (T2DM) and their health related quality of life. We adopted a qualitative exploratory study design using a thematic analysis. Twelve patients with T2DM for more than a 2-year duration were interviewed using a semi-structured interview guide. Both purposive and theoretical samplings were used for data collection. The in-depth interviews were audio-taped and transcribed verbatim, followed by line-by-line coding and constant comparison to identify the themes. Data management was facilitated using Nvivo 10. Patients shared their mixed feelings about the diagnosis of T2DM. Six domains of quality of life emerged from these interviews, namely physical and social functioning, work function and social obligations, dietary freedom and conforming to treatment standard. Diabetes management needs to take these themes and patients' feelings associated with their quality of life into consideration.

Key words: *diabetes mellitus, help-seeking behaviour, quality of life, coping, qualitative research*

Introduction

Type 2 diabetes mellitus (T2DM) and its complications represent a rapidly expanding public health concern that is expected to affect 552 million people by 2030 globally with devastating health and economic consequences[1,2]. In Malaysia, the situation is equally alarming, with one in five adults aged above 30 years suffering from it[3]. Most agree that the issue deserves full attention and effective efforts should be taken to reduce the prevalence and complications of diabetes which, in turn could save the country from its socio-economic burden. However, with the advances in the technology and modern medicine, the metabolic control among diabetic patients is far from the desired outcome[4,5]. Furthermore, the subjective outcome of T2DM such as emotional feelings and patients' quality of life are often not well addressed[6,7].

Thus, diabetes management requires not only drug therapy, but also to address the social determining factors, which include a change in patients' lifestyle[8]. The same applies to treatment outcome: the emphases should not only focus mainly on clinical outcomes but also on patients' perceived outcomes, which reflect a person's quality of life (or more specifically the health-related quality of life (HRQOL)), and also the psychological impact on her/his daily life[9].

When a person is diagnosed with T2DM, adopting a particular set of help-seeking behaviours[10] is warranted, with the aim of a better controlled blood sugar level, reduced diabetic symptoms and preventing diabetic complications. The prescribed set of help-seeking behaviours often deviates from their routine prior to the diagnosis and impacts on their quality of life[11]. Patients with T2DM have a tendency to experiment with different treatment modalities with the aim of finding an appropriate remedy to suit their needs. The patients need to find a balance to accommodate both the treatment plan and desired quality of life. The HRQOL or treatment outcome is often associated with a person's feelings, whether they are positive, negative or mixed. Ideally, health care providers

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should have the responsibility to help patients to achieve this balance, and hence the need to understand patients' perceived outcomes and HRQOL.

HRQOL is commonly described or measured by three approaches: standard disease-specific instruments, generic instruments and utility instruments[12]. As noted by the WHO, HRQOL is a subjective evaluation, which is embedded in a cultural, social and environmental context[13]. Numerous disease-specific instruments to measure HRQOL[14,15] have been developed and used for many chronic illnesses or diabetes HRQOL studies[16]. The emphasis is on the impact of the illness and its treatments on people's daily lives, taking into consideration their ability to function as well as their emotional reactions[7]. However, those standardised instruments may not be able to explore a further insight into patients' real experiences and perceptions[8], especially with the existence of social-culture differences in a country like Malaysia.

Malaysia consists of a multi-ethnic population with its own different cultures and beliefs. The majority are of Malay, Chinese and Indian ethnicity. The diversity of culture and life style, especially the dietary intake, has contributed to different ways of managing diabetes among patients with T2DM and, consequently, these have influenced their quality of life. Exploring the HRQOL among patients with T2DM in Malaysia relying solely on clinical assessments and from health care providers' perspective do not always capture the real emotional impact, as well as its dimensions.

Currently, there is no published information from exploratory studies on diabetes management among patients with T2DM or its effect on their HRQOL. Though there were extensive publications on the measurement of quality of life using generic instruments among diabetic patients, given the multi-dimensional, cultural and social context, and also the psychological differences of each individual, the in-depth exploratory information from patients' own subjective feelings are indeed more valuable[17]. Therefore, if the patients' experiences and perceptions could help in developing a better diabetic education program for improving the management of diabetic patients in the Malaysian health care system, it would be of utmost importance to understand them from the local context. This paper reports part of the larger study on help-seeking behaviour among T2DM in the primary care setting in Malaysia. The primary objective of this paper is to examine the reactions of patients with T2DM and the effect of T2DM management on the HRQOL of patients. Using a qualitative method is useful because it is able to explore openly the consequences deriving from patients' perspectives.

Subjects and Methods

Study centres were two public and five private primary care clinics in the state of Selangor, one of the thirteen states in Malaysia. Purposive sampling was used to increase the reported variability in the experiences and perceptions of the study's participants from different social and cultural backgrounds.

The conduct of the interviews

Researcher (LLL) conducted the in-depth interviews (IDI) with twelve patients with T2DM. The data was collected from September 2012 to April 2013. The interviews were guided by a semi-structured guide, which consisted of a list of open-ended questions. The questions functioned as triggers for interviews and guides to research objectives. The interviews were exploratory. The researcher probed further on points raised during the interviews to gain a deeper understanding of the patients' reaction to diagnosis, their experiences with the management of T2DM and perceptions towards T2DM and how these affect their quality of life. Questions pertaining to these were asked during IDI. To achieve data saturation, the probing technique was used to enable the researchers to access patients' emotions, feelings and insight into why and how patients manage their illness and its consequences. Though a topic guide was used, the interviewer adopted a conversational style throughout the interview sessions, thereby avoiding medical jargon. The language used during the interviews was appropriate for the participants. Hence, either English, Malay, or Chinese was used depending on the participant's preference. The interviewer is a Malaysian Chinese who grew up in Malaysia and is fluent with all three languages. A good rapport was developed between the interviewer and the participants. This was evident by the sharing of personal information by the participants. A significant level of trustworthiness in the data was achieved because of this rapport. The length of interview sessions ranged from 30 to almost 60 minutes.

Recruitment of participants

Participants were approached at public primary care clinics when they sought treatment. Date, time and the venue for the interviews were decided at participants' convenience. However, participants from private facilities were introduced by general practitioners. All participants were briefed about the study and the interview process either in person (at public facilities) or through phone calls (for those from private clinics). Once they agreed to be interviewed, appointments were made and the venues chosen mainly by the participants. The interview venues were either at the participants' place of work or their houses. However, there were some who preferred to have the interview take place at the clinic, where arrangements were made with a clinic nurse for the use of the diabetes counselling room which was free from disturbances and interruptions, either by the staff or other patients. Participant information sheets were given to them prior to the interview session and written consents were obtained from all participants. All participants were given a small gift as a token of appreciation after the interview session.

Data analysis

We used a thematic analysis approach to identify the themes[18]. The in-depth interviews were audio-taped and transcribed verbatim with all personal identifiers re-

moved, followed by line-by-line coding. Data analysis began immediately after the first interview session. Constant comparison was used to identify the themes. Data management was facilitated by Nvivo 10 (Qualitative data analysis computer software). Familiarisation of the data was done by listening to all audio recordings carefully before transcribing. Transcribing was done by an experienced research assistant and transcripts were checked for consistency prior to analysis. The concurrent and emerging themes (have) led to further interviews. The initial analysis had suggested that help-seeking behaviours of patients with T2DM were a result of trial and error of different treatment regimes, and this had led to further exploration in subsequent interviews on what were their aims of this experimentation. Interviews and analyses were completed primarily by the 1st author, and then followed by frequent discussions with the 2nd and 3rd authors and feedback on the emerging themes. The Malay and Chinese interviews were transcribed and translated into English for the purpose of publication. The translations maintained the same meaning of the original conversation.

Results

Twelve adults with T2DM were interviewed, with ages ranging from 50 to 62 years. The majority of the female (N=7) and male (N=5) participants were married except one female who was single and 2 who were widows. Seven participants had completed up to secondary school education and three completed tertiary level. Four participants were privately employed and another four were housewives. One was unemployed at the time of the interview due to kidney failure. The duration of being diagnosed with T2DM ranged from two and half years to twenty-one years. Participants' social demographic information is shown in more detail in Table 1.

Help-seeking behaviour

We observed that help-seeking behaviour of T2DM among the study's participants was a dynamic process and geared towards rebalancing their quality of life and to fulfil life satisfaction. The journey of the patients with T2DM started from the time when they were newly diagnosed with T2DM either with or without diabetic symptoms or complications. The subsequent actions involved seeking diabetic care. Their help-seeking behaviours showed elements of experimentation with different treatment regimes. The treatment modalities with which the patients had experimented could be broadly classified into trials of modern treatment, traditional treatment and self-care. Modern medicine was contemporary »western« medicine available through health clinic facilities, whereas the traditional medicine included spiritual and faith healers or, traditional home remedies made of several types of plants, natural product and herbs. Self care was often spoken about and a common form of self-management included dietary control, physical activities and self monitoring of blood sugar. The practice of traditional medicine depended on the individual; some took it together with modern medicine but with a different interval time, such as a gap of one to two hours before taking either one. However, some skipped the modern medicine whilst taking the traditional medicine. The stages and development of their help-seeking behaviors were iterative and dynamic and dependant on the influences they received during the experimenting process. The aim of experimenting with different types of treatment was to satisfy their need for rebalancing their HRQOL. The detailed process is as shown in the diagram in Figure 1.

Reactions towards T2DM with mixed feelings

By exploring their reactions and feelings, most of them experienced mixed feelings towards their diagnosis; with positive and negative feelings at the same time. One

TABLE 1
SOCIO-DEMOGRAPHIC OF PARTICIPANTS DIAGNOSED WITH T2DM*

Patient	Sex	Age (year)	Education	Occupation	Marital Status	Duration of T2DM (yrs)
P01	Male	52	Secondary School	Public Employee	Married	4
P02	Female	55	Secondary School	Private Employee	Single	8
P03	Male	52	Secondary School	Unemployed	Married	21
P04	Female	50	Secondary School	Housewife	Married	18
P05	Female	52	Secondary School	Private Employee	Married	2.5
P06	Male	58	Tertiary	Private Employee	Married	10
P07	Male	53	Tertiary	Private Employee	Married	13
P08	Male	58	Tertiary	Retired	Married	7
P09	Female	61	Primary school	Housewife	Widow	10
P10	Female	52	Secondary School	Public Employee	Widow	3
P11	Female	55	Secondary School	Housewife	Married	3
P12	Female	62	No Formal School	Housewife	Married	5

*T2DM (Type 2 Diabetes Mellitus)

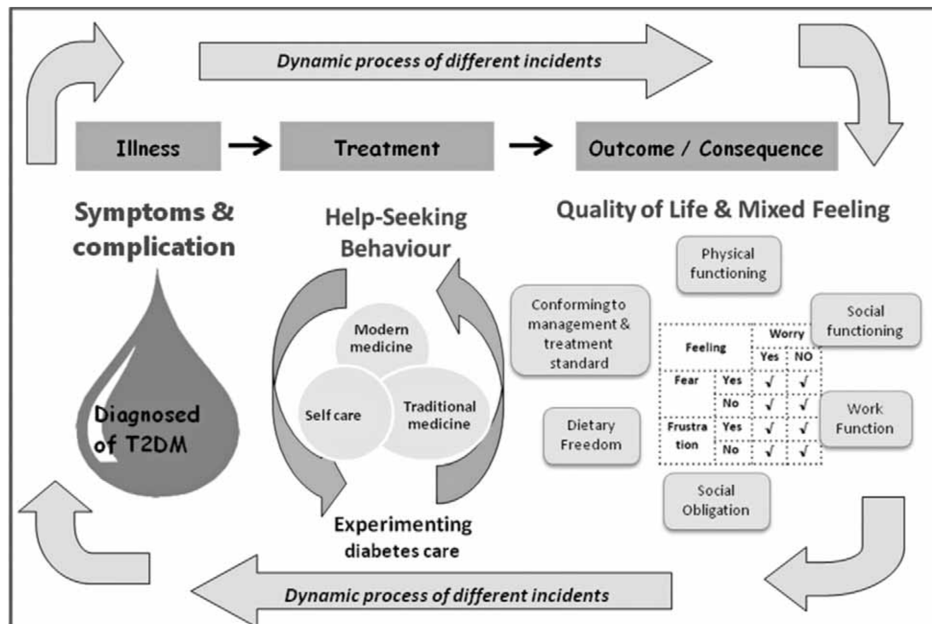

Fig. 1. Dynamic process of help-seeking behaviours among patients with Type 2 Diabetes Mellitus (T2DM).

participant expressed his reaction »Mixed feelings… happy that I am still in the initial stage, so able to control it. Then, certain things you have to be careful and to be disciplined not to take those rice, items which are sweet, and those things which you probably like very much but now have to cut down or even stop completely«. Though he felt frustration with the dietary control he was not too worried because he felt lucky compared to others who had complications. »Maybe I am a bit lucky. Because I see other people who have so many problems. Some even have problems with their legs. So, I thank God that I do not have many of the problems.« (M =male), 58 year-old, diagnosed with T2DM 10 years ago).

Positive feelings

Positive feelings may not necessarily mean being happy to have diabetes, but diabetes mellitus can have positive effects on the quest for one's health and life journey. Patients who had positive feelings were those who looked more on the brighter side of the illness and with some elements of acceptance of T2DM in their life. They perceived living with diabetes as something which made them more cautious in their choice of diet. Consequently they had begun to live a much healthier lifestyle. As with everyone's goal, feeling good and satisfied with life is the main goal for patients with T2DM. One participant shared his positive feelings – although he feared having diabetic complications, he was not too worried and had accepted it as fate after being diagnosed with T2DM, »I feel scared (to death due to diabetic complications) too, but what can I do? God wants to take my life.« (M, 52 year-old, diagnosed with T2DM 4 years ago).

There were also some who accepted diabetes as a part of their life, and thought getting diabetes was something hereditary: »I am not sad because I think I was expecting that I am going to get it because my mother has diabetic... Although, having diabetes itself is not okay, I have to live with it, it is hereditary.« One patient added that having diabetes had changed him to lead a healthier lifestyle: »once you get it (diabetes), you need of manage yourself better. The exercises come in… The food, you choose the item that you read, these all relate to diabetes.« (M, 53 year-old, diagnosed with T2DM 13 years ago).

One participant described her way of adjusting in order to improve her quality of life after living with T2DM for 18 years. To her, a relaxed mind was very important: »I am not worried at all. I am my usual self«, despite the negative reaction she had when she was newly diagnosed with T2DM. This was what she said: »Last time I was scared, too, you know, in the beginning. Why I got it? My children were worried, too. But after sometime, I got used to it and I no longer feel sad. It is important to feel relaxed.« (F=female, 50 year-old, diagnosed with T2DM 18 years ago).

Negative feelings

Negative feelings are the sense of unpleasant feelings that convey fear complications and/or harmful/adverse effect of treatment of diabetes mellitus. Those who had negative feelings were those who harbored elements of non-acceptance of their illnesses. Despite living with T2DM for a long time, they still feared and worried that the condition of their illness might deteriorate. Also, they felt frustrated at having to frequently monitor their blood sugar level.

Negative feelings as expressed among the study's participants included a fear of diabetic complication or worry of insulin injection. Noted by one participant »I will

have to have an injection. I don't want an injection, it is painful. I don't know, but I am scared whenever I see other people getting injections.« (F, 55 year-old, diagnosed with T2DM 8 years ago).

Fear of death was also a sentiment expressed by participant. She treasured her health and was willing to seek treatment even from different health facilities. She said, with much emotion, »We can't see what is happening inside our body, so, blood test must be done. If the clinic here does not perform a blood test on me, I myself will go to other place to do the blood test.« (F, 61 year-old, diagnosed with T2DM 10 years ago). She tried to achieve a balance between being able to take care of herself and also be independent at the same time, particularly when she experienced diabetic complications including the effects of hypoglycaemia. The patient added »I am staying alone in the house, if anything happens to me, for example, if I faint who can save me, as all my children are working?«.

Health related quality of life

The spectrum of mixed reactions whether there were more positive or negative feelings were closely related to how they come to adjust T2DM and its management to their quality of life. For patients with T2DM, the quality of life was about balancing functionality, personal sense of control and adhering to a management plan. Functionality included physical and social functioning, work function and social obligation. Personal sense of control and adhering to a management plan included dietary freedom and conforming to management and treatment standards.

Achieving good physical functioning

Physical functioning is the most important domains for a person's quality of life, including those with chronic illnesses. Being able to have a normal daily life without experiencing any physical shortcomings is the wish of everyone. However, for people with T2DM, fatigue is common. For some, these may be due to the effects of treatment, but for others, as claimed by one of the participants of this study, the fatigue was possibly due to strict dieting which resulted in a lack of energy. Thus, sometimes they tried to skip medication or other non-compliance of diabetes management. The following was related by a participant who shared her experience with adjusting to the quality of life but who did not necessarily adhere strictly to the advice on food intake: »… getting very tired. Tiredness is the main thing. They (the health care providers) will tell you many types of fruit you cannot eat, this fruit, that fruit but, I am still taking fruit«. She further explained that the feeling of tiredness was due to »the body...is not taking enough of normal food.« (F, 52 year-old, diagnosed with T2DM 2.5 years ago).

T2DM is a chronic illness with many symptoms and complications. The symptoms may vary from a mere feeling of thirst, the need to urinate frequent to much more serious ones such as fatigue and blurring of vision. These symptoms invariably affect a person's quality of life or daily life and the person frequently feels worried. Participants voiced their concerns as excerpted below:

»…I am not sturdy when I walk; I will sway, not stable. But it is not giddiness. I can't even walk properly. I don't know, but diabetes is like that; our body will not be normal when walking. At noon, the face will be very pale; I am worried that something can happen, like falling down in the middle of the road, because I go to work on a motorcycle.« (M, 52 year-old, diagnosed with T2DM 4 years ago).

»Whenever I am driving back … before I reach my office, I could experience hypo. I must eat along the way. I must buy one soft drink, to reach the car, to make sure that I reach here (office) safely.« (M, 53 year-old, diagnosed with T2DM 13 years ago).

The ability to perform physically demanding tasks such as driving or travelling is crucial. Physical limitation can have important and devastating emotional consequences.

There were also some who experienced the side effects of insulin injection, so much so that it impeded their daily physical activity as well as their work. To overcome this, they resorted to adjusting the dosage of insulin in order to enable them to carry on with their normal life.

»If I have insulin in the morning, I can't work because I will feel very tired; my body will be very weak. I don't know why. I have the injection at night. After the injection, I sat down, or just lie down and go to sleep. I felt nothing. In the morning, I was not okay. I felt weak and my body felt weak and sleepy.« (F, 52 year-old, diagnosed with T2DM 3 years ago).

Although this patient experienced the side effects of insulin injection, she managed to overcome it. She did not feel frustrated, instead had accepted insulin injection as part of her diabetes management. This was what she said: »...Insulin is ok, good«. In fact, when she was first being introduced to insulin by her doctor, she was worried but after getting an explanation and advice from her doctor, diabetes nurse and her friends who have experienced the insulin injection, she agreed to insulin injection.

Social functioning

As a multi-racial country Malaysia celebrates different festivals according to the various ethnicities. During such festivals, varieties of food are served. In addition, Malaysians like to socialize; socializing and eating out are common activities. These may involve eating out with friends or family members. This participant had this to share: »sometime during festive seasons, I am a bit less cautious about dieting.« (M, 58 year-old, diagnosed with T2DM 10 years ago). But some were a bit careful with their food as one participant said »even though there are always some functions here and there, whenever we go to functions, we also have to be careful with the food intake.« (F, 52 year-old, diagnosed with T2DM 2.5 years ago). So far, she was satisfied with her

management of illness in her daily life and able to adjust well with her social activities.

Although physical functioning had a huge impact on patients' daily lives, their emotional feelings and the need to have social functions were equally important. Participants voiced their frustrations about diabetes management which involved dietary intake, despite the fact that they were aware of the consequences if they failed to control their diet and to regularly monitor their blood sugar level. Hence, adherence to a healthy diet is a challenge and one always has to be more disciplined.

»Normally, after dinner I will go for my religious class which usually ends around 10 or 11pm when they start serving food. That's the problem if the food is served in front of you, I pick it up, then I know, tomorrow it's (blood sugar level) going to be up. I expected that. That's my problem, I am not disciplined enough.« (M, 53 year-old, diagnosed with T2DM 13 years ago).

Work function

Our finding shows that not only does diabetes affect a person's work function, the working environment is also a barrier for diabetes management. The participants related their concerns when their diabetic symptoms had in one way or another affected their work or work function. The following participant had this to say: »If the air conditioning is cold, not even for 5 or 10 minutes, I will have the urge to pass urine. I leave the counter (dealing customer service) too long…that's my dilemma.« (M, 52 year-old, diagnosed with T2DM 4 years ago). They felt that their quality of life was affected and this led them to seek other forms of diabetes treatment which they perceived to be effective in reducing the symptoms. The ability to self adjust the effect of symptoms by trying other forms of treatment was shared by participants. On this, one participant said: »The effect (of traditional herbs) is there. The diabetes (blood sugar level) will go down. My urination became less frequent, unlike before, every hour I had to urinate. I took this (traditional herbs) and it stopped.« (M, 52 year-old, diagnosed with T2DM 4 years ago).

The job functions or the working environment affected their medication compliance. The following participant related how she was not able to follow strictly in taking her prescribed medication because the environment where she worked was not conducive for her to do so.

»I will (didn't take medication for days), because sometimes I also forget because I am working… for example in the morning we had to take the food... then I take the medicine. I have to keep some there (work place)... because when the counter is open we also have to follow their rules...very rushed during that time. So forget the time to take medication. This can happen.« (F, 55 year-old, diagnosed with T2DM 8 years ago).

Social obligations

Social obligations (e.g. in a family or society) emerged from the interview data as one of the domains of quality of life for diabetic patients. The participants spoke about the need to fulfil the expectation or the emotional needs of their loved ones. They talked about moral obligations while at the same time they had to manage their treatment regime, the symptoms and the blood sugar level. Some even skipped the medication or opted for traditional medicine. Below are some quotes from the participants to illustrate these:

»I can feel the effect of taking the medicine. After taking the medicine, I cannot achieve erection. I apologized for saying it. I try to avoid disappointing my wife. Sorry. The medicine, to me, and I am sure, makes my … (penis) weak. So I stop taking this medicine, then I feel there is much improvement. I have the sexual urge, but physically I can't…(get an erection).« (M, 58 year-old, diagnosed with T2DM 7 years ago).

»For example, yesterday I went for some chicken rice. After the chicken rice, my son offered me a glass of carbonated drink and asked me to finish it. I was reluctant. Then I looked at the drink and said to myself if I took it my sugar level would surely go up. Nevertheless, I ended taking the whole glass of the drink! My sugar level was more than 11 this morning!« (M, 53 year-old, diagnosed with T2DM 13 years ago).

The above excerpts showed that the adjustment and coping with diabetes management required discipline on the part of the patients. However, with social obligation, this posed a challenge to many patients with T2DM. Their inability to fulfill many of the activities entailed negative feelings towards diabetes. While those who managed to negotiate diabetes control and functionality tended to have less frustration.

Dietary freedom

While most people perceive that T2DM is not as serious as cancer, it does affect many patients' daily lives, especially when it concerns dietary intake. The feeling of being restricted in the choice of their favorite or personally preferred food could affect their HRQOL, which would eventually lead to more psychological impact. Several participants lamented about the loss of what they considered to be a normal life, one that they had enjoyed before being diagnosed with T2DM. Interestingly, this participant used a metaphor to describe the feelings before and after the diagnosis.

»I used to eat some moon cake (sweet Chinese cake) before, but now I have reduced the amount. So now we know our quota for all these is up already (limitation) for ice cream and soft drink« (M, 58 year-old, diagnosed with T2DM 10 years ago).

He added »Ya, very important discipline... I try to refrain from it. You want to have a long life, you must try to stop this thing (favorite food), because this thing »quota« for you, is already up (to it)«.

Diabetic patients want to have the freedom of eating whatever they want. For example, this participant, even though she knows the consequence of non-compliance to following a strict diet for diabetic patients, she was un-

able to comply. Many times, she just did not care. She claimed that her body felt very weak if she did not get to eat her favorite food whenever she felt like eating it. The reason given by her »I cannot control eating the food I like; I just need to taste it.« (F, 55 year-old, diagnosed with T2DM 8 years ago). On the other hand, she was also worried about her uncontrolled blood sugar level which might require changing treatment regime from oral medication to insulin injection. She shared her doctor »Scolding me, my reading so high and suggested for injection (insulin). I say I don't want an injection«. So it was obvious the contradictory situation between this patient who was trying to adjust to fulfilling her quality of life and the management of diabetes, even though her doctor kept reminding her that »you have to control your food, you know!« She wished to be able to eat things that she liked. She wished for the freedom of eating any food, which was commonly restricted by the health care practitioner.

Another participant spoke about his experience with regards to controlling his dietary intake:

»I do not know. I really don't know. Because you're so confident that you know how to manage, you kind of take the risk, once in a while I take a risk. Once in a while I go and take durian (tropical fruit), you know, things like that. Although I should not be eating durian (fruit which contains a high amount of sugar), sometimes I can eat the whole durian.« (M, 53 year-old, diagnosed with T2DM 13 years ago).

He was quite happy when his nutritionist told him how to manage his diet by controlling the portion of the food instead of totally skipping his favorite food. He shared the information obtained from his health care providers: »Everybody told me that durian is so sweet and then the doctor told me durian is very sweet but the food nutritionist at the hospital told me that, yes, you can eat everything. Anything you can go and eat but it's a matter of portion«.

Conforming to management and treatment standards

Conforming to treatment standard was one of the challenges affecting patients' HRQOL. The ability to follow the treatment regime and adjusting to minimal interference of treatment in patients' daily life was one of their aims. T2DM is a chronic illness; frequently monitoring of blood sugar level is critical. This could be seen in the way patients were struggling to conform to management and treatment standards prescribed by their health care provider. One participant had this to share: she confessed that conforming to diabetes management was always a dilemma for her and at the same time she was also worried that her attending doctor would question her failure to control her blood sugar level »...ask why my blood sugar level is so high.« (F, 55 year-old, diagnosed with T2DM 8 years ago). It was obvious that her concern was not only about her diabetes condition but also her dilemma in conforming to treatment requirements. She was aware and had admitted that the reason for her uncontrolled blood sugar was due to her indiscretion in her diet.

Taking medication is part of a patient's daily ritual. When patient forgets and misses the medication, they will naturally feel frustrated. Another participant shared how he struggled with the dosage, especially when he needed to take it three times a day. »I think taking medicine also involves discipline. Sometimes, I missed taking medicine, always forget to take after lunch, because most of time, I go for lunch and forget about the medicine. I always go out for lunch; I don't come back (to the office) and the medicine I kept in the office here.« (M, 58 year-old, diagnosed with T2DM 10 years ago). Thus, his doctor had made adjustments to suit his daily life style by changing the frequency and the dosage to only twice a day.

Sometimes, patients were worried that the doctor would scold them for non compliance. »My blood sugar was high because I didn't take medication... my medication was finished... because I had missed the appointment but I didn't tell doctor... I was scared that the doctor might scold me.« (M, 52 year-old, diagnosed with T2DM 4 years ago).

Nevertheless, some of the participants complied strictly with the treatment standards and also the doctor's advice. »I am scared of getting kidney failure. My glucose level is high, so I had to take injection and followed the doctor's advice.« (F, 61 year-old, diagnosed with T2DM 10 years ago). Even when going abroad for holiday, she had no problem managing her medication. »I bring it along with me. 24 hours. Even during my vacation, I will bring my diabetic pen and the medicine along with me in my luggage bag«.

Living with T2DM is like a long journey; it has also become part and parcel of the daily life of the patients. As such, adjusting to diabetes management and treatment standard require good planning. Another participant related how she planned and made adjustments in order that her treatment schedules would not be disrupted due to the demand of her work. »If I want to go traveling, I can't take along the insulin. Sometimes, I have to attend a course, so I inject in the morning before attending, as I cannot bring it with me because there is no suitable place like a fridge to keep the medication. In such situation, I will only take oral medication. If I attend the course for 4 or 5 days, I don't have insulin for the duration...« (F, 52 year-old, diagnosed with T2DM 3 years ago).

Discussion

This exploratory qualitative study gives insights into the feelings and reactions of patients towards T2DM and their reason for choosing to experiment with different treatments for their diabetes. This study found that emotional reactions ranged from positive, negative and mixed feelings. The six HRQOL domains that emerged were physical and social functioning, work function, social obligation, dietary freedom and conforming to management and treatment standards.

A number of studies suggest that diabetic patients frequently suffer from depression and anxiety[9,19–23]. In addition, however, it is common for some of diabetic patients to begin to accept their condition over the years and become less worried[24]. The present study had found that there were mixed reactions among diabetic patients: being happy but having feelings of frustration, they can also have very negative feelings and positive feelings towards T2DM. They claimed they felt happy and lucky compared to those with more serious conditions, but felt frustrated at the same time as they needed to change their lifestyle which restricted their freedom to eat whatever they liked. Therefore, health care providers need to pay more attention to this when treating diabetic patients. Family members could give more emotional support rather than just giving instrumental support or tangible goods and services[25,26].

In terms of help-seeking behavior, there was common belief that the reasons patients with T2DM did not comply with the prescribed diabetes management due to barriers such as affordability and accessibility to health facilities[27,28]. However, the findings from our study demonstrated otherwise – the patients failed to comply or preferred to opt for traditional medicine despite easy accessibility to private or public health facilities. Affordability may not be the main barrier, as free diabetes treatments are easily available at public primary health care centres in this country[29]. It is important to realise that diabetic patients' help-seeking behaviour is influenced by patients' quality of life and life satisfaction. Hence, if these are affected much by diabetic treatment, compliance might be at stake. Health professionals should be aware of this when treating patients with T2DM.

For patients with T2DM, self-management in diabetes care plays a crucial role in the success or failure of its treatment and the prevention of complications. For it to be successful, the patients need self-discipline and a very strong will power[30]. While many studies show that knowledge and awareness are good indicators for the success of a patient's self care and good management of T2DM, our study showed that even though diabetic patients knew and understood the dire consequences of eating unhealthy foods or non-compliance with medication schedules and doctor's advice, most of the time their needs and their desire to maintain a good quality of life over-rode good diabetes management if there were competing demands of a job or social obligations. This was also found in other studies[30].

The aspect of life with diabetes that might affect their physical functioning has been well documented and recognized in many studies[31,32]. Our study confirmed that physical and social functioning including work function, especially for those on insulin injection, affected their quality of life[33,34]. Generally, the effect of insulin could push a person to either not adhering to or self adjusting the treatment regime in order to get a better quality of life. Health care providers were aware of this behavior of their patients[35]. Hence, it would be beneficial for both parties if the health care providers and patients could work together in dealing with treatment regime and minimize the diabetes symptoms in order to have a better outcome and avoiding an increase in non-compliance rates[34,36–38].

Several studies have shown the impact of T2DM on patients' performance or work productivity[39,40]. A person's nature of work may also affect adherence to diabetes management. Consequently, such non-compliance could affect a person's work life that contributes to his or her emotional feelings. Social support is crucial for patients with T2DM to overcome this limitation and minimize the barrier for compliance with diabetes management in their work life.

The study also revealed that the aim of patients who skipped medication or tried out traditional medicines was to fulfill their social obligations. Social obligations explored in this study referred to fulfilling the expectation and emotional needs of a person's loved one. Previous study had shown that the impact and management of chronic illnesses involved everyone who cared or lived with the patients. This also means that caregivers, family members and even society can affect the way patients manage their T2DM[41]. Our findings supported previous studies that the sense of responsibility or the reluctance to reject the needs of others[42], might complicate diabetes management or self-care because of the feelings of obligation[43]. In order to achieve what they thought could have less impact on their relationship with their family members; they were even willing to go to the extent of compromising their compliance with diabetes management. Despite many studies that had explored family influence (support or non-supportive behavior) in daily management of diabetes[44,45], little is known on how the influence of patients' sense of obligation has over-ridden their knowledge and awareness on compliance with diabetes management. Furthermore, there is a need to explore the mechanism of balancing between a patient's role in the family and adherence to diabetes management.

Diabetes is a complex chronic disease which requires a drastic modification of one's personal lifestyle. Many patients claimed they had to change their »normal life style« to one that was »healthy« in order to control their blood sugar level, diabetes symptoms and also preventing any diabetes complications[46]. In the current study, this appears to be an issue among study participants. Lifestyle change is a lifelong commitment which not only requires change of dietary intake but also involves physical and psychological adjustment. This has posed a feeling of restriction in a person's daily life; patients no longer feel a sense of personal or dietary freedom. This is not only experienced by people with T2DM[8,43], but also by those suffering from other illnesses especially chronic ones where a long term commitment is required[47]. Further exploratory and intervention studies into this domain could be valuable to help patients with T2DM to gain more satisfaction in life.

Our findings showed evidence that patients with T2DM adjusted to have a better quality of life out of which some had struggled to conform to their treatment standard.

While rebalancing between their HRQOL and treatment regimes, some of them experienced depression or resorted to unorthodox treatments. Previous studies had found that depression was one condition that was quite common among diabetic patients[48,49]. A review done by Gonzalez and colleagues[50] found that those who had difficulty complying with diabetes management, including self care, could suffer from stress and depression. Perhaps, a better mechanism of understanding, or a specific health education program, focusing on patients' self discipline and a positive mind, should be developed. The health care providers should look beyond diabetic signs and symptoms (i.e. blood sugar level and complications) when treating patients with T2DM and when addressing concerns with compliance in chronic disease management[41]. Perhaps, a larger scale quantitative study would be helpful to look into the relationship between adherence to management and treatment standards and HRQOL.

Strengths and limitations

Exploring a patient's experience and perception using qualitative in-depth interviewing is very important as it provides a detailed description of how a person goes through the journey of his or her illness[51,52]. In-depth interviewing also provides a good rapport with patients in order that the information obtained be reliable and valid. This is because when there is a good rapport between the researcher and the interviewees, the interviewees are more relaxed and are more willing to »open up«. The majority of studies focus only on patients in public health facilities, whereas this study covered both public and private ones, including both rural and urban settings.

As with all studies, current results should be interpreted within the context of relevant limitations. The findings of qualitative methods used in present study do not represent the average opinion of diabetic patients, but it allows the generalization of the concepts of relationship between patient feelings and adjusting to the quality of life of diabetes. However, the result should create awareness among health care providers when treating patients with T2DM, help policy makers to design future diabetes education programs. Findings from this study can be used to develop questionnaires or interview instruments to test the reliability and consensus validity in larger samples.

Conclusions

A patient's HRQOL is an important outcome in today's healthcare systems. Objective and subjective outcomes are equally important in assessing the impact of treatment, particularly for chronic illness like T2DM requiring lifelong treatment. The findings from this exploratory in-depth study indicate the quality of life of patients is subjective and personalized in nature. Thus, to understand a patient's quality of life, the patient's feelings should also be considered apart from the physician's perceptions on the clinical outcome. Not all emotional consequences of diabetic treatments are negative. The study revealed that there was mixed feelings among patients for the different incidents associated with their quality of life.

In essence, the ultimate goal of diabetes care is to enhance the quality of life of patients and their feelings. Patients' perceptions and experiences tended to intertwine with their quality of life and the condition of their illnesses. This complexity is very much translated into patients' help-seeking behavior, such as trying different treatment regimes including home-made remedies, traditional herbs or changing their dietary intake. Diabetes is a huge problem globally as well as locally. As such, if the quality of life is not addressed properly, holistic care will not be successful. Hence, understanding a patient's reaction to the diagnosis and its management allows health care providers to empathize with them and plan an optimal strategy to help patients cope with diabetes. This in-depth information could be used to provide more patient-centered information for diabetes care to clinicians. Awareness on help-seeking behavior among patients with T2DM can benefit policy makers to design diabetes programs. Patients and family members too, can benefit by learning from others on overcoming their fear of diabetes.

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POMIJEŠANI OSJEĆAJI O DIJAGNOZI DIJABETESA TIPA 2: POSLJEDICE PRILAGODBA PREMA ZDRAVSTVENOJ KVALITETI ŽIVOTA

S A Ž E T A K

Ova studija istražuje reakcije pacijenata na dijagnozu tipa 2 šećerne bolesti (T2DM) i njihovo zdravlje u svezi kvalitete života. Primijenili smo kvalitativnu studiju koristeći tematsku analizu. Dvanaest bolesnika s T2DM tijekom 2 godine je intervjuirano kroz polu-strukturirane smjernice za intervju. Oba uzorka, svrsishodna i teorijska, iskorištena su pri prikupljanju podataka. Opsežni intervjui su auditivno zapisani i zatim prepisani od riječi do riječi. Upravljanje podacima je olakšano korištenjem programa Nvivo 10. Pacijenti su podijelili svoje pomiješane osjećaje o dijagnozi T2DM. Šest domena kvalitete života je proizašlo iz tih razgovora – fizičke i socijalne funkcije, radne funkcije i društvene obveze, prehrambene slobode i prilagodba prema terapiji. Pri ophođenju sa dijabetesom treba uzeti ove teme i osjećaje pacijenata povezanih s njihovom kvalitetom života u obzir.