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# A multi-centred study on knowledge of type 1 diabetes mellitus (T1DM) and adherence towards medications among caregivers of T1DM patients

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***Abstract*---**Type 1 Diabetes Mellitus, also known as insulin-dependent diabetes mellitus (IDDM), is a chronic disease caused by the autoimmune destruction of the pancreatic β cells, which function as insulin-producing cells. This study was aimed to assess the level of knowledge about T1DM and adherence to medications prescribed to T1DM patients at two different tertiary hospitals in Malaysia. This study was a hospital-based cross-sectional study conducted using self-administered questionnaire. The respondents were among caregivers of paediatrics patients with T1DM attending Paediatrics Clinics from both study sites . The study period was between January 2018 until December 2018 while the data collection period was conducted between May to August 2018. The mean age (SD) of the respondents were 41.07 (7.699). Studied samples were found to have good knowledge (mean=65.98, SD=12.62) and poor adherence (mean=60.08, SD=24.72). The correlation between knowledge score and adherence score among caregivers of T1DM patients showed that they were significantly correlated. As for the association between

adherence to medication and HbA1c level showed that they were insignificantly associated. This study suggested that when a caregiver has a good knowledge about T1DM, they will have better adherence to medication prescribed to T1DM patients. This can eventually improve the outcome of T1DM management

***Keywords*---**Type 1 Diabetes Mellitus; Caregivers; Knowledge; Adherence; Medications.

## Introduction

Diabetes Mellitus (DM) is a metabolic disorder associated with multiple factors. It is characterised by prolonged high level of blood sugar which subsequently affects carbohydrate, fat, and protein metabolism. This process occurs due to dysfunctional insulin secretion or a reduction in insulin actions or both. Diabetes mellitus can be classified into Type 1 Diabetes Mellitus (T1DM) and Type 2 Diabetes Mellitus (T2DM). T1DM is characterised by the body's failure to produce insulin due to dysfunctional pancreatic β-cells. Most commonly, T1DM occurs among children in which it is observed in 71.8% of the patients. The median age of diagnosis was 7.6 years old. However, the disease can also develop in adults. The classical symptoms of T1DM are polyuria, polydipsia, polyphagia and unexplained weight loss.[1] It is a complicated and complex disease requiring continuous medical care with multifactorial risk-reduction strategies targeted to improve glycaemic control.[1] In diabetes, chronic hyperglycaemia state is associated with failure of different vital organs such as the eyes, kidneys, nerves, heart and the blood vessels [3]. In people with T1DM, the pancreas no longer makes insulin. The β-cells have been destroyed and insulin injections are required to use up the glucose obtained from meal intake [5]. The main microvascular complications caused by chronic hyperglycaemia are diabetic nephropathy, neuropathy, and retinopathy [6]. Knowledge on the pathophysiology of diabetes plays a vital role in disease detection, prevention and any future disease development. T1DM usually starts to develop very early in life affecting both the individuals and also the parents [7]. As T1DM affects the young ones, the family members especially parents hold responsible to manage the disorders. They are involved in overall patient management such as bringing their children to the hospital for consultation and helped in administration of medications [8]. In T1DM, frequent monitoring are required to maintain good control of blood glucose levels which is highly associated with food intake, compliance to administration of insulin therapy, modification to insulin doses to match diet, and patients' daily activities.[9] Parents involvement is vital to ensure achievement of better management outcome for T1DM including glycaemic control and patients' quality of life.[10] Knowledge on diabetes may help to delay or prevent the chronic comorbidities of DM which gives a significant impact to the patients' quality of life. Information on DM can help the public to evaluate their diabetic risks, encourage them to seek proper treatment and encourage them to be involved with the management of their disease [7]. Adherence to treatment is defined as the extent to which a person's behavior (taking medication, making lifestyle modifications) correlates with the agreed recommendations from health care providers namely doctors, pharmacists, diabetic educators and nurses.[11]

Among diabetic patients, non-adherence to prescribed treatment regimen was documented to range between 23-77% therefore achieving optimal glycaemic control is challenging.[12] Adherence to medications is influenced by several factors such as lack of information on the disease, complexity of regimen, concomitant disease, and perceptions on the benefits, side effects, medication costs, long duration and emotional well-being. Apart from that, personality and cultural factors were proven to also influence adherence-compliance rates.[1] There are many different ways used to measure adherence in TIDM. Most patients with T1DM conduct self-monitoring blood glucose (SMBG) using glucometer and continuous insulin usage using battery-operated insulin pump. Apart from that, information on patients' diabetes monitioring were obtained directly from patient through structured interviews, questionnaires or self-report during follow-ups [12]. The general objective of this study is to study on the knowledge of caregivers about T1DM and their adherence to medications prescribed to their child.

## 2. Materials and Methods

This study was a cross-sectional study using self-administered questionnaire. The study was conducted as a hospital based study among caregivers of paediatrics patients with T1DM attending Paediatrics Clinic at two different tertiary hospitals. The study period was between January 2018 until December 2018 while the proposed data collection period was between May to August 2018. Participation of respondents in this research was on voluntary basis. The inclusion criterias were caregivers with child diagnosed with T1DM who are ≥ 18 years old and caregivers who are able to understand and read Bahasa Malaysia and English. Caregivers who refuse to participate in the study and caregivers with child who were diagnosed within less than 12 months were excluded from the study. This study used convenient sampling as a method of sampling. The estimated sample size was 59 and the sample size obtained was 41. A set of questionnaire consisting of three sections were distributed to assess caregivers' knowledge on T1DM and adherence towards medications. The questionnaires were distributed to caregivers during their clinic visit and the estimated time taken for answering the questionnaire was 10-15 minutes. Any other information regarding patients conditions such as height, weight and HbA1c reading were taken from patients' report with the permission from the head of department. A pilot study was conducted on 10 respondents to test the validity of the questionnaire. Data from pilot study was tested for its validity using Cronbach's Alpha test and the value was 0.67. Changes have been made to the questionnaire as required. In order to ensure accuracy, consistency and uniformity of the data, regular checking of information on the research were conducted. The questionnaire was translated into Malay version by the Language Centre of University of Cyberjaya (UoC) to provide better understanding. Consent form and information sheet which explained about the study were also provided for reference of the respondents. The questionnaire was divided into sections; Section 1 (Demographic data), Section 2 (Knowledge of T1DM) and Section 3 (Adherence towards Medications):

**Section 1: Demographic Data**

(Adopted from A study on medication compliance and knowledge in diabetes mellitus type 2 patients in primary care setting, Siti Najlaa Izzatie Bt. Muhamad Marzuki, 2015).

**Section 2: Knowledge of Type 1 Diabetes Mellitus**

(Adopted from Diabetes Self – Management Questionnaire Diabetes Treatment Centre, Loma Linda University Medical Centre, 2013).

**Section 3: Adherence towards Medication**

(Adopted from A study on medication compliance and knowledge in diabetes mellitus type 2 patients in primary care setting, Siti Najlaa Izzatie Bt. Muhamad Marzuki, 2015).

The scoring system to evaluate knowledge and adherence was adopted and adapted from Factors Associated with Non-Adherence to Insulin in Patients with T1DM (Riaz et al., 2014).

**Knowledge scoring:** Poor knowledge were indicated by scores of < 40 % whereas moderate level of knowledge were indicated by scores between 40-60% and good level of knowledge were indicated by the scores of >60%.

**Adherence to medication**: Respondents were categorised into adherent group if they scored 100% according to the physicians' recommendations and into non-adherent group if they scored less than 100% to physicians' recommendations on treatment.

The research was registered through online at National Medical Research Registration (NMRR) website (http://www.nmrr.gov.my). Ethics approval by Malaysian Research Ethics Committee (MREC) and CRC of both study sites were obtained.

## 3. Results

### *3.1. Socio-demographic Data*

| | ***Characteristic*** | ***Frequency (%)*** ***n = 27*** | ***Mean (SD)*** |
|---|---|---|---|
| ***Age*** | | | 41.07 (7.70) |
| ***Gender*** | Male | 8 (19.5) | |
| | Female | 33 (80.5) | |

| | | |
|---|---|---|
| ***Race*** | Malay | 18 (43.9) |
| | Chinese | 9 (22.0) |
| | Indian | 13 (31.7) |
| | Others | 1 (2.4) |
| ***Religion*** | Islam | 18 (43.9) |
| | Buddha | 9 (22.0) |
| | Hindu | 13 (31.7) |
| | Others | 1 (2.4) |
| ***Education Level*** | Primary Education | 2 (4.9) |
| | Secondary Education | 10 (24.4) |
| | Tertiary Education | 29 (70.7) |

### *3.2 HbA1c Level Among Patients With T1DM*

| | Frequency (%) n = 27 | Mean (SD) |
|---|---|---|
| HbA1c level | | 9.237 (2.4660) |
| Poor control (>7.5%) | 27 (65.9) | |
| Good control (<7.5%) | 14 (34.1) | |

### *3.3 Caregivers' Knowledge about Type 1 Diabetes Mellitus (T1DM)*

| Characteristics | Frequency (%) n = 27 | Mean (SD) |
|---|---|---|

| | | |
|---|---|---|
| Knowledge score | | 65.98 (12.62) |
| Poor knowledge (0-39) | 1 (2.4) | |
| Moderate knowledge (40-60) | 7 (17.1) | |
| Good knowledge (61-100) | 33 (80.5) | |

### *3.4 Caregivers' Adherence to Medications Prescribed to T1DM Patients.*

| Characteristics | Frequency (%) n = 27 | Mean (SD) |
|---|---|---|
| Adherence | | 60.08 (24.72) |
| Adhere | 6 (14.6) | |
| Non-adherent | 35 (85.4) | |

### *3.5 Correlation between level of knowledge and adherence towards medication prescribed to T1DM Patients*

| Characteristics | Adherence |
|---|---|
| Knowledge score | r-value<br>0.494a (p=0.001*) |

[a] Pearson Correlation Test
*p<0.05 shows significant

### *3.6 Association between adherence to medication and HbA1c Level*

| Characteristics | Adherence |
|---|---|
| Knowledge score | r value<br>0.494a (p=0.001*) |

*Fisher's Exact Test

*p<0.05 shows significant

## Discussion

### Age and Gender

Overall, this study showed that most of the respondents were female. Out of 41 respondents, 33 of them were female and eight of them were male. Among patients between the age of 10 to 15 years old, parents direct involvement in the management of diabetes was found to give positive impact to the treatment outcomes in paediatrics in terms of better compliance and disease management [13]. The management of diabetic child affects the whole family hence requiring continuous awareness despite many challenges. The study also mentioned that mothers are affected more than the other family members as mothers usually care for children with T1DM [14]. Mothers typically gives special attention to the promotion of proper diet, stimulate physical activity, monitor the blood sugar levels and accompany the patients for inpatient or outpatient hospital visits. Generally, mothers play an important role in offering emotional support to the child [15]. Research conducted to examine the unique role by fathers in the management of diabetes suggested that when fathers were highly involved in care for chronically ill children, the decline in treatment adherence seen during adolescence was no longer seen.[16]

### Race and Religion

In this study, out of 41 study respondents, 18 of them were Malays embracing Islam, which represented 43.9% of the total study respondents. Followed by 13 Indians embracing Hindu religion, which represents 31.7% of the total study respondents. Followed by nine Chinese embracing Buddha religion, which represents 22.0% of the total study respondents and lastly, one of the study respondent was Orang Asli which represent 2.4% of the total study respondents. Optimal diabetic control among races were seen mostly in Chinese, followed by Malays and Indians. A report in 1998 from the National Health Survey indicated that the prevalence of diabetes mellitus was highest in Indians (12.9%), followed by Malays (9.3%) and Chinese (8.1%)(18). This strengthen the fact that genetic predisposition among the Indians added to effect of migration imposed a high prevalence of diabetes mellitus among migrant Asian Indians.[17]

### Education Level

In this study majority of the caregivers' education level was tertiary followed by secondary and lastly primary. Out of 41 study respondents, 29 respondents received tertiary education, which represents 70.7% of the total study respondents, 10 respondents received secondary education, which accounts 24.4% of the total study respondents and lastly, two respondents received primary, which represents 4.9% of the total study respondents. Parents' education and employment status play a major role in the child metabolic control. This study suggested that glycaemic control among children with T1DM is influenced by parents` higher educational level and occupational status which will give impact on the financial status. According to the present cross-sectional study, paternal education level and occupation shows significant difference whereby children of which their fathers graduated from colleges have lower HbA1c

than those fathers with elementary certificate. The study findings also stated that fathers with professional occupation have children with good glycaemic control.[10]

**HbA1c Level Among Patients With T1DM**

In this study, overall study samples showed poor control in glycosylated haemoglobin (HbA1c) level with the mean of 9.237%. The study shows that 34.1% of the patients had good HbA1c control and 65.9% had poor HbA1c control. HbA1c is used as a long-term measure of glycaemic control and was introduced into clinical practices. The Diabetes Control and Complications Trial (DCCT) and other interventional studies demonstrated the importance of achieving normal glycaemic control, measured as HbA1c in the prevention of long-term micro and macrovascular complications in diabetes mellitus regardless of types of DM [18]. Patients with T1DM are at higher risk of various health conditions including cardiovascular disease, nerve, kidney damage and retinopathy, resulting in reduced life expectancy for those who were not properly treated. The risk to vital organs damage can be greatly reduced with aggressive glycaemic control [19]. This is because a strong association between the incidence of severe hypoglycaemia and haemoglobin A1c (HbA1c) levels among adults and children had been described in previous studies with intensive insulin therapy documented among the T1DM patients [20].

**Caregivers' Knowledge about Type 1 Diabetes Mellitus**

Overall study samples showed good knowledge with the mean score of 11.88. The study showed that 80.5% of caregivers had good knowledge, 17.1% caregivers had moderate knowledge and 2.4% had poor knowledge about T1DM. Diabetes treatment usually involves complicated regimens such as calculation of carbohydrate conversion based on meals' content as well as routine self-administration of insulin and frequent insulin dosage adjustment. Hence it is essential that people with diabetes are well educated about their condition to enable confident decision-making with regards to their own disease management and treatment options [21]. Ongoing education on the prevention of and screening for the microvascular and macrovascular complications of diabetes should be made aware not only to patients but also to the caregivers. Patient counselling should always include the importance of optimising blood glucose, lipid, blood pressure treatment and avoidance of smoking or smoking cessation specifically for those patients with other comorbidities [22]. Parents with better knowledge about diabetes in addition to better education level were found to be able to control glucose level in their children. Surprisingly, this study also found that mothers of female paediatric patients has a significantly better knowledge score than those of male paediatric patients with diabetes.[9]

**Caregivers' Adherence to Medications Prescribed to T1DM Patients**

Overall study samples showed poor adherence with the mean score of 60.08. However, when the score is categorised, the study showed that 85.4% of caregivers were non-adherent and 14.6% of caregivers adhere to the medications prescribed to their child. According to the World Health Organisation (WHO),

medication adherence is defined as "the degree to which the person's behaviour corresponds with the agreed recommendations from a healthcare provider [23]. T1DM is a chronic life-threatening disease that requires strict adherence to daily treatment tasks.[24] This is important as non-adherence will increase the likelihood to diabetes complications hence leading to augmented burden to health care costs parallel to increase in morbidity. [12] . Despite advances in technology that ease insulin delivery, adherence to diabetes regimens is often difficult for patients of all ages especially adolescents.[25] As a result of non-adherence, there had been waste of medications, rapid disease progression, reduced productivity due to loss of functional abilities, lower quality of life and substantial increase in the use of medical resources [23]. Non-adherence can occur due to various reasons such as poor accessibility to medications, inability to afford the medications, ineffective therapy, safety issues with regards to medications, insufficient knowledge about the disease and environmental factors [26].

**Correlation between Knowledge and Adherence among Caregivers of T1DM Patients**

In this study, results showed that the correlation between caregiver' knowledge and adherence to medication prescribed to their child showed fair correlation and was statistically significant. Therefore, this study suggested that when a caregiver has good knowledge about T1DM, he/she is likely to adhere to the medication prescribed to T1DM patients. Many internal and external factors contribute to poor glucose control such as psychological dysfunction due to prolonged state of hyperglycaemia, absence or minimal support from the family, socio-economic status, and lack of continuous educational support regarding diabetes and achievement of goals of therapy [27]. Poor knowledge on the prevention of diabetic ketoacidosis, insulin reaction and hypoglycaemia contributes to poor glycaemic control and in turn will lead to poor adherence to insulin therapy.[28] Diabetes education to both the patients and the caregivers is a key component in the management of T1DM. It is important to ensure adherence to the multiple mandatory diabetes-related tasks. The study also mentioned that higher diabetes knowledge scores among parents were associated with a significantly lower HbA1c [29]. On the other hand, parents, caretakers or patients with poor knowledge about diabetes was documented to have children or caregivers themselves who were less adherent to diabetes recommendations [30].

**Association between Adherence to Medication and HbA1c Level**

In this study, results shows p-value of 0.157 ($p > 0.05$). This indicates that the association between adherence and blood glucose control was statistically insignificant. There is no difference in the blood glucose control when a caregiver adhere or does not adhere to the medication.

One of the main components for quality healthcare and improved disease management is adherence to recommended therapy given by healthcare providers [30]. Treatment adherence and glycaemic control are known to substantially worsen among adolescence.[31] The association between glycaemic control and adherence to therapy suggested that improvement in glycaemic control will be seen following improvement in adherence to therapy which will result in better

glycaemic control, reduction in HbA1c level and reduced diabetic complications [32].

## Conclusions

Type 1 diabetes mellitus, which is also known as insulin-dependent diabetes mellitus (IDDM), is a chronic disease that is caused by the autoimmune destruction of the pancreatic β cells, which function as insulin-producing cells. With the absence of insulin, glucose inside the body cannot be converted into glycogen and causes hyperglycaemia, which means that there are too much glucose circulating in the blood. Prolonged exposure to hyperglycaemia can lead to various complications and in the end would be fatal to health.

This study discussed about the knowledge and adherence to medication among caregivers in two tertiary hospitals in Malaysia. Overall, the results showed that, majority of the respondents were female. In terms of knowledge, respondents mostly have good knowledge about T1DM. However, when it comes to medication adherence, respondents were mostly found to be non-adherent to the medication prescribed to T1DM patients. There could be some other factors that contribute to caregivers' non-adherent such as medication cost, time spent with child and maybe lack of knowledge and awareness.

This study also discussed about the association between level of adherence and blood glucose control. Many studies have been done before which states that better blood glucose control can be achieved with increase in adherence. Therefore, it is very important and crucial for caregivers' to know the impact of adhering to the medications prescribed to their child.

## Patents

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