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Behavioural and Emotional Problems in Malaysian Children and Adolescents with Type 1 Diabetes Mellitus: A Cross-sectional Study in a Single Centre*

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Abstract

Introduction. Type 1 diabetes mellitus (T1DM) is an autoimmune disorder that requires a lifelong treatment regimen which may affect psychosocial development.

Objective. To identify behavioural and emotional problems in children and adolescents with T1DM.

Methodology. A cross-sectional study using the Child Behaviour Check List (CBCL) was conducted among all T1DM patients receiving treatment at the Paediatric Endocrine Unit, Hospital Tunku Azizah Kuala Lumpur, Malaysia.

Results. Forty T1DM patients were included. The mean age of the participants was 12.4 years (SD = 2.69), with 52.5% males, and 75% Malay. The average duration of illness was 4.8 years, 9 were pre-pubertal, while mean HbA1c was 9.4%. Thirty-five percent of the respondents had parent-reported internalizing problems and 17.5% had parent-reported externalizing problems. Those >12 years old had more internalizing problems (p = 0.004) compared to those ≤12 years old. The differences were in the anxious/depressed syndrome subscale (p = 0.001) and withdrawn/depressed syndrome subscale (p = 0.015). There were no statistically significant differences in the 3 main global scores by gender, glycaemic control, duration of illness and pubertal status by univariate analysis.

Conclusion. T1DM patients >12 years old were at higher risk of developing psychosocial difficulties. This highlighted the benefit of screening of behavioural and emotional issues in children and adolescents with T1DM.

Key words: Type 1 Diabetes Mellitus, psychosocial, Child Behaviour Check List, CBCL

INTRODUCTION

Type 1 diabetes mellitus (T1DM) is an autoimmune disorder requiring a lifelong treatment regimen of diet, exercise, and insulin injections to achieve a normal metabolic state.[1] Despite improvements in well-being of T1DM patients attributed to advancement in insulin therapy, the morbidity and mortality remains significant.[1] This may lead to psychosocial complications and possibly affect their glycaemic control. Globally, 1,211,900 children and adolescents <20 years are estimated to have T1DM.[2] It is estimated that around 149,500 children and adolescents are diagnosed each year.[2] In Southeast Asia, it is estimated that there are 25,700 newly diagnosed T1DM in children and adolescents each year.[2]

It is known that internalizing problems such as depressive mood and anxiety are significantly higher in children with T1DM compared to healthy controls.[3-5] In a study of 84 T1DM children aged 6 to 14 years in India, there was a higher prevalence of psychosocial illness (including irritation, depression and anxiety) in the T1DM group compared to the control group (55.95% vs 20%; p<0.0001).[6] Another study from China consisting of 45 T1DM children also showed similar findings, with the T1DM group having significantly higher scores in psycho-social behavioural problems in T1DM group compared to the control group.[7]

Generally, adolescents with diabetes scored lower in social acceptance compared with healthy adolescents.[8] Over time, depressive symptoms and anxiety increased and

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self-worth decreased for female T1DM patients.[8] Hence, psychological problems in children with diabetes necessitate multidisciplinary management and collaboration between paediatricians and mental health professionals. [9]

Glycosylated haemoglobin (HbA1c) reflects the average level of serum glucose for the last 5-8 weeks and it is one of the metabolic control indicators in diabetes. Poor mental health[10-12] and high levels of stress[13,14] can affect metabolic control and impair treatment processes. Depression, along with poor metabolic control, may result in more complications, poorer outcomes, and more frequent hospitalization.[15] Late adolescence has been identified as a period with a higher rate of acute complications and relative mortality risks for individuals with diabetes.[16] Psychological evaluation and intervention are important in the management of T1DM in children and adolescents because diabetes care could be compromised during this period. A study on behavioural and emotional problems in children and adolescents with T1DM has never been done in our centre, and no similar study has been reported in Malaysia. Physician's awareness on the psychological issues surrounding T1DM patients will be beneficial as a more holistic approach in diabetes care can be planned and developed.

The main purpose of this study is to determine behavioural and emotional problems in children and adolescents with T1DM in a single centre in Malaysia. In addition, this study examines the association between unfavourable behavioural and emotional characteristics and other factors such as glycaemic control and pubertal status in T1DM.

METHODOLOGY

Study type and design

A cross-sectional study using a parent self-report questionnaire was conducted in Paediatric Endocrine Unit, Hospital Tunku Azizah which is a tertiary centre in Malaysia. The study was carried out from 29th April 2019 and 15th July 2021. T1DM patients in the age group of 6 to 18 years old were identified and their parents or caretakers were approached to participate in the study. Consent was obtained from parents who were willing to participate in the study.

Inclusion criteria

Universal sampling of all T1DM patients aged between 6 to 18 years receiving treatment at the Paediatric Endocrine Unit in Hospital Tunku Azizah Kuala Lumpur between 29th April 2019 and 15th July 2021.

Exclusion criteria

1. Presence of conditions associated with neurodevelopmental impairment including intellectual disability or learning disability, cerebral palsy, head injury, brain tumours, etc.
2. Syndromic conditions such as Down syndrome.
3. Pre-existing psychiatric illnesses e.g., Major Depressive Disorder, Schizophrenia, Autism.

Study instrument

The Child Behaviour Check List (CBCL)[17] was used in this study. The CBCL, developed by Thomas M. Achenbach, is a parent-reported questionnaire consisting of 118 items used as screening tool to assess behavioural and emotional problems. There are 8 syndrome subscales in CBCL; anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems, attention problems, rule-breaking behaviour, and aggressive behaviour. Each subscale score is interpreted based on T-scores and percentile scores. T-scores of <65 (<95th percentile) are considered to be within normal range, T-scores of 65-70 (95-98th percentile) are considered to be in the borderline range, while T-scores >70 (>98th percentile) are considered to be in clinical range. There are also 3 global scores, internalizing problems (consisting of 3 syndrome scales - anxious/depressed, withdrawn/depressed, somatic complaints), externalizing problems (consisting of 2 syndrome scales - rule-breaking behaviour, and aggressive behaviour) and total problems (total score of all 8 syndrome subscales). These global scores are also categorised based on T-scores whereby scores <60 are considered within the normal range; 60-63 are in the borderline range; and >63 are in the abnormal range. The CBCL is used worldwide, has been validated for use and translated into multiple languages. In this study, the Bahasa Malaysia (BM) version was used. An internal validation study for the BM version of CBCL has been conducted locally and the Cronbach's alpha for internal consistency ranged from 0.7 to 0.9.[18]

Demographic, clinical and biochemical data were obtained from medical records. Data obtained such as age, gender, race, pubertal status, onset of diagnosis, and latest HbA1c results to evaluate the age distribution, duration of illness and their glycaemic control. Age was categorized as a binary variable (≤12 years versus >12 years) as well as duration of illness (<4 years versus ≥4 years). Glycaemic control was assessed based on glycosylated haemoglobin (HbA1c) level, where an HbA1c[19] value of <8.0% was considered to indicate "well-controlled" diabetes mellitus. These data were documented from routine or standard clinical practice in the management of all children and teenagers with T1DM.

Sample size

All 53 T1DM patients, between 6 to 18 years old receiving treatment at the Paediatric Endocrine Unit in Hospital Tunku Azizah Kuala Lumpur between April 29, 2019 to July 15, 2021 were invited to participate in the study.

A minimum sample size of 47 achieves 80% power to estimate the prevalence of psychosocial problems among

adolescents with T1DM assuming that the prevalence of this outcome is within (56% ± 5%)[20] with 95% confidence level. This sample size was adjusted for 15% non-response.

Statistical analysis

Data was analysed using IBM SPSS Statistics version 22.[21] Quantitative data with normal distributions were expressed as mean ± SD. The T-scores were categorised as normal or abnormal and expressed as frequencies, and percentages. Chi-square test and Fisher's exact test were used to make comparisons between the categorised T-scores and the demographic variables. For all tests, the level of significance was set at 0.05. Pearson's correlation and simple linear regression analysis were performed to evaluate the associations between global scale T scores with age, duration of illness and HbA1c.

Ethics

Approval from the Medical Research and Ethics Committee (MREC) in the National Institutes of Health Malaysia located in Selangor, Malaysia was obtained with reference number NMRR-18-2930-43850 (IIR).

RESULTS

Demographic characteristics

A total of 53 parents of T1DM patients who met the inclusion criteria were approached but only 46 agreed to participate in the study. Out of the 46 respondents, 4 dropped out and 2 had incomplete data and therefore were excluded. In the final sample, there were 40 respondents. The demographic characteristics of the patients are shown in Table 1. The mean age was 12.4 years (SD = 2.69), 52.5% were males, and the majority (75.0%) were Malays. Mean age of onset was 7.6 years (SD = 2.81) while the average duration of illness was 4.8 years (SD = 2.89). The majority (75%) of the patients had poor glycaemic control with a mean HbA1c of 9.4% (SD = 2.30). Nine were pre-pubertal (22.5%) while 31 were pubertal (77.5%).

CBCL scores

In the analysis, the borderline range and clinical range scores were grouped together as abnormal due to the small number in both groups. As shown in Table 2, 32.5% of the respondents have abnormal total scores, 35% had some form of internalizing problems and 17.5% had some form of externalizing problems.

CBCL scores by subgroups

Comparisons of CBCL subscales were made between two age groups of: ≤12 years and >12 years. The differences were tested using chi-square test and Fisher's exact test. The results are presented in Tables 3-5. More older children had abnormal CBCL scores than younger children. There was a significant difference in parent-reported internalizing problems ($p = 0.004$) between the two age groups, especially in the anxious/depressed syndrome subscale ($p = 0.001$) (Table 6). In the other parent-reported problem areas, overall, a higher proportion of the older children had problems. However, the differences were not statistically significant.

Aside from this, the three main global scores were compared by gender, glycaemic control, duration of illness and pubertal status. The results are shown in Tables 3-5. In proportion, females had more parent-reported problems in all the 3 global scores. Similarly, those with poor glycaemic control, longer duration of illness (only for internalizing problems, not global score) and those who have achieved puberty, showed higher scores in the global scores. However, the differences were not statistically significant.

Similarly, Pearson's correlation also showed a significant correlation between age and total scores and internalizing scores (Table 7).

Table 1. Demographic characteristics and clinical characteristics of patients

	n = 40
Age (yr)*	12.4 ± 2.69
Gender	
Male	21 (52.5%)
Female	19 (47.5%)
Race	
Malay	30 (75.0%)
Chinese	5 (12.5%)
Indian	5 (12.5%)
Pubertal status	
Pre-pubertal	9 (22.5%)
Pubertal	31 (77.5%)
Onset of diagnosis (yr)*	7.6 ± 2.81
Disease duration (yr)*	4.8 ± 2.89
HbA1C (%)*	9.4 ± 2.30
Glycaemic control	
Well-controlled	10 (25%)
Poor-controlled	30 (75%)

*values are presented in mean ± standard deviation

Table 2. Types of problems comparing those with normal and abnormal CBCL scores

	n = 40	
	Normal CBCL score	**Abnormal CBCL score**
Total problems	**27 (67.5%)**	**13 (32.5%)**
Internalizing problems	**26 (65.0%)**	**14 (35.0%)**
Anxious/depressed	32 (80.0%)	8 (20.0%)
Withdrawn/depressed	32 (80.0%)	8 (20.0%)
Somatic complaints	28 (70.0%)	12 (30.0%)
Externalizing problems	**33 (82.5%)**	**7 (17.5%)**
Rule-breaking behaviour	36 (90.0%)	4 (10.0%)
Aggressive behaviour	36 (90.0%)	4 (10.0%)
Others		
Attention problems	33 (82.5%)	7 (17.5%)
Social problems	34 (85.0%)	6 (15.0%)
Thought problems	37 (92.5%)	3 (7.5%)

Table 3. Comparison of CBCL scores according to age, gender, glycaemic control, duration of illness and pubertal status *(Total problems)*

	Total n	Abnormal, n (%)	Normal, n (%)	*p*
Age (years)				0.217[a]
≤12	21	5 (23.8%)	16 (76.2%)	
>12	19	8 (42.1%)	11 (57.9%)	
Sex				0.056[a]
Male	21	4 (19.0%)	17 (81.0%)	
Female	19	9 (47.4%)	10 (52.6%)	
Glycaemic control				1.000[b]
Poor-controlled	30	10 (33.3%)	20 (66.7%)	
Well-controlled	10	3 (30.0%)	7 (70.0%)	
Duration of illness (years)				0.581[a]
<4	16	6 (37.5%)	10 (62.5%)	
≥4	24	7 (29.2%)	17 (70.8%)	
Pubertal status				0.690[b]
Pre-pubertal	9	2 (22.2%)	7 (77.8%)	
Pubertal	31	11 (35.5%)	20 (64.5%)	

[a] Chi square test; [b] Fisher's exact test

Table 4. Comparison of CBCL scores according to age, gender, glycaemic control, duration of illness and pubertal status *(Internalizing problems)*

	Total n	Abnormal; n (%)	Normal; n (%)	*p*
Age (years)				0.004[a]
≤12	21	3 (14.3%)	18 (85.7%)	
>12	19	11 (57.9%)	8 (42.1%)	
Sex				0.119[a]
Male	21	5 (23.8%)	16 (76.2%)	
Female	19	9 (47.4%)	10 (52.6%)	
Glycaemic control				0.718[b]
Poor-controlled	30	10 (33.3%)	20 (66.7%)	
Well-controlled	10	4 (40.0%)	6 (60.0%)	
Duration of illness (years)				0.685[a]
<4	16	5 (31.3%)	11 (68.7%)	
≥4	24	9 (37.5%)	15 (62.5%)	
Pubertal status				0.124[b]
Pre-pubertal	9	1 (11.1%)	8 (88.9%)	
Pubertal	31	13 (41.9%)	18 (58.1%)	

[a] Chi square test; [b] Fisher's exact test

DISCUSSION

Young people with diabetes appear to have a greater incidence of depression, anxiety, psychological distress, and eating disorders compared to their healthy peers.[22-24] In our study, 35% of the respondents had parent-reported internalizing problems and 17.5% had parent-reported externalizing problems. The result of our study is similar to another study which reported that internalizing problems were more common compared with externalizing problems.[25]

By age group, those >12 years had statistically significantly more internalizing problems compared to the younger ones, especially in the anxious/depressed and withdrawn/depressed syndrome scales. These problems may be associated with (1) a decline in self-esteem during adolescence; (2) peer pressure when they compare their restrictive lifestyle with their peers; (3) lack of social acceptance including school bullying; (4) changes in school environment from primary school to secondary school.

T1DM patients are at risk of developing psychosocial complications, such as anxiety and depression. However, they often do not have proper psychiatric evaluation and support. This may adversely affect their management and disease control. A previous study showed that those who had higher CBCL scores had poorer glycaemic control.[26] A meta-analysis of 24 studies also showed that depression in diabetic patients was significantly associated with hyperglycaemia.[27] The poor-control group had higher scores for somatic complaints and withdrawal.[28]

Guidelines have previously recommended that practitioners managing children and adolescents with T1DM should have resources made available to them including professionals with expertise in the mental and behavioural health of children and adolescents such as psychologists, social workers, and psychiatrists.[29] These professionals should work within an interdisciplinary diabetes health care team. In our local setting, there is a need for the development of preventive and management strategies to promote behavioural and emotional well-being among young people with diabetes. This includes increasing awareness among healthcare workers as well as increasing the resources of social welfare, psychological and counselling services which are limited in our local setting.

In contrast to previous studies, those with poor glycaemic control in our study did not show a statistically significant

Table 5. Comparison of CBCL scores according to age, gender, glycaemic control, duration of illness and pubertal status *(Externalizing problems)*

	Total n	Abnormal, n (%)	Normal, n (%)	*p*
Age (years)				0.226[b]
≤12	21	2 (9.5%)	19 (90.5%)	
>12	19	5 (26.3%)	14 (73.7%)	
Sex				0.226[b]
Male	21	2 (9.5%)	19 (90.5%)	
Female	19	5 (26.3%)	14 (73.7%)	
Glycaemic control				0.656[b]
Poor-controlled	30	6 (20.0%)	24 (80.0%)	
Well-controlled	10	1 (10.0%)	9 (90.0%)	
Duration of illness (years)				1.000[b]
<4	16	3 (18.8%)	13 (81.2%)	
≥4	24	4 (16.7%)	20 (83.3%)	
Pubertal status				1.000[b]
Pre-pubertal	9	1 (11.1%)	8 (88.9%)	
Pubertal	31	6 (19.4%)	25 (80.6%)	

[b] Fisher's exact test

Table 6. Comparison of CBCL subscores between age ≤12 years and >12 years

	≤12 years, n = 21 (%)		>12 years, n = 19 (%)		*P*
	Normal	Abnormal	Normal	Abnormal	
Total problems	16 (76.2%)	5 (23.8%)	11 (57.9%)	8 (42.1%)	0.217[a]
Internalizing problems	18 (85.7%)	3 (14.3%)	8 (42.1%)	11 (57.9%)	0.004[a]
Anxious/depressed	21 (100.0%)	0 (0.0%)	10 (52.6%)	9 (47.4%)	0.001[b]
Withdrawn/depressed	19 (90.5%)	2 (9.5%)	12 (63.2%)	7 (36.8%)	0.060[b]
Somatic complaints	17 (81.0%)	4 (19.0%)	11 (57.9%)	8 (42.1%)	0.112[a]
Externalizing problems	19 (90.5%)	2 (9.5%)	14 (73.7%)	5 (26.3%)	0.226[b]
Rule-breaking behaviour	20 (95.2%)	1 (4.8%)	19 (100.0%)	0 (0.0%)	1.000[b]
Aggressive behaviour	20 (95.2%)	1 (4.8%)	16 (84.2%)	3 (15.8%)	0.331[b]
Others					
Attention problems	19 (90.5%)	2 (9.5%)	16 (84.2%)	3 (15.8%)	0.654[b]
Social problems	19 (90.5%)	2 (9.5%)	15 (78.9%)	4 (21.1%)	0.398[b]
Thought problems	21 (100.0%)	0 (0.0%)	16 (84.2%)	3 (15.8%)	0.098[b]

[a] Chi square test; [b] Fisher's exact test

Table 7. Correlation between Global scale T scores with age, duration of illness and HbA1c

		R	*P*
Age (n = 40)	*Internalizing*	0.405	0.005
	Externalizing	0.216	0.090
	Total	0.321	0.022
Duration of illness (n = 40)	*Internalizing*	0.083	0.306
	Externalizing	0.076	0.320
	Total	0.005	0.487
HbA1c (n = 40)	*Internalizing*	0.074	0.325
	Externalizing	0.226	0.081
	Total	0.154	0.171

R: Pearson's correlation coefficient

difference in CBCL scores.[10-14,30] In a similar study conducted in China, compared with a control group, the well-controlled T1DM patients had higher scores for withdrawal, anxiety/depression, and internalizing problems while the poorly-controlled T1DM patients had higher scores for withdrawal, somatic complaints, anxiety/depression, delinquent behaviours, aggressive behaviours, externalizing and internalizing problem.[7] The majority (75%) of the patients in our study had poor glycaemic control, and this factor may dilute any potential association between poor glycaemic control and behavioural and emotional issues. This suggests that there may be factors negatively impacting their overall glycaemic control such as a lack of awareness about the disease and its proper management among others. Determining non-compliance to treatment and other factors resulting to poor glycaemic control in T1DM, and emphasizing the importance of good control through re-education and counselling need to be instituted and practised.

Our study also showed that gender had no association with CBCL scores, which is similar with the findings from previous studies from Asian countries.[26,28] However, a greater proportion of female patients with T1DM do tend to have abnormal scores in total as well as internalizing and externalizing problems, with total problems nearly reaching significant levels. This suggests that female patients may be struggling with psychological issues more than expected. Puberty is associated with poorer glycaemic control due to its association with a decrease in insulin sensitivity.[8] However, similar to glycaemic control and gender subgroups, T1DM patients during puberty did not show significantly higher CBCL scores.

In contrast to a previous study which showed that duration of illness had a significant association with CBCL scores[26], this association was not observed in our study. One reason to account for this could be differences in disease duration classification used (<4 years or <1 year) in different studies. In our study, there are only 5 patients with ≤1-year duration from the onset among the total of 40 patients. However, even after analysing the cut-off point of 1 year, the variable did not demonstrate an association with

CBCL scores. A larger sample size may help establish the association better as our study was not adequately powered to establish the associations between these possible factors and behavioural or emotional problems. A multicentre study may be necessary to provide more information on its association.

The education level of caregivers is an important contributing factor in the management of these patients. Previous studies found an association between maternal education levels and internalization problems.[25] However, this was not evaluated in this study as this data was not collected. It is important to include maternal education in future studies as it may play a role in the development of behavioural and emotional problems in children and adolescents with T1DM.[25]

Limitations

This assessment is based on parents' perspective and may not truly reflect what the children are going through. As in all self-administered surveys, whether the respondents answered the questions honestly cannot be assessed, and thus responses are taken at face value. This study was conducted in only one hospital and the sample size was small. Our study was inadequately powered to investigate the associated factors which may be linked to behavioural and emotional problems. The small sample size is likely the greatest limitation of the study, especially when assessing association of specific factors within subsamples, making generalisability of the findings to the general population challenging. A multicentre study with a large sample size would be more informative. Further information, such as parental education level and socioeconomic status, were also not collected in this study.

CONCLUSION

This study showed that TIDM children and adolescents >12 years old are at higher risk of developing psychosocial difficulties such as anxiety and depression. It is important to recognise and screen for symptoms of psychosocial complications in this group of patients to make an early diagnosis and address them, as well as involve psychologyand mental health professionals as part of a multi-disciplinary team to improve the overall care of T1DM patients.

We recommend future studies in this field to further elucidate issues, and suggest a much larger multi-centre study to establish the association between factors which may be linked with adverse behaviours and psychological outcomes among children and adolescents with T1DM.

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The authors certified fulfillment of ICMJE authorship criteria.

CRediT Author Statement
WLC: Formal analysis, Investigation, Data Curation, Writing – original draft preparation, Visualization; **ANI:** Conceptualization, Methodology, Validation, Resources, Writing – review and editing, Supervision, Project administration; **NKN:** Resources, Writing – review and editing; **LPG:** Writing – review and editing.

Conflict of Interest
The authors have no conflicts of interest to disclose.

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