

A Qualitative Exploration of Diabetes Self-Management among Young People with Type 2 Diabetes Mellitus in Malaysia

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ABSTRACT

INTRODUCTION: Diabetes self-management, an essential part of diabetes care, involves complex cognitive abilities such as performing medical, physical, and emotional management tasks. Nonetheless, little knowledge is available on how the young population with type 2 diabetes mellitus (T2DM) in Malaysia engages in self-management, despite the growing prevalence of T2DM in this group. Therefore, this study aimed to explore self-management behaviours among young people with T2DM. **MATERIALS AND METHODS:** In-depth interviews were conducted with sixteen young people aged between 10 and 24 years old at two tertiary hospitals in Malaysia, and data were analysed thematically. **RESULTS:** The themes that emerged revealed that young people demonstrated different levels of activation in self-managing their T2DM, which can be grouped into proactive, adaptive, inadequate, and negligent. **CONCLUSION:** The young people in this study recognised the importance of diabetes self-management; however, they needed the support from caregivers, friends, and healthcare professionals to maintain emotional well-being and sustain daily diabetes self-management.

Keywords

Diabetes self-management; Type 2 diabetes mellitus, young people, qualitative study

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INTRODUCTION

Type 2 diabetes mellitus (T2DM) has become a major public health concern among young people (aged 10 to 24 years) worldwide, including in Malaysia.¹ This phenomenon has been associated with urbanisation and industrialisation, the general transition to a sedentary lifestyle, globalisation, and the commercialisation of fast food products and consumption.^{2,3} As young people with T2DM are at higher risk of developing diabetes-related micro- and macrovascular complications, diabetes self-management is the foundation of better T2DM health outcomes.⁴

Whilst several studies have explored diabetes self-

management among adults with T2DM, the self-management behaviours of young people and adults may differ because the former might be less mature⁵ and display lower self-efficacy in executing diabetes self-management tasks.^{6,7} In addition, the management and treatment among young people is challenging since most of them have poorer illness control, behavioural problems, or risk-taking behaviours as compared to other groups of persons without chronic illness.^{8,9} Previous studies of adolescents with T2DM have focused mainly on Western settings and generally aimed to identify the factors that influence diabetes self-management among young people.¹⁰ There is also a lack of studies on the

patterns of diabetes self-management practices among young people from a multi-racial country such as Malaysia. Such information could aid in the development of interventions for young people at various stages of diabetes self-management. Therefore, this study aimed to explore the practices and self-management styles among young people with T2DM in Malaysia.

MATERIALS AND METHODS

Study design

Using descriptive phenomenology to explore the authentic experiences of individuals living with a common phenomenon, a qualitative study was conducted in the endocrine clinics of two Malaysian tertiary hospitals from November 2019 to September 2020. The purposive sampling method was used to recruit the informants, who were young people aged 10 to 24 years old¹¹, with a T2DM diagnosis for at least six months, and who could communicate in Malay or English. Potential informants were first identified by endocrinologists and nurses based on their medical records. Next, potential informants waiting for a doctor's consultation during their routine medical follow-ups were approached by the first author (NO) for an interview after obtaining informed consent.

Data collection

The informants were interviewed either in a secluded corner near the clinic or *via* telephone. As all the investigators were proficient in English or Malay, the interviews were conducted in either language, depending on the informants' preferences. The interviews were conducted using a semi-structured interview guide, which had been developed based on the literature review and the findings from a previous meta-synthesis conducted by the investigating team.¹⁰ The interview sessions were audiotaped and lasted approximately 20-40 minutes.

In-depth interviews were conducted until saturation.¹² The informants' sociodemographic data, types of treatment, and anthropometric data were obtained from their medical records.

Data analysis

The data was first familiarised by iteratively listening to the audio recordings before transcription. For the interviews conducted in Malay, the transcripts employed the same language to maintain the exact meaning of the original conversations. Analysis was conducted in Malay and English to maintain contextual validity, and the selected participants' quotes were translated into English. The transcripts were read and verified by the informants and the other investigators (YYW and QYL) to ensure the accuracy of information.¹³

Thematic analysis was used to analyse and report themes within the data.¹⁴ All the transcripts were line-by-line coded by NO to generate as many open codings as possible.¹⁵ Then, NO held regular meetings with the team (YYW and QYL) to review, arrange, or collapse similar codings into sub-themes and finally generate the overarching themes.¹⁶ The final themes were subsequently cross-checked and agreed upon by all the authors. The informants were identified and categorised into "pro-active", "adaptive", "inadequate", or "negligent", based on their diabetes self-management practices that emerged during the analysis process.^{17,18}

All the qualitative data were managed using NVivo (QSR NVivo version 12, QSR International), whilst the informants' sociodemographic and anthropometric data were managed using Microsoft Excel® (Microsoft Corp, Redmond, WA, USA) and analysed using IBM® SPSS® version 20. The continuous data were presented as the median and interquartile range (IQR).

RESULTS

Characteristics of the young people

Sixteen young people with T2DM participated in this study. The majority were female (n=12) with a median (IQR) age of 19 (16.8-21.0) years old. Only one informant was diagnosed with nephropathy, whilst others did not suffer diabetes-related complications at the time of data collection. Table I summarises the clinical characteristics and the management of T2DM among the informants.

Table I: Young informants' sociodemographic characteristics (n = 16)

Characteristics	Median (IQR)	n (%)
Age (years)	19 (16.8-21.0)	
Gender		
Female		12 (75)
Male		4 (25)
Anthropometry		
BMI (kg/m ²)	28.9 (22.9-34.0)	
BMI category*		
Normal		5 (31)
Pre-obese		4 (26)
Obese I		3 (19)
Obese II		3 (19)
Obese III		1 (6)
Age at diagnosis (years)	13 (10.8-16.5)	
Duration of diagnosis (years)	3 (1-8.5)	
HbA _{1c} (%)**		
≤7.0%	9.9 (6.7-11.5)	5 (31)
>7.0%		11 (69)
Physical activity***		
Yes		12 (75)
No		4 (25)
Management of T2DM		
Therapeutic lifestyle changes		2 (13)
Metformin		6 (38)
Insulin		2 (13)
Metformin and insulin		6 (38)
Types of insulin regimens		
Basal only		3(37.5)
Basal-bolus		1(12.5)
Pre-mixed		4 (50)

IQR, Interquartile range; T2DM, type 2 diabetes mellitus; BMI, Body Mass Index; HbA_{1c}, Glycated haemoglobin *Classification of weight by BMI (kg/m²); Underweight = <18.5; Normal range = 18.5-22.9; Pre-obese = 23.0-27.4; Obese I =27.5-34.9; Obese II =35.0-39.9; Obese III = >40 ¹⁹ **The most recent HbA_{1c} obtained from the informant's medical record at the point of interview ***Physical activity is defined as engagement in at least 150 minutes per week of moderate-intensity activity. For the answer "Yes", it indicated the respondents were able to complete physical activity for 150 minutes per week, while the answer "No", it indicated the respondents were unable to complete physical activity for 150 minutes per week.

Themes

Theme 1: Diabetes self-management activities

All the informants expressed the view that lifestyle modification is imperative for achieving optimal health outcomes. The diabetes self-management behaviours frequently practised by the informants were dietary changes, medication taking, physical activity, symptom monitoring, risk reduction, and healthy coping.

Dietary Changes

Almost all the informants attempted to eat healthily, for instance, by avoiding foods with high sugar content, reducing rice portion sizes, intermittent fasting, starting to consume brown rice, and monitoring their calorie intake.

"I tried to reduce my glucose intake by reducing sweet foods and drinking lots of water." (P#10)

However, the young people were sometimes unable to resist the temptation of certain foods or drinks, such as when going out with friends or seeing advertisements on

social media.

"I still ate fast food and sweet drinks, once a month, when I am going out with my friends." (P#14)

"... Of course, I have the desire to eat, especially viral food [food that had been advertised on social media]. So that was the hardest part." (P#08)

Medication taking

Most informants acknowledged that taking medications was crucial for optimal glycaemic control. The subjects of the study practised medication adherence strategies, such as punctual post-meal medication taking or keeping medication close to hand. Informants with long-standing (11 years) T2DM claimed that medication taking had become part of their daily rituals.

"I took medicine as usual, to manage, I will make sure I take medicine right after a meal." (P#12)

However, some informants expressed concern about the side effects of medications, such as headache, fatigue, and weight gain. Moreover, some of them neglected their medication routine as they felt overwhelmed by the daily demands of diabetes self-management. Another reason might be attributed to the overwhelming daily demands of multiple insulin injections.

"Because of the medicine, sometimes I become easily tired and sleepy. At work, I kept drinking water to keep fresh, because I am afraid that anything might happen to me." (P#01)

"Sometimes I am too lazy even to look at my medicines. I just look at the medicine; sometimes, I do not inject at all." (P#14)

Physical activity

Physical activity tended to be performed by the school-age informants, as sport is on the school syllabus. However, in general, the involvement of young people in sports activities was minimal, especially among females. Common reasons for their lack of physical activity included time constraints, low self-esteem, feeling uncomfortable when exercising alone in public, living in a

rural area, and feeling too tired to exercise.

"For me, the difficult part is exercise, as it will take my time and energy." (P#01)

Self-monitoring blood glucose (SMBG)

SMBG was frequently performed by young people using insulin, but rarely by those treated only with metformin or therapeutic lifestyle changes.

"I did glucose monitoring at home. Previously, 7 times per day, 7 times, before and after a meal. But now, the doctor asked me to do it just once daily. From there, I know my blood glucose level, and I control my meals based on the glucose reading." (P#08)

Meanwhile, not having a glucometer or glucose strips, fear of finger pricking, and not knowing how to use a glucometer were the reasons given by the informants for not performing SMBG.

"... My mother has her glucometer, but I don't know how to use it, so I rarely check my glucose at home." (P#10)

Risk reduction

To resolve hypoglycaemia, several informants who had experienced this acute event mentioned their strategies, such as keeping sweets nearby, adjusting insulin doses, and taking medications punctually.

"I have experienced hypoglycaemia before, I took sweet, 3 sweets, I took sweet anywhere I go." (P#04)

Healthy Coping

The young people encountered stress due to the disease and its management, yet they found ways to cope. For example, the female informants preferred to talk and seek advice from their friends during their T2DM journey.

"Sometimes I feel I want to rebel, then I always call my friend, tell her my problem about this [T2DM management], then she gives me advice." (P#14)

Theme 2: Diabetes self-management styles

Although the activities mentioned above are essential to controlling the disease and delaying its advancement, not

all the self-management behaviours were collectively practised by the young patients. The data obtained suggests that the informants could be grouped into four diabetes self-management styles: proactive, adaptive, inadequate, and negligent, based on their levels of effort in diabetes self-management. Table II summarises the diabetes self-management styles adopted by the young people with T2DM in this study.

Table II: Diabetes self-management styles among the young people with type 2 diabetes mellitus

Self-management styles	Pro-active	Adaptive	Inadequate	Negligent
Young informants' diabetes self-management behaviours	They were strict in their diet, medication taking, and SMBG.	Maintained a healthy diet and performed physical activity, but the people around them might influence their diabetes self-management behaviours.	Performed certain self-management tasks, but they tended to make excuses to avoid practising the behaviours.	Not performing any diabetes self-management due to diagnosis denial.
Caregiver's involvement	No caregiver involvement due to independence.	Need involvement from caregivers.	Improper guidance from caregivers or rejection by informants.	Little to no caregiver involvement.
Informant(s)	P#03, 23 years old, duration 1 year, HbA1c=8.6% P#08, 21 years old, duration 1 year, HbA1c=6.5% P#09, 21 years old, duration 1 year, HbA1c=6.0% P#12, 21 years old, duration 11 years, HbA1c=6.1%	P#02, 18 years old, duration 8 years, HbA1c=12.6% P#04, 18 years old, duration 2 years, HbA1c= 12.6% P#13, 22 years old, duration 12 years, HbA1c= 11.0% P#14, 19 years old, duration 10 years, HbA1c=12.0% P#15, 19 years old, duration 8 years, HbA1c=11.3% P#16, 15 years old, duration 2 years, HbA1c=6.0%	P#01, 19 years old, duration 1 year, HbA1c=9.2% P#06, 17 years old, duration 4 years, HbA1c=16.4% P#07, 21 years old, duration 10 years, HbA1c=11% P#10, 16 years old, duration 3 years, HbA1c=7.7% P#11, 13 years old, duration 0.5 years, HbA1c=13.5%	P#05, 14 years old, duration 1 year, HbA1c=6.7%

SMBG = Self-monitoring blood glucose, HbA1c= glycated haemoglobin

Pro-active: The pro-active informants tended to accept responsibility for self-managing the disease and were committed to change by adhering to a healthy diet, medication taking, and SMBG. The proactive informants were older, and the majority had achieved good glycaemic control (Table II).

"I really take care [of my T2DM]. Even when I get pregnant, I can reduce [my HbA1c] to 6.5% as compared to before, 8.4%." (P#08)

Adaptive: Those who demonstrated the adaptive style recognised the importance of diabetes self-management;

however, they were not prepared for the autonomy of behavioural change. Most informants in this category were younger than those in the proactive category and had been diagnosed with T2DM for over 2-12 years. and had relatively poor glycaemic control, with most falling into the HbA_{1c} range of 11%-12.6%. The informants indicated that the involvement of parents is essential in their daily diabetes self-management, especially in ensuring healthy eating and medication taking, as narrated by one of the informants:

"I reduced my carbohydrate, fat, and sweet foods. My mum always cooks for me, fish and vegetables. She cooks either curry or steamed dishes." (P#04)

Moreover, support from friends was crucial in sustaining diabetes self-management, especially in out-of-home settings.

"... they [friends] are helpful. They will ask me whether I have already taken my medicines or not." (P#15)

Inadequate: The young people with inadequate diabetes self-management tended to manage their T2DM without proper guidance from their caregivers.

"My mother is also diabetic; she eats as usual. So, I just eat whatever I want as well." (P#07)

Some informants even exhibited rebellious behaviour and rejected their caregivers' instructions.

"Sometimes after school they ask me to take medicine. I am stressed. So, I told them to keep quiet and go. I know what to do." (P#06)

Negligent: Only one informant, having been categorised as negligent, was in denial about his diabetes status, as his HbA_{1c} was low and therefore, he made no progress in learning and practising disease self-management. Moreover, the patient mistakenly thought that his HbA_{1c} was 3.3%, given that he was in denial mode.

"... I am fine. My glucose level (HbA1c) is just 3.3% [correct value was 6.7%]. I ate 3 plates of rice and chicken for each

mealttime. I ate 3-4 pieces of chicken or fish. I ate rice and chicken three times, morning, evening, and for dinner." (P#05)

Due to his condition, he had been mocked by his friends.

"... I frequently need to go to pee [at school], and my friends make fun of me. I don't want to go to school, I want to change to another school, but my teacher said I had been dismissed from school." (P#05)

DISCUSSION

This study aimed to explore the diabetes self-management practices and styles of young people with T2DM in Malaysia. The current study findings echoed those of previous research, with healthy eating, medication taking, and physical activity identified as the most frequently performed diabetes self-management tasks among young people.^{20,21} Meanwhile, a few young people who performed SMBG had an awareness of hypoglycaemia and displayed effective coping with T2DM, which are indispensable for patient empowerment.²²

Previous meta-synthesis identified that individual knowledge, coping skills, and health status might influence diabetes self-management among young people with T2DM.¹⁰ Our current findings suggested that the age of the informants and the duration of diagnosis may affect the style of diabetes self-management. The older informants tend to proactively self-manage their own illness. This is also confirmed in previous qualitative studies that the older young people are more mature than the younger group, thus having more understanding, better skills, and a willingness to take responsibility in managing their own illness.^{23,24} Having said that, our findings speculated that individuals with longer duration of T2DM and suboptimal HbA_{1c} readings are found to have poorer diabetes self-management, which is in agreement with previous studies.²⁵⁻²⁷ This study also clearly demonstrated that the patient's treatment modalities influence diabetes self-management style, particularly when combining insulin injections and oral medication. Most young people in the proactive group were managed by a single therapy, whereas the majority

of individuals in the adaptive and inadequate group were treated by a combination therapy including insulin injection. This situation suggests that young people with T2DM face challenges in self-management, especially those with complex insulin regimen therefore, future studies may seek to fill this gap.^{28,29}

In addition, the young people from the pro-active group exhibited more discipline and autonomy in diabetes self-management, so they were the most likely to demonstrate controlled HbA_{1c}. The characteristics of the pro-active informants in this study resembled the attitudes of young people with pre-diabetes and T2DM reported in a previous study: those displaying highly disciplined, autonomous, and strategised diabetes self-management tended to achieve better HbA_{1c} control.¹⁷ Furthermore, pro-active adults with T2DM were reported to be active in knowledge seeking and peer support groups.¹⁸ Importantly, most informants in this group also had a shorter duration of T2DM, which may have contributed to better glycaemic control compared with the adaptive group, who generally had a longer disease duration and poorer HbA_{1c} outcomes. Early in the disease trajectory, compensatory insulin secretion and fewer cumulative metabolic complications may facilitate glycaemic stability, thereby reinforcing the effects of proactive self-management behaviours.

Although the “adaptive” young people were shown to understand the importance of diabetes self-management, social support could influence the long-term sustainability of their diabetes self-management, as mentioned in the meta-synthesis.¹⁰ In contrast, those classified as ‘inadequate’ were at the contemplation stage because they understood diabetes self-management but lacked motivation and action. This was possibly due to the influence of caregivers with diabetes, who tended to be poor role models for their children. The caregiver must be a positive role model in promoting self-management.²¹ On the other hand, one patient was categorised as negligent despite having an HbA_{1c} level of 6.7%. The relatively favourable HbA_{1c} observed in this patient may be attributable to the short duration since disease diagnosis (approximately one year). During the early phase of diabetes, residual pancreatic b-cell function and

endogenous insulin secretion may be partially preserved, permitting a transient compensatory response to hyperglycaemia and consequently contributing to lower HbA_{1c} levels.³⁰ The “negligent” young patient, however, denied his diabetes status and was unmotivated in performing daily diabetes self-management tasks, which could potentially deter him from sustaining good glycaemic control. This corresponded with other study findings identifying that individuals who denied their diabetes diagnosis were less likely to assume responsibility for adopting lifestyle changes and diabetes self-management, which consequently jeopardised their health outcomes.^{18,31}

The current findings revealed that the 'pro-active' group of young people, who possessed diabetes self-management discipline, awareness, and abilities, could serve as role models for effective diabetes self-management behaviour. Continuous support from family and friends is likely required by young people in the ‘adaptive’, ‘inadequate’, and ‘negligent’ groups. More enforcement by healthcare professionals is needed for those in the ‘inadequate’ and ‘negligent’ groups. These include frequent discussions with the young people and caregivers to identify the issues and to provide support in their self-management activities.^{23,32,33} In addition, young patients need to accept responsibility for making lifestyle changes and cultivate a sense of empowerment to control their disease,²³ and intervention in diabetes self-management education should include the participation of caregivers and peers to allow young people with T2DM to cope with external environments.¹⁷

This stratification of the young population based on their diabetes self-management styles might help healthcare professionals to identify which forms of support and services are needed to enable more proactive diabetes self-management among young people. The trustworthiness of this study was determined by employing four-dimensional criteria, namely credibility, transferability, dependability, and confirmability.³⁴ Accordingly, the credibility of the study was enhanced, whereby the researcher employed member checking by continually engaging authors who had rich experience in diabetes management to ensure the results reflected the

informants' perspectives. Furthermore, data triangulation was performed as the informants' clinical data were extracted from their medical records. The information about the study design and the data collection method was succinctly described in the method section of this manuscript for transferability. A maximal variation sampling strategy from two different hospitals was used in this study to maximise the range of relevant information and diversity of participants. For dependability and confirmability, the themes were generated based on the coding by three authors and further confirmed by all authors. Furthermore, the themes obtained were derived and supported by direct informants' quotations. An additional qualitative and quantitative study using a large sample size from various settings would be useful to confirm the influences on the different types of self-management practices and styles employed by young people with T2DM.

CONCLUSION

Most of the young people performed diabetes self-management, especially in terms of healthy eating, medication taking, and physical activity, exhibiting four identified categories of diabetes self-management style: proactive, adaptive, inadequate, and negligent. An understanding of the strengths and weaknesses of each diabetes self-management style would enable healthcare professionals to channel the appropriate support and services to enhance young people's ability to self-manage their T2DM.

INSTITUTIONAL REVIEW BOARD (ETHIC COMMITTEE)

The study was approved prior to its commencement by the Medical Research and Ethics Committee, Ministry of Health, Malaysia [NMRR-18-3476-44989 (IIR)] and the Universiti Teknologi MARA Research Ethics Committee [UiTM_600-IRMI (5/1/6)].

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