

**Assessment of the quality of care delivered
at the diabetes clinic of Ain Shams
University Children's hospital**

STUDY

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بسم الله الرحمن الرحيم

(قَالُوا سُبْحَانَكَ لَا عِلْمَ لَنَا
إِلَّا مَا عَلَّمْتَنَا
إِنَّكَ أَنْتَ الْعَلِيمُ الْحَكِيمُ)

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List of Abbreviations

ACEI	Angiotensin converting enzyme inhibitor
ADA	American Diabetes Association
AER	Albumin excretion rate
BG	Blood glucose
BMI	Body mass index
BS	Blood sugar
CHO	Carbohydrate
CVD	Cerebro-vascular disease
DCCT	Diabetes control and complication trial
DKA	Diabetic ketoacidosis
DM	Diabetes mellitus
DSME	Diabetes self-management education
EDIC	Epidemiology of diabetes intervention and control trial
GAD	Glutamic acid decarboxylase
HbA1c	Glycated hemoglobin
HDL	High density lipoprotein
HLA	Human leucocytic antigen
HNF	Human necrosis factor
IAA	Insulin auto antibody
ICA	Islet cell antibody
IDF	International diabetes federation
IFCC	International Federation for Clinical Chemistry and Laboratory Medicin.
ISPAD	International society of pediatric and adolescent diabetes
IT	Information technology
IZS	Insulin zinc suspension
JKAHO	Joint Commission on accreditation of Health Care Organization
LDL	Low density lipoprotein
MDGs	Millennium Development Goals
MODY	Maturity onset diabetes mellitus of youth
NPH	Neutral Protamine Hagedorn insulin
OGTT	Oral glucose tolerance test
Q	Quality
QA	Quality assurance
QAP	Quality Assurance Process

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QOC	Quality of care
QOL	Quality of life
QSP	Quality, Satisfaction, Performance model
SMBG	Self monitoring of blood glucose
SMS	Short message service
SPSS	Statistical program for social science version 12
SQC	Suboptimal quality of care
T1D	Type 1 diabetes mellitus
T2D	Type 2 diabetes mellitus
TDEI	Total daily energy intake
USA	United state of America
WFS1	Wolfram syndrome1
WHO	World health organization

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Introduction

Type 1 diabetes mellitus (T1D) is the most common chronic illness in childhood and adolescence, with important consequences for physical and emotional development. Individuals with T1D confront serious life style alterations that include an absolute daily requirement for exogenous insulin, the need to monitor their own glucose control, and the need to pay attention to dietary intake and exercise. Morbidity and mortality stem from acute derangements (DKA) and from long term complications (usually in adulthood) that affect small and large vessels resulting in retinopathy, nephropathy, neuropathy, ischemic heart disease, and arterial obstruction with gangrene of the extremities (**Alemzadeh and Ali; 2011**) .

Factors affecting long-term outcomes include patient's education, awareness, motivation, and intelligence level. The 2012 American Diabetes Association (**ADA**) standard of care emphasizes the importance of long-term, coordinated care management for improved outcomes and suggests structural changes to existing systems of long-term care delivery (**Khardori, 2013**).

The child with diabetes who receives limited care is more likely to have a lower quality of life and develop diabetes long-term complications at an earlier age. Improvement in quality of care determined by care practices that improve outcomes will decrease the overall lifetime cost of diabetes by decreasing acute and chronic complications of diabetes and will normalize life expectancy. More importantly improving outcomes will improve quality of life for individuals with diabetes and their families **(IDF and ISPAD combined guidelines, 2011)**. Moreover, the great variation in quality of medical performance between different organizations has an impact on the outcome in terms of acute and chronic complications adding to the importance of assessing the quality of health services **(ADA, 2012)**.

In one study at a university hospital in a developing country, it was found that the overall aspects of diabetes care were far below any recommended standards with the majority of patients not achieving targets of glycemic control **(Gudina et al., 2011)**.

Aim of the work;

To evaluate the quality of care delivered at the Diabetes Clinic of Ain Shams University Children's Hospital in order to guide future improvement of services according to international standard guidelines of quality to ensure the best possible clinical outcomes for patients and satisfaction for all customers (patients, relatives and team of the work), as follow;

- 1- To identify the level of diabetic patients' satisfaction and providers' satisfaction (Doctors) with the health services in the children's diabetes clinic.
- 2- To assess the adherence of providers' performance to the standard guidelines and recommendations of diabetic children care.
- 3- To specify areas for quality improvement of diabetes care services in the Diabetes clinic of the Children's Hospital of Ain Shams University.

Chapter 1 :

Type 1 diabetes mellitus in children (T1D):

General considerations;

Definition :

Diabetes mellitus (DM) is a common, chronic, metabolic syndrome characterized by hyperglycemia as a cardinal biochemical feature (**Alemzadeh and Ali; 2011**).

Diabetes mellitus is a group of metabolic diseases characterized by chronic hyperglycemia resulting from defects in insulin secretion, insulin action, or both (**ISPAD, 2009**).

The chronic hyperglycemia of diabetes is associated with long-term damage, dysfunction, and failure of various organs, especially the eyes, kidneys, nerves, heart, and blood vessels (**American Diabetes Association, 2009**).

Type 1 diabetes mellitus (T1D) in childhood is the most common paediatric endocrine disorder affecting approximately 1 in 300 to 500 children younger than 18 years old worldwide, the annual incidence of T1D is

increasing steadily but with significant geographic differences (**Jospe et al, 2006**).

Diabetes is the third most common chronic condition in the childhood and the poor glycemic control leads to serious short-term and life- limited long-term complications (**McNamara et al,2010**)

Etiology and pathophysiology :

The major forms of diabetes are divided into those caused by deficiency of insulin secretion due to pancreatic B cell damage (T1D) and those that are a consequence of insulin resistance occurring at the level of skeletal muscle, liver, and adipose tissue with various degree of B cell impairment type 2 diabetes mellitus) (T2D) (**Alemzadeh and Ali; 2011**)

T1D is the culmination of lymphocytic infiltration and destruction of insulin-secreting beta cells of the islets of Langerhans in the pancreas. As beta-cell mass declines, insulin secretion decreases until the available insulin no longer is adequate to maintain normal blood glucose levels. After 80-90% of the beta cells are destroyed, hyperglycemia develops and diabetes may be diagnosed. Patients need exogenous insulin to reverse this catabolic condition, prevent ketosis, decrease hyperglucagonemia,