ORIGINAL ARTICLE

Trajectory, Perceived Causes and Efforts in Diabetes Self-management: A Qualitative Study Among Young People With Type 2 Diabetes Mellitus and Caregivers

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ABSTRACT

Introduction: Previous studies have suggested that young individuals with type 2 diabetes mellitus (T2DM) face challenges in achieving optimal diabetes self-management, leading to difficulties in attaining the recommended glycaemic target. The reasons behind these suboptimal practices remain unclear due to the limited number of studies conducted in Malaysia that focused on diabetes self-management among young people. This qualitative study aimed to understand the lived experience of young people with T2DM on self-management in Malaysia. **Methods:** Young people at the age of 10 to 24 years, who had been diagnosed with T2DM and the caregivers who managing young people with T2DM were interviewed. Data were thematically analysed with the aid of QSR NVivo version 12. **Results:** Sixteen young informants and eleven caregivers participated in this study. Three major themes conceptualised the lived experience of diabetes self-management: (1) the trajectory to T2DM diagnosis; (2) perceived causes of T2DM; (3) the efforts in diabetes self-management. The route of diagnosis and experiential knowledge about T2DM might determine their efforts in the self-management among the young people. Healthy eating, medication taking and physical activity were perceived as important tasks in diabetes self-management. The involvement of the caregivers in diabetes self-management evolved over time. **Conclusion:** The study highlighted the experience of young people and caregivers since the beginning of the diagnosis and their strategies in diabetes self-management. More understanding of the lived experiences of patients and caregivers in disease management within the socio-ecological context could help to improve health-care services and intervention for this population.
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INTRODUCTION

Type 2 diabetes mellitus (T2DM) accounts for 90% of all diabetes cases (1). Whilst T2DM is commonly diagnosed among the adults, recent reports have marked an increasing prevalence of T2DM in young people aged between 10-24 years old (2,3). The prevalence of newly diagnosed youth-onset T2DM is increasing in Western countries (4,5) and the South-East Asian region (6,7). In Malaysia, the prevalence of diabetes in young people aged between 18-19 years had increased 160% within four years (from 2.1% in 2011 to 5.5% in 2015) (8,9). Likewise, an increasing diabetes trend is observed among those aged between 20-24 years, with the latest prevalence reported at 5.4% in 2019 (8–10).

Young-onset T2DM has a higher lifetime risk of

hyperglycaemia and progresses more disruptively than adult-onset T2DM (11). Diabetes self-management is the cornerstone of good glycaemic control and reduces the risks of diabetes-related complications (1). Diabetes self-management requires high cognitive functions to understand the disease and its treatment, manage medications, self-monitor disease and symptoms, reduce health risks, and collaborate with healthcare professionals (HCPs) (12). Diabetes self-management is principally driven by patients outside of the clinic setting (13) and necessitates pervasive behavioural changes that are interwoven with an individual's daily routine (11).

Previous studies in United States identified that most young people are unable to reach the recommended glycaemic target (14,15). This could be due to the immaturity and low self-efficacy among young people in executing the diabetes self-management tasks (16,17). A recent meta-synthesis identified the factors contributing to diabetes self-management activities among young people (intrapersonal, family, community or institution) exists as two-pronged process in which each factors might either hinder or facilitate diabetes self-management (18). However, the findings from the meta-synthesis unable to elicit the extent of the involvement of young people and their family in diabetes self-management activities. While the meta-synthesis analysed the studies conducted among adolescents in the Western countries, the findings cannot be directly generalised to a multi-racial country like Malaysia which consists of different ethnicities, cultures and beliefs. To date, two Malaysian studies had focused on reporting the extent of glycaemic control and the prevalence of T2DM-related complications among young people (19,20). For instance, a study by Yeow et al., (2017) identified that youth with T2DM is characterised by marked impaired β-cells in presence of insulin resistance (21). Furthermore, study by Siew et al., (2022) showed almost 50% of adolescents with T2DM attending endocrine unit were diagnosed with diabetic nephropathy (20). In addition, a recent cross-sectional study conducted in paediatric setting in Malaysia found that adolescents with T2DM had lower diabetes self-care behaviour scores than in adolescents with type 1 diabetes mellitus (22).

These studies however did not delve into investigating the needs and challenges of performing diabetes self-management outside of clinic setting, with limited input from healthcare professionals. It is imperative to delve into the patients' lived experiences before developing any effective and impactful diabetes self-management education intervention for young people with T2DM in Malaysia. Moreover, this study aimed to triangulate responses from the young people and the caregivers to gain a broad contextual understanding of the lived experience in diabetes self-management.

MATERIALS AND METHODS

Study design and setting

This phenomenology study was conducted to capture the experience in diabetes self-management activities among young people with T2DM from the perspectives of the young people and the caregivers (23). Previous meta-synthesis (18) showed that caregivers' attitudes and perceptions could influence diabetes self-management behaviours among the young people with T2DM. Therefore, including caregivers in this study can offer valuable insights into the lived experiences of young individuals in managing T2DM outside of a clinical setting. This study was conducted in two tertiary hospitals in Malaysia, from November 2019 to September 2020. The purposive sampling was employed to recruit young people and the caregivers. The inclusion criteria were the young people age between 10- to 24-year-old and diagnosed with T2DM for at least 6 months, while the caregivers were parents or guardians directly involved in taking care of the young people with T2DM for at least 6 months. Both groups of informants should be able to converse in either Malay or English. The study was approved by the Medical Research and Ethics Committee, Ministry of Health, Malaysia [NMRR-18-3476-44989 (IIR)] and Universiti Teknologi MARA Research Ethics Committee [UiTM_600-IRMI (5/1/6)] prior to the study commencement.

Data collection

Upon verbal agreement to participate, the young and caregiver informants were provided with separate consent and assent forms to sign. Adolescents aged between 10- to 17-year-old were required to hand in signed assent forms and parental consent forms. They were subsequently interviewed at a secluded corner near the clinic or via telephone interview, depending on the informants' preferences. Interviews with the young people and the caregivers were conducted separately. The interviews were conducted by one of the investigators (NO) using a semi-structured interview guide (Appendix A) developed based on the literature review and the findings from a meta-synthesis conducted by the investigators (18). Probing questions were posed to gain better explanations and clarifications in order to encourage the participants to express their thoughts and perceptions (24). Each interview session was audiotaped and ranged from 20 to 40 minutes. The young informants' sociodemographic data, types of treatment, clinical data (e.g. HbA1c, treatment and duration of diagnosis) and anthropometric data were obtained from the medical records. The caregivers' sociodemographic data and diabetes status were obtained from the caregivers whilst the details of their child's diabetes status (HbA1c, treatment and duration of diagnosis) were obtained from the medical records. The

inclusion of caregivers' diabetes status in this study holds significant importance, as their personal experience can greatly influence their understanding and ability to assist in managing the child's diabetes. The interviews were conducted until theme saturation was reached and further confirmed with two subsequent interviews for both groups of young people and caregivers respectively (25,26).

Data analysis

The data was first familiarised by iterative listening to the audio recordings and transcribed verbatim. The transcripts were read and verified by the informants to ensure the accuracy of information. Furthermore, the transcripts were read and verified by the second (QYL) and last authors (YYW). Thematic analysis was used to identify the themes which described the essence and core commonality of the lived experience (23,27). Briefly, the analytical process involved becoming familiar with the data by repeatedly reading the transcripts, generating initial codes, grouping and naming the data into codes, arranging codes into themes, reviewing and refining themes, defining and naming themes, and writing the report that fully described the informants' lived experience (28). The field notes documented the informants' body languages and facial expressions during interviews were also reviewed to provide rich context about informants' expressions towards their lived experience. Moreover, the informants' background information was considered while interpreting the data and the contextual living experience were grounded from the informants' own words. Both the data from young and caregiver informants were triangulated to provide a comprehensive understanding of young people's lived experience in self-managing T2DM. Furthermore, triangulation of two different resources could enhance the study trustworthiness (24). The audit trail and trustworthiness of this study are provided in Appendix B. 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. Since all continuous data were not normally distributed, the data were therefore presented as the median and interquartile range (IQR).

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

Characteristics	Median (IQR)	n (%)
Age	19 (16.8-21.0)	
Gender		
Female		12 (75)
Male		4 (25)
Ethnicity		
Malay		8 (50)
Chinese		3 (19)
Indian		4 (25)
Others		1 (6)
Status		
Student (secondary education)		7 (44)
Student (tertiary education)		4 (25)
Student and part-time worker		1 (6)
Full-time worker		2 (13)
Housewife		1 (6)
Not working		1 (6)
Family history with diabetes		
Yes		15 (94)
No		1 (6)
Anthropometry		
BMI (kg/m^2)	28.9 (22.9-34.0)	
BMI category*		
Normal		5 (31)
Overweight		2 (13)
Pre-obese		2 (13)
Obese I		3 (19)
Obese II		3 (19)
Obese III		1 (6)
Age at diagnosis (year-old)	13 (10.8-16.5)	
Duration of diagnosis (years)	3 (1.0-8.5)	
HbA_{1c} (%),	9.9 (6.7-11.5)	
≤7.0%		5 (31)
>7.0%		11 (69)
Management of T2DM		
Therapeutic lifestyle changes		2 (13)
Metformin		6 (38)
Insulin		2 (13)
Metformin and insulin		6 (38)

*IQR, Interquartile range; BMI, Body Mass Index; HbA_{1c}, Glycated haemoglobin *Classification of weight by BMI; Underweight = <18.5; Normal range = 18.5-22.9: Overweight = >23; Pre-obese = 23.0-27.4; Obese I =27.5-34.9; Obese II =35.0-39.9; Obese III = >40* [26].

RESULTS

Demographic data of the informants

Sixteen young people aged between 13 to 23 years old agreed to participate in this study (Table I). The majority of the young informants were Malays (n = 8), female (n = 12), full-time students (n = 11) with a median (IQR) age of 19 (16.8-21.0) years old. Of the 16 informants, only five (31%) had normal body mass index (BMI). The HbA1c of most of the informants (n = 11; 69%) had exceeded the target range [HbA1c < 7.0% (53.0 mmol/mol)] recommended for the young population (29), with the median (IQR) of 9.9% (84.7 mmol/mol) [6.7-11.5% (49.7 – 102.2 mmol/mol)]. Informants' treatment regimens varied from metformin only (n = 6), both metformin and insulin (n = 6), insulin therapy only (n = 2) and therapeutic lifestyle changes (n = 2).

On the other hand, 11 primary caregivers were interviewed (Table II). The majority of the informants were Malays (n = 5), female (n = 8), and mothers (n = 7) of the young people with T2DM. A total of eight caregivers (73%) have a medical history of T2DM.

Table II: Caregivers' sociodemographic characteristics (n = 11)

Characteristics	Median (IQR)	n (%)
Age	49 (44-45)	
Gender		
Male		3 (27%)
Female		8 (73%)
Ethnicity		
Malay		5 (46)
Chinese		3 (27)
Indian		3 (27)
Relationship with the informants		
Mother		7 (64)
Father		3 (27)
Grandmother		1 (9)
Child's duration of diabetes (years)*	2 (1.0-3.5)	
Self-reported T2DM status		
Yes		8 (73)
No		3 (27)

IQR, Interquartile range; T2DM= Type 2 diabetes mellitus
**The duration of diabetes in Table 2 differs from those in Table 1 because not all the interviewed caregivers were the direct parents/guardians of the young informants in this study.*

Themes

Three major themes and thirteen subthemes (Table III) emerged from the data to describe the experience of young people and the caregivers in diabetes self-management. Firstly, the informants recalled the trajectory of their disease diagnosis along with the acceptance of their diagnosis. Secondly, the informants stated the perceived causes that attribute to the diagnosis of T2DM and finally the efforts from both young people and the caregivers in diabetes self-management.

The trajectory of T2DM diagnosis

This theme encapsulated the informants' (both the young people and caregivers) experience of the T2DM diagnosis and perceptions. The informants described the situations that led to their T2DM diagnosis, as well as their reactions to the news.

Unanticipated route of diagnosis: The young people experienced disturbing body signs such as fever, frequent urination, swollen leg, boils, and severe dandruff that prompted further medical investigation. The diagnosis of T2DM was then confirmed following a series of in-depth medical investigations. Likewise, an unusual urine test result identified during the medical check-up for boarding school admission prompted further investigations by the HCPs leading to T2DM diagnosis of one of the young informants.

"*She did a medical check-up for boarding school admission… her urine [analysis] did not look well. Then we submit her [check-up] result to the teacher, and the teacher questioned the result…. Two hours later, we went to the emergency department, and her blood glucose was 16. Then, the doctor referred her to a specialist." (Primary caregiver (PCG)#09, mother)*

Anticipated route of diagnosis: In the anticipated route of diagnosis, the caregivers with T2DM were aware of the disease's risk factors such as being overweight and having sedentary lifestyle, common signs and symptoms of T2DM. Therefore, the caregivers were proactive in sending their children for medical investigation.

"*My mum forced me to come here [for a diabetes check-up] because I am overweight, and she was a bit worried [at that time] as both my parents are having diabetes." (Patient#09, 21-year-old, HbA1c =6.0%)*

Interestingly, one of the caregivers was concerned with her child's weight and had initially enrolled her child in a clinical study for obstructive sleep apnoea. However, the HCPs advised her child rather to take part in a weight management study. Her child was then diagnosed with T2DM during the study.

"*I suspect since she was 12 because she is overweight. After that, I enrolled her in OSA (Obstructive sleep apnoea) study… but they [HCPs] were concerned about her weight. After further assessment, they found out that she has T2DM." (PCG#10, mother)*

A mixed reaction to diagnosis: "Sadness, frustration, disappointment, and shock upon diagnosis" were the most common descriptions brought up by the informants when they were first informed about T2DM diagnosis. These emotions stemmed from the awareness about the health consequences of T2DM, worry about the treatment, the food's restrictions and fear of social stigma. Moreover, the caregivers blamed themselves for neglecting their children's lifestyle before diagnosis.

"I cried when she was diagnosed. She is my daughter. I regret because I did not stop her from taking sweet drinks and sweetened food. But what to do? I got diabetes since I am pregnant with her." (PCG#09, mother)

On the other hand, two informants described that they were naïve towards the T2DM diagnosis as they were too young (at the age of 9-10 years old) to understand the chronicity of T2DM and entirely relied upon their caregivers in the disease management. As they grew older, they understand the possible complications of uncontrolled T2DM, they started to feel demotivated by their suboptimal HbA1c levels.

"Initially, I did not overthink. I recognised, oh, I got T2DM. But people started to watch my diet and told me don't eat this to avoid my blood sugar from increasing. When I grew up, I started to feel demotivated, disappointed because now I know the complications and what will happen in the future. I always think, why me?" (Patient#13, 22-year-old, HbA1c = 11.0%)

"It's written by the God": Some informants were readily accepting the disease diagnosis and perceived

Table III: Themes, subthemes, categories and example of quotations

Themes	Subthemes	Categories		Example of quotations
		Young people	Primary caregiver	
The trajectory of T2DM diagnosis	Unanticipated route of diagnosis	Experienced disturbing body signs	Detected during medical check up	*"She did a medical check-up for boarding school admission… her urine [analysis] did not look well. Then we submit her [check-up] result to the teacher, and the teacher questioned the result…. Two hours later, we went to the emergency department, and her blood glucose was 16. Then, the doctor referred her to a specialist." (Primary caregiver (PCG)#09, mother)*
	Anticipated route of diagnosis	-	Pre-existing T2DM diagnosis	*"I suspect since she was 12 because she is overweight. After that, I enrolled her in OSA (Obstructive sleep apnoea) study… but they [HCPs] were concerned about her weight. After further assessment, they found out that she has T2DM." (PCG#10, mother)*
	A mixed reaction to diagnosis	Sad, frustration, disappointment, and shock upon diagnosis Too naïve to understand T2DM. Acceptance	Parents' self-blame for neglecting their child It's written by the God	*"I cried when she was diagnosed. She is my daughter. I regret because I did not stop her from taking sweet drinks and sweetened food. But what to do? I got diabetes since I am pregnant with her." (PCG#09, mother)* *"Initially, I did not overthink. I recognised, oh, I got T2DM. But people started to watch my diet and told me don't eat this to avoid my blood sugar from increasing. When I grew up, I started to feel demotivated, disappointed because now I know the complications and what will happen in the future. I always think, why me?" (Patient#13, 22-year-old, HbA1c = 11.0%)*
Perceived causes of T2DM	Unhealthy lifestyle	High sugary diet Sedentary lifestyle Lack of diabetes prevention campaign	High sugary diet Sedentary lifestyle	*"For me, diabetes is all about the sugar. The food intake causes elevated sugar in our bodies. For example, the rice will be processed into sugar and maybe because of the [excess intake of] rice, it caused diabetes." (Patient#09, 21-year-old, HbA1c =6.0%)*
	Genetics	-	inherited illness	*"I think my children got diabetes from the generation, genetic. Both my parents and parents in law had diabetes. But most Indians had diabetes. I heard that Indians had smaller pancreas, but I am not sure. My niece told me. She is a doctor". (PCG#05, father)*
	History of GDM	-	Mothers with GDM during pregnancy	*I got diabetes when I am pregnant. It is dangerous if the mother cannot control their desire to eat, then it will become a habit. I had an experience when I was first diagnosed with GDM when I am pregnant with my third child in my first trimester. The endocrinologist told me that if I can't control my GDM, it will become permanent 7 or 10 years later. And that is true. Because when we can't control our food, it is dangerous (PCG#10, mother)*
The efforts in diabetes self-management	Change of diet	Reduce rice intake Intermittent fasting Calorie tracking using app	Preparation of home-cooked meal	*"I have installed "my fitness pal". I will keep track the [food] that I consumed." (Patient#09, 21-year-old, HbA1c =6.0%)* *"I will encourage my children to control their food intake. Regardless they have diabetes or not. They must control the sugar level and my children normally do not buy junk food and canned drinks. (PCG#02, mother)*
	Physical activity	Part of school curriculum Involve in indoor activities	Providing reminder and companion	*"I don't need extra time to exercise because I already joined " olahraga" [sports] at school, so I am already used to run." (Patient#06, 17 years-old, HbA1c =16.4%)* *"Every day, I took her for exercise…like today one round, second day, 2 rounds, third day 5-8 rounds…until she is sweating…If I did not go, then she will not exercise" (PCG#02, mother)*
	Medication taking	Keep medicine near sight	Enforce medication taking	*"At home, I will put the medicine on the table, or I will put it near to my water dispenser machine, so every time I drink plain water, I will remember, I have not taken medicine yet." (Patient#09, 21-year-old, HbA1c =6.0%)* *"She did not like to take insulin, she likes to take medicine in tablet form only… she refuses to inject insulin. Only tablet because she is not comfortable with that….I have to force her. If not, she will skip." (PCG#05, father)*
	Glucose monitoring	Limited to young people managed with insulin	Perform finger prick and the result is interpreted	*"I checked 2 to 3 times in a week, and my mother helps me to prick my finger. I need to record the reading and submit it to the doctor." (Patient#04, 18 years-old, HbA1c = 12.6%)*
	Risk reduction	Spare some chocolates for hypoglycaemia	-	*I had an experience with hyperglycaemia rather than hypo [hypoglycaemia]. I noticed I got hyper [hyperglycaemia] when I had to go to the toilet frequently and felt thirsty. To avoid [the hyperglycaemia], I have to reduce the sugar in my body and keep drinking plain water. (Patient#15, 19-year-old, HbA1c =11.3%).*
	Coping	Meditate and listen to music	Emotional support	*"If I am stressed, I hear to music, sleep and talk with my friend." (Patient#15, 19-year-old, HbA1c =11.3%)* *"Control her diet, exercise, give them space to choose, don't put too many restrictions, don't make them stress out, now they already have diabetes, if too stressful, it may lead to other complications, who know such as hypertension. Can't be too strict, they are sick, for the sick people, it will demoralise them (PCG#05, father)*

T2DM, Type 2 diabetes mellitus; HCP, Healthcare professional; HbA1c, glycated haemoglobin; GDM, Gestational diabetes mellitus

that having T2DM is part of their life journey. These informants tend to have a family history of T2DM, derive from the category of anticipated route of T2DM diagnosis and held strong beliefs towards God's fate.

"I don't think managing T2DM is a burden, and managing T2DM is a part of my life. It is like, some people used one hand-side to eat, that is a lifestyle." (Patient#12, 21-year-old, HbA1c =6.1%)

Likewise, caregivers who suffered from chronic diseases embraced their children's condition as "written by the God" and believed that while T2DM cannot be reversed, it may be well-controlled with efforts.

"I accepted her condition. God writes it, when the time comes, we just accept it. I have my own experience; I had the uncured disease until now. I had skin diseases, like psoriasis, since I am 10 years old. You can see from my hand. The doctor said no cure for my illness, but I can control it." (PCG#08, father)

Perceived causes of T2DM

Most informants attributed the T2DM diagnosis to genetic factors and unhealthy lifestyles. Additionally, mothers recognised that their children were diagnosed with T2DM because of their history of gestational diabetes mellitus (GDM) during pregnancy.

Unhealthy lifestyles: The informants perceived the consumption of unhealthy foods, particularly with high sugary foods and drinks, oily foods and the sedentary lifestyle as the main causes of T2DM.

"*For me, diabetes is all about the sugar. The food intake causes elevated sugar in our bodies. For example, the rice will be processed into sugar and maybe because of the [excess intake of] rice, it caused diabetes." (Patient#09, 21-year-old, HbA1c =6.0%)*

Nonetheless, some young people attributed their lack of awareness about T2DM to a dearth of diabetes-related campaigns in Malaysia.

"At that time [upon diagnosis], around the year 2010, we were not exposed to diabetes. The media campaign focused on heart disease and cancer. Only now people talk about diabetes." (Patient#15, 19-year-old, HbA1c =11.3%)

Genetics: The majority of the young people and the caregivers in this study had their first-degree family members with T2DM and believed that their genetics predispose them to the disease. Interestingly, one Indian caregiver believed that the small pancreas size was a risk factor of T2DM among the Indians.

"I think my children got diabetes from the generation, genetic. Both my parents and parents in law had diabetes. But most Indians had diabetes. I heard that Indians had smaller pancreas, but I am not sure. My niece told me. She is a doctor". (PCG#05, father)

History of GDM: The mothers, reflected having GDM and the inability to control food craving during pregnancy as the risk factors of their children's T2DM diagnosis.

"I got diabetes when I am pregnant. It is dangerous if the mother cannot control their desire to eat, then it will become a habit. I had an experience when I was first diagnosed with GDM when I am pregnant with my third child in my first trimester. The endocrinologist told me that if I can't control my GDM, it will become permanent 7 or 10 years later. And that is true. Because when we can't control our food, it is dangerous" (PCG#10, mother)

The efforts in diabetes self-management

Among the diabetes self-management tasks, most of the informants focused on adopting healthy eating, performing physical activities, medication taking, blood glucose monitoring, and reducing diabetes-related risks. Moreover, to cope well with the disease, informants perceived that emotional support from others is essential.

Change of diet: Both groups of study informants recognised healthy eating is vital for people with T2DM. After diagnosis, they were more conscious in dietary control include avoiding sweetened beverages and reducing the food portion. Most informants monitored rice portions, changed the types of rice consumed and cooking style, as they believed that such practices could help to reduce the content of starch. Moreover, one informant used a calorie tracker mobile application to monitor the calorie intake.

"I have installed "my fitness pal". I will keep track the [food] that I consumed." (Patient#09, 21-year-old, HbA1c =6.0%)

Other than that, the primary caregivers made efforts to ensure the practice of healthy eating is cultivated in the family.

"I will encourage my children to control their food intake. Regardless they have diabetes or not. They must control the sugar level and my children normally do not buy junk food and canned drinks." (PCG#02, mother)

Physical activity: Most of the informants in both groups were aware of the importance of physical activities in T2DM management. Most of the young people who are studying at secondary school were attached to the scheduled sports activities at secondary schools. Therefore, they had more opportunities to perform physical activities compared to older informants who were working.

"I don't need extra time to exercise because I already joined " olahraga" [sports] at school, so I am already used to run." (Patient#06, 17 years-old, HbA1c =16.4%)

For children who were reluctant to perform physical activities, the caregivers perceived that being a companion can motivate their children in performing exercises.

"Every day, I took her for exercise…like today one round, second day, 2 rounds, third day 5-8 rounds… until she is sweating…If I did not go, then she will not exercise" (PCG#02, mother)

Also, lack of companion was specifically highlighted by some female informants as the main barrier for them to exercise in the public areas. Alternatively, one informant performed indoor exercise to avoid exercising in public.

"Sometimes, I exercised in my room. For example, I did zumba from YouTube. But [most of the time], I was too tired, shy, and now I am not doing it [exercise] anymore. I think I need a friend if I want to do outdoor exercise." (Patient#13, 22-year-old, HbA1c= 11.0%)

Medication taking: Most informants acknowledged the importance of taking medications for achieving optimal glycaemic control. To ensure medication adherence, some informants applied strategies such as medication-taking regularly after a meal or keeping the medications near sight.

"At home, I will put the medicine on the table, or I will put it near to my water dispenser machine, so every time I drink plain water, I will remember, I have not taken medicine yet." (Patient#09, 21-year-old, HbA1c =6.0%)

Most of the parents emphasised their role to constantly educate their children on the importance of medication taking. A daily checklist, reminders and strict discipline were the approaches that used by caregivers to ensure that their children do not skip their medications.

"She did not like to take insulin, she likes to take medicine in tablet form only…she refuses to inject insulin. Only tablet because she is not comfortable with that….I have to force her. If not, she will skip." (PCG#05, father)

Glucose monitoring: Most of the informants who were treated with insulin performed self-monitoring of blood glucose (SMBG) as requested by the doctors. The caregivers who were involved in the SMBG activity would help their children in finger pricking and result interpretations.

"I checked 2 to 3 times in a week, and my mother helps me to prick my finger. I need to record the reading and submit it to the doctor." (Patient#04, 18 years-old, HbA1c = 12.6%)

Risk reduction: Risk reduction includes the action to minimise or prevent both the complications related to T2DM, such as hypoglycaemia and hyperglycaemia. Some informants experienced hypoglycaemia symptoms such as shakiness while waking up in the morning or injecting insulin without a meal. They mentioned a few strategies to deal with such a situation include keeping sweets nearby, adjusting or titrating insulin doses and taking medications on time.

"I always standby chocolate. But I prefer to avoid hypo rather than eating chocolate because the chocolate will elevate my blood sugar. I had my dinner quite early, and after that, I injected the insulin before bed, so I reduced the dosage for injection. I always hypo [experience hypoglycaemia] at night." (Patient#08, 21-year-old, HbA1c =6.5%)

Moreover, two informants perceived that hyper- and hypoglycaemia were related to the body's blood glucose level. Hence, they presumed that taking plain water will flush the sugars from their bodies and eradicate both the hyper- and hypoglycaemia symptoms.

"I had an experience with hyperglycaemia rather than hypo [hypoglycaemia]. I noticed I got hyper [hyperglycaemia] when I had to go to the toilet frequently and felt thirsty. To avoid [the hyperglycaemia], I have to reduce the sugar in my body and keep drinking plain water." (Patient#15, 19-year-old, HbA1c =11.3%).

Coping: To cope with the disease, most young people seek emotional support from their best friends by sharing their problems. Besides, to deal with stress, one of the participants prefer to listen to music, meditate and sleep.

"If I am stressed, I hear to music, sleep and talk with my friend." (Patient#15, 19-year-old, HbA1c =11.3%)

The caregivers realised the burden of disease in their children, thus making an effort to constantly console their children to accept the disease as part of their lives and to make concerted efforts in diabetes self-management.

"I reminded her not to stress, be positive and keep motivating yourself even though now you have to control your food intake. If you are stressed, then the glucose level will spike. I told her since the beginning. Just be positive." (PCG#09, mother)

A grandmother who is caring for two orphaned grandchildren motivated the child in T2DM management by reinforcing his responsibility as an elder brother for taking care of the young one.

"I told him, you must take care of your health because you must take care of your brother because you are the only one to take care of him. If you are sick, you can't take care of your brother." (PCG#04, grandmother)

This study reflected that both caregivers and children required space and time to adapt to a new lifestyle. The caregivers believed that being excessively rigid and forcing their children to comply with prescribed treatments would pressurise their children, creating conflicts and potentially ruining the daily diabetes self-management.

"Control her diet, exercise, give them space to choose, don't put too many restrictions, don't make them stress out, now they already have diabetes, if too stressful, it may lead to other complications, who know such as hypertension. Can't be too strict, they are sick, for the sick people, it will demoralise them" (PCG#05, father)

"I am stressed, I am young. Then I compared with other people without diabetes, I have to routinely go for a check-up, I feel stressed also, ..but once I get controlled, I feel if other people with diabetes, they can control their diabetes, so, why I can't. Then I begin to accept [my condition]." (P#08, 21 year-old, HbA1c=6.5%)

When a child is diagnosed with T2DM at a young age, the caregivers recognised their responsibility in managing the child's diabetes. As the child grows older, the caregivers supported the transition of their children toward emerging adulthood and believed that they were capable of independently managing their disease conditions. Furthermore, a mother attempted to establish herself as a role model to encourage her child to be responsible in disease management and to remain motivated in diabetes self-management.

"He must be responsible for his disease. when he is still a young kid, parents must take care of them. now he knows his responsibilities. Like going to exercise, he must be responsible, must take medicine on time. [Like me], I always take medicine or inject insulin on time. Normally 30 minutes before a meal." (PCG#07, mother)

DISCUSSION

To the best of our knowledge, this is the first qualitative study that triangulates findings from young people and the caregivers to provide a novel window into the lived experience of T2DM among young people in Malaysia. The majority of the informants in this study were surprised by the diagnosis; but they began to incorporate self-management tasks into their everyday lives, with a greater emphasis on lifestyle adjustments. In addition, the parents' involvement was highlighted as critical to the long-term success of diabetes self-management. This research allows more practical assessment of diabetes self-management strategies that are in line with the patient's intrinsic personality.

The diagnosis of T2DM is not limited to identifying and naming the disease (30), yet it is a turning point requiring patients to take aggressive steps in controlling the disease (31); as reported in this study. Similar to previous studies, the informants diagnosed with the "unexpected route" showed negative responses to their diagnosis, which subsequently faced more challenges in their diabetes self-management (32,33). Furthermore, negative disease acceptance was also more prominent in those with fear of diagnosis, medical uncertainty, perceived social stigma and compounded by the unexpected responsibilities in managing T2DM (34). Nonetheless, young people in this study echoed previous studies in adults with T2DM who hold spiritual beliefs were less anxious about the disease and more likely to be motivated to make lifestyle changes (35,36). Prior exposure to patient's responsibilities, disease complications, diet restrictions, and treatment of T2DM influenced the informants' acceptance or rejection of the diagnosis and their subsequent behaviours in diabetes self-management (37,38).

Healthy eating was the primary focus among young people and caregivers in diabetes self-management in this study. Monitoring the calorie intake using mobile applications, reducing food portion and avoiding sweetened foods and beverages were common practices which are in line with the common dietary recommendations for young people with T2DM (11). Meanwhile, the strategies in rice intake are in agreement with the previous research conducted in Asian countries; where rice is a staple food in these countries (35,39). Nevertheless, the foreign investment in the food industry, unfettered marketing of processed foods and the wide accessibility and affordability of unhealthy foods and beverages can potentially lead to uncontrolled consumption thus increased the risk of T2DM complications among the young patients (40). None of the informants in this study described healthy meal planning strategies learnt from HCPs-led medical nutrition therapy despite such service had shown to reduce 0.5%–2% HbA1c and 0.8 to 5.0 kg weight loss among the adults with T2DM (41). As individuals with T2DM in Malaysia were prone to have an excess intake of carbohydrates (4 or more meals a day and more than 2 carbohydrate portions per snack) (42); the effectiveness of HCPs-led medication therapy service in educating the young people in planning a culturally appropriate healthy diet needs to be explored in future research.

The availability of the "One Student One Sport" policy by the Ministry of Education among the school children in Malaysia (43) could have encouraged the adolescents to be physically active as compared to the school-leavers. It is uncommon that school-leavers perceived their daily movement (i.e. helping with housework, climbing stairs) as part of their physical activity, despite the lack of objective measures to determine whether such activities are sufficient to meet their physical activity needs (44). Physical inactivity among school-leavers may be influenced by the high demands of college or work,

which may limit their time for physical exercise (45). Alternatively, having family or peers as companions during physical activity may encourage young people to engage in physical activity (46). Moreover, finding in this study suggests that proper indoor exercise guidance maybe helpful for the young people with low self-esteem to exercise in public.

In this study, less attention was given to SMBG although some young people with insulin performed SMBG as they are required to inform their HCPs about the glucose readings. The patients should be convinced of the importance of SMBG in providing information about their glycaemic status in response to diet and medications thus avoiding hypoglycaemia or hyperglycaemia (47). Furthermore, the finding of current study revealed that there remain misconceptions among the young informants on hyper- and hypoglycaemia management despite the informants had experienced the event. Young people with T2DM and their caregivers should be educated on the symptoms and how to deal with the situations promptly and accurately.

The assimilations of daily diabetes self-management tasks should be tailored to the young people's physical abilities and preferences (11). Our findings show that incorporating new routines of diabetes self-management into daily routine needs time and space (48). Parents who are caring for their children at a young age need to be involved in day-to-day diabetes self-management compared to parents who are caring for their children at an older age who focused on emotional supports such as reminding and motivating their children to reduce the overwhelming feeling of diabetes care (49). The informants in late adolescents should also learn to plan their diabetes self-management particularly in SMBG, risk reduction and coping with the guidance from caregivers and HCPs (50).

The qualitative approach in this study triangulated the experience of the young people and the caregivers while receiving the diagnosis of T2DM and how they progressed proactively to undertake the diabetes self-management tasks. However, the limitations of this study include most of the informants were females from both the young people and the caregivers' groups. Secondly, the majority of the informants were mothers who accompanied their children during a clinical appointment, therefore the view from the father is limited. Thirdly, inherent bias from investigator may arise thus can affect the interpretation of the study. As this is an exploratory study, the findings cannot be generalised, and hence quantitative studies need to be conducted to establish the true impact and factors affecting diabetes self-management among young people with T2DM.

CONCLUSION

This study highlights the underlying situations that stemmed from the events of diagnosis, the perceived causes and the strategies in diabetes self-management elicited by both the young people and caregivers. The findings reflected the actual reality of the self-management outside of the clinic settings in Malaysia and provide potential mechanisms that are useful for the patient-caregiver-HCP partnership in designing an individualised approach for supporting young people in diabetes self-management.

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