QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS IN HUSM

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ABBREVIATIONS

BMI	Body Mass Index
CDC	Centers for Disease Control
DKA	Diabetic Ketoacidosis
DiCARE	Diabetes in Children and Adolescents Registry
EURODIAB	European Community Concerted Action Program in Diabetes
GCP	Good Clinical Practice
HbA1c	Glycosylated Hemoglobin Type 1c
HUSM	Hospital Universiti Sains Malaysia
ISPAD	International Society for Paediatric and Adolescent Diabetes
ICH	International Conference on Harmonisation
SMBG	Self-monitoring of blood glucose
T1DM	Type1 Diabetes Mellitus
QOL	Quality of Life

ABSTRAK

BAHASA MALAYSIA

PENGENALAN

Penyakit Kencing Manis Jenis 1 (T1DM) merupakan sejenis penyakit kronik yang seringkali terjadi di kalangan kanak-kanak dan remaja. Faktor-faktor yang mempengaruhi kualiti hidup pesakit T1DM adalah pelbagai. Soalan kaji selidik yang telah divalidasi dan diadaptasi ke Bahasa Malaysia telah digunakan untuk menilai tahap kualiti hidup kanak-kanak dan remaja menghidap T1DM di HUSM. Maklumat yang diperolehi dapat mengenal pasti pesakit yang memerlukan intervensi awal dan berupaya untuk mengelakkan komplikasi kesihatan pada masa hadapan.

OBJEKTIF

Kajian ini bertujuan untuk menilai tahap kualiti hidup pesakit T1DM di HUSM, mengenal pasti faktor-faktor penyebab kepada tahap kualiti hidup yang tidak memuaskan di kalangan pesakit dan menilai korelasi di antara tahap kualiti hidup dan tahap kawalan gula pesakit melalui bacaan HbA1c.

KAEDAH

Sebuah kajian cross sectional telah dijalankan di Klinik Endokrin Kanak-Kanak yang melibatkan kanak-kanak dan remaja menghidap penyakit T1DM berusia di antara 10-18 tahun di HUSM. Kesemua peserta kajian telah menjawab soalan kaji selidik Ukuran Kualiti Hidup Diabetes (DQOLY) yang telah diterjemahkan ke Bahasa Malaysia. Jumlah markah yang rendah adalah refleksi kepada kualiti hidup yang baik. Jumlah markah yang diperolehi dianalisa menggunakan kaedah Fisher's Exact, logistic regression analysis dan ujian Pearson Correlation.

KEPUTUSAN

Sejumlah 54 pesakit yang terdiri daripada kanak-kanak dan remaja berusia 10 sehingga 18 tahun (min SD 14 ± 2.7) telah dijemput untuk mengambil bahagian di dalam kajian ini. Ujian Fisher's Exact menunjukkan kaitan di antara kualiti hidup yang baik dan bacaan HbA1c pesakit ($p<0.001$). Ujian Pearson Correlation menunjukkan korelasi di antara bacaan HbA1c dan ukuran kualiti hidup ($p<0.001$). Analisa menggunakan kaedah logistic regression menunjukkan faktor risiko penyebab kepada kualiti hidup yang tidak baik adalah berkaitan dengan bacaan HbA1c yang tidak terkawal.

KESIMPULAN

Majoriti kanak-kanak dan remaja mengidap T1DM di HUSM mempunyai kualiti hidup yang baik. Faktor risiko kepada kualiti hidup yang tidak baik di kalangan pesakit kecenderungan pesakit untuk tidak mempunyai kawalan bacaan HbA1c yang baik. Terdapat korelasi yang kuat di antara kawalan parasa gula dalam darah melalui bacaan HbA1c dan tahap kualiti hidup pesakit T1DM di HUSM menjadikan HbA1c sebagai indikator penting untuk menilai tahap kualiti hidup di kalangan pesakit.

ABSTRACT

INRODUCTION

Type 1 diabetes mellitus (T1DM) is a chronic lifelong disease commonly diagnosed in children and adolescents. Factors that contribute to quality of life (QOL) outcome in T1DM patients were multivariable and remain controversial. A validated questionnaire translated to Bahasa Malaysia was used to measure QOL in children and adolescents with T1DM in Hospital Universiti Sains Malaysia (HUSM). The QOL assessment is important for better patient management as it allows identification of patients with difficulties who require early intervention.

OBJECTIVES

The aim of this study is to evaluate the QOL in children and adolescents with T1DM in HUSM, to determine factors associated with poor QOL in these patients and to determine correlation between QOL and metabolic control (HbA1c).

PATIENTS AND METHODS

A cross sectional study was conducted in children and adolescents with T1DM aged 10-18 years old attending follow-up in Paediatric Endocrinology Clinic, HUSM. The Malay translated version Diabetes Quality of Life for Youth (DQOLY) questionnaire were used using 5 Likert scales where low score indicate good QOL. Outcomes were analysed using Fisher's Exact test, simple and multiple logistic regression analysis and Pearson correlation test.

RESULTS

A total of 54 patients aged 10-18 years old (mean SD 14 ± 2.7) were included in the study. Fisher's Exact test showed association between good HbA1c control and good QOL (p<0.001). Pearson correlation showed statistically significant correlation between HbA1c and QOL (p<0.001). From logistic regression analysis, the risk factor found for poor QOL for T1DM patients in HUSM were increased in HbA1c (3.95 times increased odds in domain satisfaction, 3.5 times increased odds for domain impact and 4.21 times increased odds in domain worry) for poor QOL per one unit increase of HbA1c.

CONCLUSION

Majority of children and adolescent with T1DM in HUSM have good QOL. Risk factors associated with poor QOL in these patients were poor HbA1c control. There were strong correlation between HbA1c control and QOL thus HbA1c is an important marker to determine QOL in T1DM patients in HUSM

CHAPTER 1:

INTRODUCTION

CHAPTER 1: INTRODUCTION

Diabetes mellitus is a metabolic disorder characterized by hyperglycaemia. The two most common types are Type 1 and Type 2 diabetes mellitus. Type 1 Diabetes Mellitus (T1DM) is a chronic lifelong disease commonly diagnosed in children and adolescents. It is sometimes referred to "juvenile diabetes" due to age onset of the disease (Gregory et al., 2013).

Incidence of T1DM has been increasing in most regions in the world. A project called EURODIAB in 2009 comparing type 1 diabetes incidence in 17 countries showed an average incidence of 3.9% a year; especially among children 5 years old and younger. By 2020, it was predicted new cases of T1DM in children would almost doubled, from 3,600 to an approximately 7,076 children (Patterson et al., 2009).

The cause of T1DM is not fully understood however autoimmune process, genetics and environmental factors are believed to contribute to the cause of the disease. The primary challenge in patients with T1DM is the requirement of lifelong dependency on exogenous insulin due to permanent destruction of pancreatic islets of Langerhans. There is currently no definite prevention for T1DM but adequate understanding of the disease and supreme commitment are the recommended clinical goals to minimise disease complications (Gregory et al., 2013). A comprehensive T1DM management routinely consist of regular subcutaneous insulin injection, self-monitoring of blood glucose (SMBG), carbohydrate counting and dietary plan together with appropriate physical activities (ISPAD, 2014).

Management of a chronic disease like T1DM especially in children and adolescents were never straightforward and imposed its own challenges. The treatment regimes are strict hence require substantial commitment from the patient themselves, health providers, family members, peers and surrounding individuals as it potentially disrupt the patient's ability to negotiate with good psychosocial adjustments (ISPAD, 2014). A holistic approach is essential in the management of T1DM and measuring quality of life (QOL) can identify patients who need attention and early intervention (Karvonen et al., 2000).

Until recently, most of the QOL research in patients with T1DM has been conducted in countries such as North America, Australia, United Kingdom and the Middle East. Data collected from these countries were not much applicable to our community in view of great differences in culture, family dynamics, socioeconomic status, health care delivery and facilities thus urging the need to conduct our own local study to evaluate QOL amongst children and adolescents with T1DM in our community.

There were so far no published data on QOL in children and adolescents with T1DM in Malaysia. Only small studies have been done in Hospital Universiti Kebangsaan Malaysia (HUKM) and Pusat Perubatan Universiti Malaya (PPUM), in which both institutions are located in urban area of Klang Valley. No data collection has been done to assess the QOL of children and adolescents with T1DM and its relation to metabolic control in Hospital Universiti Sains Malaysia (HUSM); an endocrine referral centre for East Coast Malaysia that portrays different socioeconomic gradient and racial distribution. The aim of this study is to determine the QOL of children and adolescents with T1DM in HUSM and potential risk factors for poor metabolic control.

The Diabetes Quality of Life in Youth (DQOLY) instrument was adapted from original paper developed by Ingersoll and Marrero (1991) "The Modified Quality of Life Measure For Youths: Psychometric Properties". It was the revolutionary tool to evaluate quality of life in children and adolescents with diabetes. The original questionnaires were translated to Bahasa Malaysia and validated by Jalaludin et al. (2013). It was designed suitable to the Malaysian multi-ethnicity with Bahasa Malaysia being the national language to measure quality of life in T1DM children and adolescents in Malaysia (Jalaludin et al., 2013).

The DQOLY instrument used in this study consists of 49 items in 3 sections, which evaluate domain of satisfaction with life, impact of diabetes and worries about diabetes. A lower score indicates better quality of life. In the original Ingersoll and Marrero instrument, lower scores on satisfaction subscale indicated poorer QOL (Hoey et al., 2001). The satisfaction with life part consists of 17 items assessing satisfaction with management (8 items), social life (6 items) and school life (3 items). The impact of diabetes part consists of 23 items assessing the impact of diabetes on physical (4 items), social (13 items), family (4 items) and school (2 items) aspects of participants' life. The worry about diabetes part consists of 9 items assessing about worry towards education, future job, body shape, complication of diabetes and social relations.

CHAPTER 2:

LITERATURE REVIEW

CHAPTER 2: LITERATURE REVIEW

2.1 UNDERSTANDING TYPE 1 DIABETES MELLITUS

T1DM is a medical condition resulting from destruction of the pancreatic islet β-cells leading to severe insulin deficiency resulting in absence of C-peptide plasma concentration. There were few markers of the immune-mediated β-cell destruction process that were important to consider and worth knowing in order to understand the pathophysiology of T1DM (Brook et al., 2009).

More than 90% of newly diagnosed T1DM patients were associated with autoantibodies. Amongst the well-researched autoantibodies associated with T1DM were the glutamic acid decarboxylase antibody (GADA), anti-islet antibody (ICA), insulin autoantibodies (IAA), protein thyrosine phosphatase antibody (ICA512 or IA2A) and zinc transporter 8 (ZnT8) (Brook et al., 2009). There were also another type of T1DM not related β-cell autoimmunity known as "type 1B diabetes" (Atkinson, 2012).

According to the National Diabetes in Children and Adolescents Registry; DiCARE 2010 (Hong et al., 2015), approximately 490 children and adolescents with T1DM reported from year 2006 until 2009 in Malaysia. It is considered as a chronic autoimmune disease that can potentially become an important damaging disease in Malaysia if no proper preventive actions taken.

Typical symptoms for T1DM are hyperosmolar symptoms such as increase urinary frequency, thirst, hunger and significant weight loss over two to six weeks. Common serious presentations include moderate to severe dehydration, abdominal pain with vomiting, polyuria despite dehydration, weight loss, acetone smell breath and rapid breathing. All these leads to hypotension and shock which potentially resulting to decreased level of consciousness and even death (Atkinson, 2012).

2.2 DIABETIC KETOACIDOSIS

Diabetic ketoacidosis (DKA) is the most serious metabolic disturbance in T1DM. The rate of DKA incidence in T1DM patients ranges from 15 to 70% in Europe and North America (Rewers et al., 2014) and 57.5% in Malaysia (Fuziah et al., 2014).

The biochemical criteria for DKA include hyperglycaemia (blood sugar level of more than 11.1 mmol/L) with a venous pH less than 7.3 and bicarbonate level less than 15 mmol/L. The severity of DKA can be categorised as mild DKA defined as a venous pH less than 7.3 and bicarbonate of less than 15 mmol/L; moderate DKA as a pH less than 7.2 with bicarbonate less than 10; and severe DKA as a pH less than 7.1 and bicarbonate less than 5 (Lawrence, 2005).

The Malaysian Diabetes in Children and Adolescents Registry 2006 to 2008 has reported 71.8% of children under the age of 20 years old in Malaysia with diabetes mellitus have T1DM. Fifty-eight percent of them presented with DKA during first presentation with the median age of 7.6 years old.

Cerebral oedema is an important cause of DKA associated mortality in childhood. Twenty percent of all deaths in children with diabetes less than 20 years of age were associated with cerebral oedema (Finberg, 1996).

2.3 GLYCAEMIC CONTROL

Glycosylated haemoglobin (HbA1c) depicts the glycaemic control over the preceding 4 to 12 weeks. The recommended HbA1c target for all patients younger than 18 years old is less than 7.5% however each patient should have their targets individually determined with the goal of achieving value as close to normal (ISPAD 2014). Many studies found lower glycaemic control (HbA1c) was associated with better QOL regardless of the duration of the disease. Although the cause-effect relation was unclear, the association between HbA1c and QOL is equally important in the management of T1DM (Abdul-Rasoul et al., 2013).

2.3.1 Age specific glycaemic control

For children aged 6 to12 years old, the HbA1C goal of less than 8% is recommended (American Diabetes Association, 2004). The management of T1DM in this age group is challenging because many require insulin administration while at school, which demands flexibility and close communications between the parents, peers, school personnel and the healthcare team (American Diabetes Association, 2004).

In adolescent aged 13 to 19 years old, HbA1C of less than 7.5% is recommended (Bryden, 2003). Several studies in the United States and Europe (Mortensen et al., 1998 and Chase et al., 2003 and Bryden, 2003) have documented that mean HbA1c levels in this age group were generally more than 8.0% and reduction comes a significant increase in the risk of severe hypoglycaemia.

Hypoglycaemia is the major barrier to achieve near-normal glycaemic control in children with T1DM on insulin (Cryer et al., 2002). The definition of hypoglycaemia is controversial, but studies have shown cognitive impairment can occur at blood glucose concentrations less than 3.3 mmol/L (Ryan et al., 1990). Acute phase hypoglycaemia has been associated with transient reduction in mental efficiency, altered electroencephalogram and increased cerebral blood flow. Some cognitive deficits may persist beyond the acute phase especially in children below 5 years old (Northam et al., 2001).

2.4 MANAGEMENT OF DIABETES

Comprehensive treatment is critical to prevent acute and chronic complications of T1DM. Diabetes management is challenging as it involves insulin therapy either conventional or intensive regime with either multiple daily injections or insulin infusions, daily blood glucose monitoring, tracking carbohydrate consumption and participating in regular physical exercise (ISPAD, 2014). Patients and caregivers have to adapt to new routine while developing children and adolescents struggle to achieve self-government. Studies have shown that enhancing the QOL and wellbeing of children and adolescents with T1DM is as important as metabolic control in preventing secondary morbidity. Therefore the main objective of modern diabetes care in this population has changed from purely medical approach to aiming towards optimal glycaemic control, normal psychological development and maximum QOL (Hoey et al., 2001).

2.4.1 Insulin therapy

Insulin therapy aims to imitate body's physiological insulin as close as possible. The choice of insulin regimen will depend on multiple factors including age of patient, duration of diabetes, dietary patterns, exercise schedules, schooling, target of metabolic control and patient or caregivers preference (Danne et al., 2014).

Insulin requirements were usually based on body weight, age, and pubertal status. Newly diagnosed T1DM children and adolescents typically require an initial total daily dose of 0.5 to 1.0 units/kg. In general, pre-pubertal children need lower doses while higher doses are required in the presence of ketoacidosis, use of steroids, and during hormonal changes of puberty (Danne et al., 2014).

Conventional insulin or twice-daily regimens are the two daily injections of a mixture of short or rapid acting insulin with intermediate-acting insulin two times a day. Children on twice daily regimens require two thirds of their total daily insulin dose in the morning and one-third in the evening which one-third of each insulin dose is rapid or short-acting insulin and about two thirds is intermediate-acting insulin (Rewers et al., 2014).

Intensive insulin therapy refers to three or more insulin injections per day including basal bolus and insulin therapy via insulin pumps (Rewers et al., 2014). DCCT have shown that intensive insulin therapy have the efficacy to slow the progression of long-term diabetic complications in patients with T1DM compared to conventional insulin therapy (Keen, 1993).

The multiple daily injections refers to three injections daily which consist of rapid or short acting insulin together with intermediate-acting insulin before breakfast, rapid or regular insulin before lunch or dinner and intermediate-acting insulin before bedtime (Rewers et al., 2014).

The basal-bolus regimen is the intermediate acting insulin or long acting basal given once or twice daily and rapid-acting or regular boluses with meals and snacks (Danne et al., 2014). Children on basal-bolus regimen require nocturnal intermediate-acting insulin between 30% (if on regular insulin) and 50% (if on rapid-acting insulin) of total daily insulin dose. About 50% as rapid acting or about 70% as regular insulin were divided up between three and four pre-meal boluses (Rewers et al., 2014).

2.4.2 Nutrition in children and adolescents with Type 1 Diabetes

Nutrition therapy when used with other component of diabetic care can further improve clinical and metabolic outcome (Delahanty et al., 2009). It is essential for the whole family to get involved in making appropriate changes based on healthy eating principles. Nutrition education should include behaviour change approaches, motivational sessions and counselling. The therapy should be regularly reviewed to meet the constantly changing needs and requirements of the developing child hence optimum QOL can be achieved. In order to be most effective, dieticians need to develop a consistent and supportive bonding with patients and their family members (Funnell et al., 2004).

2.4.3 Carbohydrate counting

Carbohydrate counting is an organised meal approach that focuses on carbohydrate as the primary nutrient affecting post-meal glycaemic response. It can improve glycaemic control, diabetes-specific quality of life and coping mechanism in daily life (Ulahannan et al., 2007). Methods of quantifying carbohydrate include carbohydrate gram increments, 10 to 12 grams carbohydrate portions and 15 grams carbohydrate exchanges (Danne et al., 2001).

2.5 QUALITY OF LIFE

One of the greatest challenges facing the healthcare system globally in the twenty-first century will be the increasing burden of chronic diseases (WHO, 2005). WHO (2016) has defined chronic illness as diseases that are "not passed from person to person, instead they are of long-term duration and generally slow in its progression".

Regardless of the various medical conditions that contribute to chronic diseases, the common theme is that these conditions require a complex response over an extended time period. The management includes coordinated feedbacks from extensive range of health professionals and access to essential medicines and monitoring systems, all of which must be optimally embedded within a system that encourage patient empowerment (Nolte et al., 2008).

Type 1 diabetes mellitus in children and adolescents is a perfect example of a chronic medical condition that suffers suboptimal health outcome thus leading to rising health-care expanses. It requires a multidisciplinary approach from general paediatrician, paediatric endocrinologist, diabetic nurses and dieticians. Due to the

unique challenges dealing with youngsters with chronic medical condition, T1DM in children and adolescents certainly able to attract attention mainly on targeting improvement in health-care quality delivery aiming to reduce medical expenditures (Wolfsdorf et al., 2009).

Evaluation on the impact of chronic debilitating illness such as T1DM is one of the main areas being assessed in the health related quality of life. Assessing the impact of the illness and treatment outcome will help maximise patients' function in daily life to achieve the highest level of function. For health providers, quality of life evaluation able to reflect and expand the treatment goals from prolonging life and symptoms alleviation to amplifying patients' contentment with life (Karvonen et al., 2000).

Evaluation of the QOL has been considered as a significant method to understand the impact of T1DM in children and adolescents since it evaluates the consequences of chronic disease from the perspective of the individual. The concept of "treating patient as a whole and not as a disease" is believed to potentially facilitate treatment compliance, as it is essential in the management of T1DM in this age group (Karvonen et al., 2000).

The main aim of diabetes in children and adolescents is to achieve optimal glycaemic control. Normal psychosocial development and support for the young person and family in developing strategies to cope with lifetime diabetes. Da Costa, et al. (2015) found that specific factors that lead to deterioration of QOL in children and adolescents include longer duration of diabetes, sedentary lifestyle and female gender. Al-Akour, et al. (2008) found that diabetes gave negative impact to youths and worsened overall QOL was associated with higher HbA1c values, being a female and older adolescents. Abdul-Rasoul, et al. (2013) concluded similar findings where girls were found to be in greater difficulties compared to boys with T1DM.

Hoey, et al. (2001) found that factors associated with poor QOL in children and adolescents were patients from broken disruptive family, girls and ethnic minorities as QOL evaluation indicate specific problem in these groups. Individuals with higher QOL will be better prepared physically and psychologically to deal with burdens of diabetes management. Better QOL facilitates better metabolic control through improved self-care as part of positive circle (Hoey et al., 2001).

Certain personality types of children or adolescent and their parents foresee an increased risk for diabetes management challenges. This include presence of other health problems such as asthma, eating disorders, poor school attendance, learning disabilities, and emotional and behavioural disorders, including risk-taking behaviours resulting in delinquent behaviour and depression (Delamater et al., 1999).

CHAPTER 3:

OBJECTIVES OF THE

STUDY

CHAPTER 3: OBJECTIVES OF THE STUDY

3.1 General Objective

- To evaluate quality of life in children and adolescents with T1DM treated and followed-up in HUSM

3.2 Specific Objectives

- To determine factors associated with poor QOL in T1DM in HUSM
- To determine correlation between QOL and metabolic control (HbA1c)

CHAPTER 4:

METHODOLOGY

CHAPTER 4: METHODOLOGY

4.1   Study design

A cross-sectional study

4.2   Study area

Paediatric Endocrine Diabetic Clinic, Paediatric Department, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan

4.3   Study Population

Children and adolescents age 10 to 18 years old diagnosed to have T1DM at least 6 months duration. The study was conducted on patients attending Paediatric Endocrine Diabetic Clinic, Paediatric Department, Hospital Universiti Sains Malaysia (HUSM) follow-up from 1st February 2017 until 1st May 2017 (4 months).

4.4   Subject criteria

4.4.1 Inclusion Criteria

- T1DM patients age 10 to 18 years old under HUSM follow-up
- Diagnosis of duration at least 6 months

4.4.2 Exclusion criteria

- Children and adolescents with T1DM with significant psychiatric illness, intellectual disability and illiterate
- Patients with other chronic illnesses
- Patients or parents who refuse to give assent or consent

4.5   Recruitment of subject and informed consent seeking

Children with T1DM aged 10 to 18 years old attending follow-up in Paediatric Endocrine Clinic Hospital Universiti Sains Malaysia were invited to participate in the study.

Researcher approached patients during consultation with the doctor. They were briefed regarding the study and the instrument. Patients or parents were free to raise any question or concerns regarding the study before participation.

After verbally agreed to participate, they were required to fill in an informed consent form. Patients between 10 to 11 years old can provide verbal assent. Patients between 12 to 14 years old filled in an assent form. Patients aged between 15 to 17 years old signed the informed consent form with their parents. Participants who were 18 years old consented by signing the normal consent form.

The study was conducted in accordance with legal and regulatory requirements as well as the general principles set forth in the International conference on Harmonization (ICH) Good Clinical Practice (GCP). Risks to subjects were explained further in the Information and Consent form.

4.6 Sample size determination and calculation

Sample size calculated based on one single mean analysis using PASS 11 software

Alpha (α)	Power (1-β)	Mean 1	Mean 2	SD (σ)	n	Total Sample Size (n) + 10% of non-response rate
0.05	80%	25.0	30.0	11.0	53	53/0.9=58

The estimated sample size is 53 subjects

With anticipation of 10% non-response rate, the sample size required was

approximately 58

Reference article: Hoey, H., et al. (2001). Good Metabolic Control Is Associated With Better Quality of

Life in 2,101 Adolescents With Type 1 Diabetes Diabetes Care 24:1923

Summary Statements

A sample size of 53 achieve 80% power to detect a difference of 5.0 between the null

hypothesis mean of 25.0 and the alternative hypothesis mean of 20.0 with an

estimated standard deviation of 11.0 and with a significance level (alpha) of 0.05000

using a single mean analysis

4.7   Sampling method

- Children and adolescents aged 10 to 18 years old who attended Paediatric Endocrine Diabetic Clinic in HUSM were invited to participate in the study during consultation session with the doctors

- Instrument used was the Diabetes Quality of Life in Youths (DQOLY) by Ingersoll et al. (1991) which was adapted, translated and validated to Bahasa Malaysia by Jalaludin et al. (2013)

- Participants were subjected to history taking focusing on age, gender, race, household income, duration of diabetes, types of insulin, number of insulin injections, number of self-monitoring blood glucose per day (SMBG) and caretakers involvement in diabetes home monitoring

- Information such as type of insulin used, body mass index (BMI) and HbA1c were taken from patient's folder (latest 3 months from date of study)

- Types of insulin used were divided into conventional and intensive. Conventional insulin therapy comprises of twice daily injections of a mixture of short or rapid acting insulin with intermediate-acting insulin. Intensive insulin therapy refers to three or more injections per day either three injections daily, basal-bolus or insulin delivery via insulin pumps (Rewers et al., 2014)

- Body mass index were categorized into underweight (less than 25th percentile in CDC growth chart), ideal weight (25th to 50th percentile in CDC growth chart) and overweight between 85th to 95th percentiles in CDC growth chart

- HbA1c readings were collected and subsequently divided into two groups either HbA1c 4.0% to 8.5% which indicate good control and HbA1c above 8.6% which indicate poor control group (American Diabetes Association, 2004, Mortensen et al., 1998 and Chase et al., 2003 and Bryden, 2003)

- Patients and guardians were briefed regarding the study and the study instrument. Patients who were 12 to 18 years old gave their own consent to participate in the study

- Participants later spent approximately 20 to 30 minutes to answer the questionnaires outside the consultation room to ensure privacy. The questionnaire then returned to the doctor after completion

- There were no identification data in the questionnaire to ensure patients' privacy

4.8 Research tools

- The research tools were case recording form and questionnaire

- Patients' details such as age, gender, ethnicity, household income and caretaker involvement in diabetes care was recorded. Disease details such as duration of diabetes, body mass index (BMI), insulin type, number of insulin injection, number of self-monitoring blood glucose per day (SMBG) and HbA1c values were collected.

- Information such as type of insulin used, body mass index (BMI) and HbA1c were taken from patient's folder (latest 3 months from date of study)

- Questionnaire used was the Malay translated version of Diabetes Quality of Life for Youth (Jalaludin, et al. 2013). It was validated with internal validity and consistency Cronbach's alpha=0.917. A written approval from the author received and enclosed in the Appendix section

- The questionnaire was originally adapted from the Modified Diabetes Quality of Life Measure for Youths: Psychometric Properties (DQOLY) (Ingersoll, et al. 1991)

- The instrument consists of 49 items, which evaluates domain of Satisfaction, Impact and Worry

- The satisfaction with life part consists of 17 items assessing satisfaction with management (8 items), social life (6 items) and school life (3 items)

- The impact of diabetes part consists of 23 items assessing the impact of diabetes on physical (4 items), social (13 items), family (4 items) and school (2 items) aspects of participants' life

- The worry domain consists of 9 items assessing about worry towards education, future job, body shape, complication of diabetes and social relations

- 5 Likert scale answers with five options were used from very satisfied to very unsatisfied in the Satisfaction subscale and from never to always in the Impact and Worries subscales

- The lower score for each domain reflects better satisfaction with life, less impact of diabetes and less worry about diabetes and reflect good quality of life

Figure 1: STUDY FLOW CHART

Sampling Frame
- The eligible study sample

Exclusion Criteria

Demographic Data

Malay version DQOLY Questionnaire

Data Entry and Analysis

Data Interpretation and Conclusion