# **Deanship of Graduate Studies Al-Quds University**



# Health Related Stigma and Self-Adherence to Treatment among Adolescents with Type 1 Diabetes in the West Bank, Palestine

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# Health Related Stigma and Self-Adherence to Treatment among Adolescents with Type 1 Diabetes in the West Bank, Palestine

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# Al-Quds University Deanship of Graduate Studies Pediatric nursing



# Thesis Approval Health Related Stigma and Self-Adherence to Treatment among Adolescents with Type 1 Diabetes in the West Bank, Palestine

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#### **Declaration**

I certify that this thesis submitted for the degree of Master is the result of my own research, except where otherwise acknowledged, and that this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institution.

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#### **Dedication**

To the greatest man I have in my life, the light of my life... my lovely

#### Father.

To the biggest heart with the most loving care, who sacrificed a lot for me to become what I am now,

#### **My Mother**

to the person who ignited a light inside of me, the love of my life

#### My Wife

To all those who encouraged, supported, and helped me all the way.

I dedicate this research for you.

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#### **Abstract**

Background: Type 1 diabetes (T1D) is a chronic illness caused by the destruction of B cells in the pancreas, leading to complete insulin deficiency. It is a highly demanding illness that requires regular treatment, care, and medical follow-up. T1D has many complications related to the degree of exposure to hyperglycemia. T1D treatment involves continuous blood glucose monitoring, insulin injecting or inserting an insulin pump infusion set, regulating food intake, and calculating insulin doses. These treatment methods can cause psychological issues, such as fear of rejection, low self-esteem, and anxiety about how others will react to the illness. Stigma is also a major issue faced by individuals with T1D, which can negatively impact social, emotional, and behavioral status. Stigma arises from the visibility of self-management instruments such as insulin pump or insulin needle injections, and the high potential for symptomatic hypoglycemia. Nevertheless, adherence to treatment is crucial to ensure glycemic control and prevent complications.

Objectives: The overall aim of this research is to assess the level of health-related stigma and self-adherence to treatment among adolescents with T1D in the West Bank, Palestine, and to identify factors that may influence these outcomes. It aims to assess differences in socio-demographic characteristics, such as age, gender, and socioeconomic status, in relation to self-adherence to treatment and health-related stigma. In addition, medical characteristics, such as diabetes duration, mode of insulin administration, and HbA1C, will also be examined to identify any differences in relation to health-related stigma and self-adherence to treatment. Furthermore, this study will examine the correlation between health-related stigma and self-adherence to treatment among children with T1D. By identifying factors that may influence health-related stigma and self-adherence to treatment, this research can inform interventions aimed at improving the health outcomes and quality of life for adolescents with T1D in the West Bank, Palestine.

**Methodology:** a cross-sectional quantitative design was used to assess level of health related stigma and self-adherence to treatment among adolescent aged from 12-18 years old who have type 1 diabetes mellitus (T1D). An adapted questionnaire containing demographic, medical data, stigma scale and self-adherence to treatment was filled by adolescents who have T1D after the consent of their parents.

**Results**: 192 individuals participated in this study, the mean age of participants was 15.1 years old, the Min age was 12 years old and the Max age was 18 years old. More than half of the participants were female 58.8%, while 45.8% were male. According to the data analysis the participants have a moderate level of adherence 57% and have no stigma. Also A negative small correlation was found between health related stigma and self-adherence to treatment among adolescents (r=-0.153, p=0.034). This means when stigma increase, adherence will decrease. Also the results shows a significant difference between stigma and self-adherence to treatment and socio-demographic data (school grade, place of residence, father's and mother's education, and economic status) and medical characteristics (date of diagnosed and way of insulin administration, p=<0.001).

**Conclusions:** Children and adolescents with T1D in West Bank, Palestine have a moderate level of adherence to treatment and a significant level of stigma between the independent variables (sociodemographic data and medical characteristics. Also the results shows a small correlation between health related stigma and self-adherence to treatment among adolescents with T1D, which means that the higher level of stigma, the less is the adherence.

**Recommendation:** The study is cross-sectional; it only gives an overview of participants' experiences at one specific time. a longitudinal study that follows participants over time might offer a more dynamic understanding of the relationship between stigma and adherence to treatment. Uses a quantitative approaches as well, which might not adequately represent the complex nature of the experiences of young people with T1D. It may be possible to gain a deeper knowledge of the social, cultural, and psychological aspects that affect stigma and

treatment adherence in this population by using qualitative research techniques like focus groups and interviews.

Keywords: stigma, health related stigma, type 1 diabetes mellitus, adherence

الوصمة ومدى الالتزام بالخطة العلاجية بين الأطفال المصابين بداء السكري من النوع الأول: دراسة مقطعية الضفة الغربية – فلسطين.

إعداد: همام ياغي

إشراف: د. كوثر العيسة

الملخص: مرض السكري من النوع 1 هو مرض مزمن ينجم عن تدمير خلايا بيتا في البنكرياس، مما يؤدي إلى نقص كامل في هرمون الأنسولين. إنه مرض مطلوب من الغاية يتطلب علاجًا منتظمًا ورعاية صحية ومتابعة طبية. يتسبب السكري من النوع 1 في العديد من المضاعفات المرتبطة بدرجة التعرض لفرط السكر في الدم. تتضمن علاج السكري من النوع 1 مراقبة مستمرة لمستوى السكر في الدم، حقن الأنسولين أو إدخال مجموعة بمضخة أنسولين، وتتظيم تناول الطعام وحساب جرعات الأنسولين. يمكن أن تسبب هذه الطرق العلاجية مشاكل نفسية، مثل الخوف من الرفض وانخفاض تقدير الذات، والقلق بشأن كيفية رد فعل الآخرين تجاه المرض. كما أن الوصيمة هي مشكلة كبيرة يواجهها الأفراد المصابون بالسكري من النوع 1، مما يؤثر سلبًا على الوضع الاجتماعي والعاطفي والسلوكي. وتتشأ الوصيمة من رؤية أدوات إدارة الذات مثل مضخة الأنسولين أو حقن الأنسولين، وارتفاع الاحتمالية لانخفاض السكر في الدم. ومع ذلك، فإن الالتزام بالعلاج ضروري لضمان التحكم في مستوى السكر في الدم والوقاية من المضاعفات.

الهدف: الهدف العام لهذه الدراسة هو تقييم مستوى التمييز الصحي والالتزام الذاتي بالعلاج بين المراهقين المصابين بالسكري من النوع 1 في الضفة الغربية، فلسطين، وتحديد العوامل التي قد تؤثر على هذه النتائج. وهدفت إلى تقييم الفروق في الخصائص الاجتماعية والديموغرافية، مثل العمر والجنس والوضع الاقتصادي، فيما يتعلق بالالتزام الذاتي بالعلاج والتمييز الصحى. بالإضافة إلى ذلك، سيتم فحص

الخصائص الطبية، مثل مدة الإصابة بالسكري ووسيلة إدارة الأنسولين و HbA1C ، لتحديد أي فروق في العلاقة بين التمييز الصحي والالتزام الذاتي بالعلاج. وعلاوة على ذلك، ستدرس هذه الدراسة الارتباط بين التمييز الصحي والالتزام الذاتي بالعلاج لدى الأطفال المصابين بالسكري من النوع 1. من خلال تحديد العوامل التي قد تؤثر على التمييز الصحي والالتزام الذاتي بالعلاج، يمكن لهذه الدراسة أن تساعد في تصميم تدخلات تهدف إلى تحسين النتائج الصحية وجودة الحياة للمراهقين المصابين بالسكري من النوع 1 في الضفة الغربية، فلسطين.

الأساليب: تم استخدام تصميم عرضي كمي لتقييم مستوى التمييز الصحي المتعلق بالمرض والالتزام الذاتي بالعلاج بين المراهقين والاطفال الذين تتراوح أعمارهم بين 12-18 عامًا ولديهم مرض السكري من النوع 1. تم ملء استبيان يحتوي على بيانات ديموغرافية وطبية ومقياس التمييز والالتزام الذاتي بالعلاج من قبل الاطفال الذين يعانون من السكري من النوع 1 بعد موافقة الآباء والأمهات.

النتائج: شارك 192 فردًا في هذه الدراسة، وكان متوسط عمر المشاركين 15.1 عامًا، وكان الحد الأنتى العمر 12 عامًا والحد الأقصى 18 عامًا. كان أكثر من نصف المشاركين من الإناث 54.2% بينما كانت نسبة الذكور 45.8%. ووفقًا لتحليل البيانات، تم العثور على ارتباط سلبي صغير بين الصلة بين الوصمة المتعلقة بالصحة والالتزام بالعلاج بين المراهقين (r = -0.153)، (r = -0.034). وجود فروق كبيرة بين التمييز يعني عندما تزداد الوصمة ، سينخفض الالتزام بالعلاج. كما تبين النتائج وجود فروق كبيرة بين التمييز والالتزام بالعلاج والبيانات السكانية (الصف الدراسي ، مكان الإقامة ، تعليم الأب والأم ، والوضع الاقتصادي) والخصائص الطبية (تاريخ التشخيص وطريقة إدارة الإنسولين ، (-0.001)

الخلاصة: لدى الاطفال المصابون بمرض السكري النوع الاول مستويات متوسطة من الالتزام بالعلاج والوصمة المتعلقة بالصحة كما اشارت نتائج الدراسة.

توصية: هذه الدراسة هي عبارة عن دراسة مقطعية، حيث تقدم نظرة عامة فقط على تجارب المشاركين في وقت محدد. يمكن أن توفر دراسة طويلة المدى تتبعاً للمشاركين عبر الزمن فهما أكثر ديناميكية للعلاقة بين التمييز والالتزام بالعلاج. كما يستخدم أساليب كمية، والتي قد لا تمثل بشكل كافي الطبيعة المعقدة لتجارب الشباب المصابين بالسكري من النوع 1. ومن الممكن أن نكتسب معرفة أعمق بالجوانب الاجتماعية والثقافية والنفسية التي تؤثر على التمييز والالتزام بالعلاج في هذه الفئة العمرية عن طريق استخدام تقنيات البحث النوعي مثل المجموعات المركزة والمقابلات.

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#### **List of Abbreviations**

T1D	Type 1 diabetes
MOH PHC	Palestinian ministry of health
CGM	Continues glucose monitoring
HLA	human leukocyte antigen
INS	Insulin gene
ADA	American diabetic association

# Chapter One Introduction

#### 1.1 Background

Chronic illness is a lifelong, incurable condition, requires ongoing care, treatment, and monitoring by a doctor (Eiser, 1997). It can affect a patient's life and the lives of their family members; they may feel stress, frustration, and concern, especially if the illness is difficult (Golics et al., 2013). Type 1 diabetes (T1D) is one of the most prevalent chronic disorders. It is characterized by total insulin insufficiency and pancreatic B cell destruction (Ozougwu et al., 2013).

T1D is an autoimmune disorder in which genes and environmental factors play a role and trigger the onset of the disease (Ozougwu et al., 2013). Moreover, it is categorized as either microvascular (including retinopathy, nephropathy, and neuropathy) or macrovascular because of its various complications (i.e., cardiovascular disease [CVD], cerebrovascular accidents, and peripheral vascular disease). These problems relate to the level of hyperglycemia exposure (Melendez-Ramirez et al., 2010).

Individuals with T1D worldwide in (2022) were 8.75 million, 1.52 million of the total population were less than 20 years old (IDF Diabetes Atlas, 2021). Among youth who are 19 years or younger in USA, 4958 of 3.35 million had T1D in 2001, 6672 of 3.46 million had T1D in 2009, and 7759 of 3.61 million had T1D in 2017; among those aged 10 to 19 years and this shows an increase in the prevalence of T1D (Lawrence et al., 2021). The reported cases In 2021 with diabetes Mellitus in Palestinian ministry of health diabetic clinics in the West Bank were 4,700 cases with an incidence ratio of 166.9 per 100,000 populations, spread to 2,079 cases among males with an incidence ratio of 144.8 per 100,000

male population, and 2,621 among females with an incidence rate of 189.9 per 100,000 female population (Palestinian Health Information Center, 2015).

T1D treatment involves continuous blood glucose monitoring (CGM), insulin injection (around 4 times daily) or inserting insulin pump infusion set (at least every 2–3 days); regulating food intake and counting carbohydrate and calculating insulin doses. Recognizing and taking action to prevent or treat hypoglycemia and hyperglycemia is what makes T1D highly demanding chronic illness.(Streisand et al., 2014).

These treatments could trigger psychological issues in children, such as feeling different from their friends, fear of rejection, low self-esteem, fear of being bound by the circumstance, and anxiety about how others, particularly their peers, will react to their sickness (Chatterjee et al., 2013) and (Liu et al., 2017).

Hence these treatment methods are on the surface are demanding and complex. There is also a hidden burden that affects many aspects of the life of those with TID and that is stigma (Abdoli et al., 2013). And it is a negative attribute that diminishes a person's worth; it is also a complex construct comprised of interpersonal and intrapersonal experiences (Goffman, 1963). It is described as discrimination directed towards individuals (Bogart et al., 2008). Individuals with T1D reported that they view themselves as "patients," "intoxicated," and "drug addicts" since they inject or swallow medications (Abdoli et al., 2013). This illness's diversity has detrimental effects on social, emotional, and behavioral status, resulting in stigmatization (Browne et al., 2014).

On the other hand, Individuals with T1D feel anger, stress, and social anxiety, postpone their insulin injections, and have difficulty with diet control as a result of the concern surrounding their disease, which increases their risk for complications (Ceylan et al., 2017).

Many children aged 14-19 years old don't want to be seen monitoring glucose and administering insulin in front of friends because the feeling of stigmatization, and thus lack of glycemic control. Management of T1D is considered complex and visible self-management instruments such as insulin pump or insulin needle injections and CMG. It also has high potential for symptomatic hypoglycemia with confusion, distress, or loss of consciousness. The visibility of the equipment required for testing, glucose check, injections, and hypoglycemic symptoms if they happen are the attributes that makes this illness lead to stigma (Abdoli et al., 2013; Browne et al., 2014; Irani et al., 2014).

Nevertheless treatment of T1D requires self-adherence to guarantee glycemic control and prevent complications. Generally, adherence is defined as how well the patient is able to manage the recommended treatment by health care providers (Zolnierek et al., 2009). Children face challenges in adhering and following up with the recommendation of therapy, injections, diet and exercise (AlBuhairan et al., 2016). Most individuals with T1D have difficulties in following up with the treatment recommended by their doctor, because it is complex and demanding (Gonzalez et al., 2016). They also experience different barriers to treatment adherence such exhaustion (Gandhi et al., 2015; Helgeson et al., 2007) social stigma, parental role influence, High prices for medical supplies or insulin, inadequate doctor-patient communication, family functioning, and psychosocial problems (Datye et al., 2015).

In addition, there have only been a few researches that have demonstrated how the feeling of stigma might function as a barrier to adherence to treatment. The majority of these studies looked at these aspects in either teenagers or adults who had type 2 diabetes (Schabert et al., 2013).

#### 1.1.1 The Palestinian context and occupation

Palestine is a region located in the Middle East. The area of Palestine is estimated to be around 27,000 square kilometers with a diverse population of Arabs, Jews, and other ethnic groups. The region has been the center of conflict and political turmoil for decades, with ongoing disputes over land, resources, and sovereignty.

The structure of the Arab society is influenced by cultural values, traditions, and religious beliefs. Consequently, it is observed that it has an impact on both the frameworks and practices of the community. Within Arab-Muslim societies, such as Palestine, the family unit is recognized as the fundamental social structure through which children are passed on beliefs, values, and traditions. Additionally, it is acknowledged as the primary social safety net for individuals. The Palestinian family is a masculine and traditional structure (Arabiat, DH et al., 2013).

The Palestinian people have faced numerous challenges, including displacement, violence, and discrimination. The Israeli-Palestinian conflict has been ongoing since the establishment of the state of Israel in 1948, with both sides claiming the right to the land. The conflict has resulted in the displacement of millions of Palestinians, with many living in refugee camps in neighboring countries.

The Israeli occupation of Palestine has had a significant impact on the health system and daily lives of Palestinians. Resulted in social justice violations and wide-ranging effects on health experienced daily by the Palestinian people (Qato, D, 2004). Occupation has caused brutal effects and damages on the Palestinians, including the deprivation of natural wealth and resources (Arra, M, 2021). The daily practice of human resource management is a real

challenge, especially under the Israeli occupation and the different strategies Israel employs to destroy any improvement plans (Abdullah, M et al., 2021). The occupation has resulted in daily conflicts that take place due to Israeli occupation of the land (Mokbel, S, 2018). It tends to seize and loot all the natural wealth and resources, depriving the Palestinians of exploitation and sovereignty on them (Arra, M, 2021). Overall, the Israeli occupation of Palestine has had a significant impact on the health system and daily lives of Palestinians, and efforts to address these issues should consider the political and social context of the occupation.

#### 1.2 Problem Statement

Living with a chronic condition such as T1D can impact various daily life aspects, including psychological issues such as stigma. Previous studies reported that the sociocultural and religious beliefs can influence how people perceive their illness. Stigma can have negative outcomes on children with T1D such as impaired psychosocial wellbeing and avoiding self-care activities, with an effect on physical health.

It is reported that fear of stigmatization causes patients with type 1 diabetes to experience anger, stress and social anxiety, to postpone their blood Glucose measurements and insulin injections and to have problems with their T1D treatment such as regular blood glucose monitoring, calculating insulin requirements, administering insulin as needed, and following dietary recommendation are challenging. These challenges might affect adolescents' self-adherence to treatment. Low self-adherence can lead to an increased risk for hospitalization, further complications (e.g., retinopathy, neuropathy, diabetic ketoacidosis, and even early death.

Therefore, assessing health-related stigma and self-adherence to treatment in adolescents with T1D in the West Bank has the potential to improve psychological well-being and self-management.

#### 1.3 Justification of the Study

T1D is a chronic autoimmune illness that often manifests in children and young adults. It is marked by complicated and obvious self-management needs, including as using insulin injections or an insulin pump, capillary blood glucose monitoring, and paying attention to the time of meals, dietary choices, and physical activity levels (Brazeau et al., 2018).

The illness elements that have the potential to contribute to stigma include things like the visibility of the equipment, blood tests, making modifications to therapy, and the occurrence of hypoglycemia symptoms, if they do occur (Nishio et al., 2017).

When a chronic condition such as T1D develops in children and adolescents, the most common reactions are denial of the illness, refusal of therapy, or noncompliance with treatment (Adal et al., 2015).

Consideration of insulin therapy as difficult and confining to one's life, fear of stigmatization, and a negative view that insulin treatment is inefficient or dangerous are all factors that contribute to noncompliance with insulin treatment among diabetic patients (Sorli et al., 2014).

Previous studies have reported impact of stigma on daily life of children with chronic illnesses as physical and mental illness. Studies in the related literature have demonstrated that fear of stigmatization causes patients with T1D to experience anger, stress and social anxiety, to postpone their blood glucose measurements and insulin injections and to have problems with their diets. Most of the studies about health related stigma and self- adherence to treatment in adolescents with T1D have been conducted qualitatively and quantitatively in Western countries.

To date, no quantitative studies have been published about health related stigma and adherence to treatment among Palestinians' adolescents with T1D.Consequently assessing self- adherence and self-perceived stigma and its associated factors of adolescents with T1D can help in identifying children who are at risk for intervention, and may provide health care providers with information that contributes to help care for children quality of physical, psychological, and social life.

#### 1.4 Aim of the Study:

To assess health related stigma and self-adherence to treatment among adolescents with T1D in the West Bank, in Palestine.

#### 1.5 Objectives of the Study

- 1. To assess level of health related stigma and self-adherence to treatment among adolescents with T1D in the West Bank, Palestine.
- 2. To assess factors that related to treatment adherence and health-related stigma for adolescents with T1D in the West Bank, Palestine.
- 3. To assess the differences between socio-demographic characteristics in terms of self- adherence and health related stigma among adolescents with T1D.
- 4. To assess the differences between medical characteristics such as diabetes duration, mode of insulin administration and HbA1C in terms of health related stigma and self-adherence to treatment among children with T1D.
- 5. To examine the correlation between health related stigma and self-adherence to treatment among children with T1D

#### 1.6 Research questions:

- 1. What is the level of health related stigma and self-adherence to treatment among adolescents with T1D?
- 2. What are the factors that related to health related stigma and self-adherence to treatment among adolescents with T1D?
- 3. Is there a relationship between socio-demographic characteristics in terms of self-adherence to treatment and health related stigma among adolescents with T1D?
- 4. Is there a relationship between medical characteristics in terms of health related stigma and self-adherence to treatment among adolescents with T1D?
- 5. Is there a relationship between health related stigma and self-adherence to treatment among adolescents with T1D?

#### 1.7 Study hypothesis:

- There are no significant differences between socio-demographic characteristics in terms of health related stigma and self-adherence to treatment among adolescents with T1D.
- 2. There is no significant differences between medical characteristics in terms of health related stigma and self-adherence to treatment among adolescents with T1D
- 3. There is no correlation between health related stigma and self-adherence to treatment among adolescents with T1D.

#### 1.8 The following are the assumptions of this study:

- 1. The researcher assumed that adolescents with T1D might have health related stigma and have trouble following up the recommended treatment.
- Children with higher levels of hemoglobin A1c (HbA1C) are assumed to be more stigmatized and have lower self-adherence to treatment.
- 3. Health-related stigma has a negative impact on the mental health and well-being of adolescents with type 1 diabetes, which in turn can affect their self-adherence to treatment.
- 4. Adolescents with type 1 diabetes who receive support from their families, peers, and healthcare providers are more likely to adhere to their treatment regimen and experience better health outcomes, even in the face of health-related stigma.

#### **1.9 Summary:**

The introduction chapter of the study focuses on the relationship between health-related stigma and self-adherence to treatment among adolescents with type 1 diabetes. The chapter highlights the challenges that adolescents with type 1 diabetes face, including managing their illness while trying to fit in with their peers. Health-related stigma can exacerbate these challenges, leading to poor adherence to treatment and worse health outcomes. So, in this chapter, the background, the statement of the problem, aim and objectives of the study, as well as the justification of the study were. In addition, the research assumptions were defined.

#### **Chapter Two**

#### **Literature Review**

#### 2.1 Introduction

This chapter illustrates the aims of the literature review, search strategies, results of search and, discussion. Furthermore, it discussed in details factors that have an impact on stigma and the relationship between health-related stigma and self-adherence to treatment among adolescents with T1D.

#### 2.2 Search Strategy

A thorough and systematic search was undertaken to extract relevant studies on Stigma and Self-Adherence among children who have T1D. The search investigated publications published in English-language, peer-reviewed journals between 2005 and 2022 on Stigma, Self-Adherence, and Children with T1D. These terms were utilized in the search: (Stigma in Children with T1D; Self-Adherence in Children with T1D, Type 1 diabetes). Several research sites (PubMed, research gate, science direct, Google scholar, and refseek) were explored, and the search was completed on May 30, 2022.

#### 2.3 Type 1 Diabetes

Type 1 diabetes (T1D) is a chronic autoimmune disease that is characterized by the destruction of insulin-producing beta cells in the pancreas. It is estimated that around 1.6 million people worldwide are affected T1D, and the incidence of the disease is growing, especially among children (Patterson et al., 2018). The etiology and pathogenesis of T1D are complex, involving genetic, environmental, and immunological factors.

#### 2.3.1 Etiology:

Type 1 diabetes is thought to be caused by the interaction of genetic and environmental factors that trigger an autoimmune response against the insulin-producing beta cells in the pancreas (Atkinson et al., 2014). The genetic component T1D is complex, involving multiple genes that contribute to susceptibility to the disease. Some of the most important genetic risk factors for T1D include human leukocyte antigen (HLA) genes, which are involved in immune regulation, and insulin gene (INS) variants, which are included in insulin production (Pociot et al., 2016). Environmental factors are significant contributors to the occurrence of T1D. Enteroviruses in particular have been linked to the pathogenesis of it (Laitinen et al., 2014). Exposure to cow's milk, a lack of vitamin D, and early introduction of solid meals are three other environmental factors that have been connected with an increased risk of T1D (Rewers et al., 2016).

#### 2.3.2 Pathogenesis:

The destruction of insulin-producing beta cells in the pancreas causes a lack of insulin synthesis and hyperglycemia, which is the characteristic of type 1 diabetes. The autoimmune response that causes beta cell destruction is thought to be activated by auto reactive T lymphocytes in the pancreatic lymph nodes. These T lymphocytes detect and target beta cell antigens, resulting in type 1 diabetes. The activation of auto reactive T cells in type 1 diabetes is thought to be caused by a variety of processes. One of the suggested explanations is that viral infections or other environment factor cause beta cell antigens to be released, activating auto reactive T cells. Defects in immunological control, such as a failure of regulatory T cells to decrease auto reactive T cells, may also play a part in the

onset of T1D (Atkinson et al., 2014; Insel et al., 2015; Kolb et al., 2017; von Herrath, 2011).

#### 2.3.3 Clinical presentation and Investigations

The diagnosis of type 1 diabetes in children relies on a combination of clinical symptoms and laboratory tests. The initial presentation of type 1 diabetes in children can be sudden, with symptoms such as polyuria, polydipsia, weight loss, and fatigue. These symptoms are often accompanied by hyperglycemia and glycosuria, which can be detected through blood glucose and urine tests, respectively (Maahs et al., 2015).

The American Diabetes Association (ADA) recommends that individuals with symptoms of hyperglycemia should undergo diagnostic testing for diabetes. The ADA diagnostic criteria for diabetes include a fasting plasma glucose level of 126 mg/dL or higher, a random plasma glucose level of 200 mg/dL or higher with symptoms of hyperglycemia, or a two-hour plasma glucose level of 200 mg/dL or higher during an oral glucose tolerance test (American Diabetes Association, 2021).

In addition to these diagnostic tests, the presence of diabetes-related autoantibodies can aid in the diagnosis of type 1 diabetes in children. The most common autoantibodies associated with type 1 diabetes are directed against the islet cells (ICA), insulin (IAA), glutamic acid decarboxylase (GAD65), and tyrosine phosphatase-like protein (IA-2) (Greenbaum et al., 2012). The presence of two or more diabetes-related autoantibodies in a child with hyperglycemia is highly suggestive of type 1 diabetes (American Diabetes Association, 2021).

#### 2.3.3 Management of T1D

Involves the lifetime use of exogenous insulin to help maintain normal blood sugar levels. Good diabetes management is typically defined as reducing the occurrence of high and low blood glucose readings in correlation with engaging in tasks, behaviors, and time (Hunter, 2016). Preventing complications and maintaining well-controlled glucose readings draw on a challenging daily routine, making it difficult for most individuals to follow the recommended standard prescribed by their doctor (J. S. Gonzalez et al., 2016). It includes testing blood glucose levels with a glucometer approximately 10–20 times (both before meals and during the day for monitoring), 3–4 insulin injections with up to two different types of insulin (long-acting and short-acting), and monitoring carbohydrates during meal times (Association, 2015; Hunter, 2016).

#### **Diet**

Type 1 diabetes can only be managed by good nutrition, which entails following a rigorous diet. As a result, it is critical to change dietary control measures after diagnosis by conducting extensive study on the glycemic index and carbohydrate content of various meals. Consume high-fiber, low-GI meals, protein-rich lentils, and veggies to control blood sugar levels. Lean protein, healthy fats, and fiber-rich carbohydrates are very filling and give sustained energy. Because they boost blood sugar levels more slowly, solid carbs should be ingested in moderation. Avoid liquid carbohydrates and highly processed foods, which release a large amount of sugar into the circulation at once. Consuming omega-3 fats and drinking at least 2 liters of water every day is also good in lowering the risk of heart disease and dissolving blood glucose.

#### Physical activity

Physical activity is an important part of living a healthy lifestyle for children with type 1 diabetes. Physical activity on a regular basis can improve glycemic management, reduce insulin resistance, and lower the risk of cardiovascular disease (Brazeau et al., 2018). Children with type 1 diabetes, on the other hand, must exercise with caution and under proper supervision. Before and during physical exercise, features such as insulin dosage, carbohydrate consumption, and blood glucose monitoring must be carefully examined. Physical activity intensity and duration should be customized to the individual's ability and goals, and blood glucose levels should be checked before, during, and after exercise (Colberg et al., 2016). A multidisciplinary strategy combining a healthcare team comprised of a physician, certified diabetes educator, and exercise specialist can assist adolescents with type 1 diabetes in engaging in physical activity safely.

#### 2.3.4 Complications of T1D

T1D is a chronic illness that, if left unchecked, can develop to a range of problems in children, according to the American Diabetes Association (2022). Hyperglycemia, or high blood glucose levels, is a primary risk factor for type 1 diabetes complications. High blood glucose levels can damage blood vessels and neurons over time, resulting in a number of problems such as diabetes retinopathy, neuropathy, and nephropathy. Cardiovascular disease, peripheral vascular disease, and diabetic ketoacidosis are some of the other consequences of T1D in children. Children with T1D should see their doctor on a frequent basis to monitor their blood glucose levels and catch any signs of difficulties early on.

Also, leading a healthy lifestyle that includes regular physical activity and a well-balanced diet might help to prevent or postpone the beginning of difficulties. Parents should

collaborate closely with their child's healthcare team to build a thorough treatment plan to control T1D and prevent complications.

#### 2.4 T1D Epidemiology

The vast majority of cases of diabetes in childhood are T1D, which accounts for over 90% of all diabetes cases, and its incidence varies greatly between different countries, within countries, and between different ethnic populations (Barkai et al., 2020). Worldwide, the incidence of T1D diabetes is increasing by approximately 3–5% per year (Tuomilehto, 2019). However, the rates of increase and temporal trends are variable, and recently, a slowing rise in incidence has been reported in some countries, with the greatest increases in the incidence rate observed in those aged under 5 years (Bratina et al., 2018).

T1D is the most common chronic metabolic disease in children and is responsible for 5–10% of the total cases of diabetes worldwide (Rittiphairoj et al., 2022). Numbers of new (incident) and existing (prevalent) T1D cases are increasing each year due to rising incidence in many countries and reductions in mortality. In total, 1,211,900 children and adolescents younger than 20 years are estimated to have T1D globally. It is expected that around 108,200 children and adolescents under 15 are diagnosed each year. This number increases to 149,500 when the age range extends to those younger than 20 years (IDF Diabetes Atlas, 2021).

The rate of T1D in people aged 1–14 years old around the world varies a lot from one population to the next. For example, the three Scandinavian countries—Finland, Sweden, and Norway—feature in the top ten places in the list of countries with annual rates of 52.2, 44.1, and 33.6 per 100,000, respectively. While Arab countries—Kuwait, Qatar, Algeria,

and Saudi Arabia—feature in the top ten places in the list of countries with annual rates of 41.7, 38.1, 34.8, and 31.4 per 100,000, respectively (IDF Diabetes Atlas, 2021).

In the Middle East and North Africa regions, there were 192,500 children and adolescents between the ages of 1 and 19 with T1D in 2021. While the number of newly diagnosed children and adolescents of the same age each year is 25,000 (IDF Diabetes Atlas, 2021).

The reported cases In 2021 with diabetes Mellitus in Palestinian ministry of health diabetic clinics in the West Bank were 4,700 cases with an incidence ratio of 166.9 per 100,000 populations, spread to 2,079 cases among males with an incidence ratio of 144.8 per 100,000 male population, and 2,621 among females with an incidence rate of 189.9 per 100,000 female population.

#### 2.5 Stigma between concept and theory

Stigma is a Greek word that originally referred to a tattoo cut or burned into the skin of criminals, slaves, or traitors in order to identify them as blemished or morally polluted persons. These people were to be avoided or shunned, particularly in public places (Ottersen et al., 2012).

Conventionally, "stigma refers to any attribute, trait, or disorder that marks an individual as being unacceptably different from the "normal" people with whom he or she routinely interacts and that elicits some form of community sanction" (Goffman, 1963).

One of the twentieth century's greatest sociologists, Goffman, defined stigma as "the phenomenon by which an individual with an attribute is deeply discredited by his or her society and is rejected as a result of the attribute." "Stigma is a process by which the reaction of others spoils normal identity" (Goffman, 1963).

The essence of these stigmas is moral and judging in nature, and disgrace and shame are more significant than physical evidence of them. Labeling, stereotyping, distancing, status loss, and discrimination can all occur concurrently and are all considered stigma components (Larsen, 2009).

Goffman expanded prior work on stigma by introducing the concept of social identity. When we encounter strangers, certain appearances help us predict social identity, which includes both personal traits like competence and structural ones like occupation (Goffman, 1963). Physical activities, professional duties, and the concept of self can all contribute to a person's social identity. Something that alters one of these, such as a disability, alters the individual's identity and, as a result, may produce a stigma (Markowitz, 1998).

Stigma, according to Goffman's idea, is something that disqualifies an individual from full social acceptability. Goffman stated that social identification is a fundamental force in the creation of stigma since a person's identity categorizes them. Which categories to expect are revealed by social contexts and practices. As a result, when people fail to satisfy expectations due to different and/or unpleasant characteristics, they are demoted from accepted to discounted status—that is, they are stigmatized. Consequently, for the forces of society to identify a person as different or deviant is to inflict a stigma (Goffman, 1963).

"Because stigma is socially constructed, it varies from setting to setting; additionally, individuals and groups react differently to the stigmatizing process; and those reactions must be taken into account when planning strategies to improve the quality of life for individuals with chronic illnesses" (Larsen, 2009).

#### 2.6 Types of Stigma

The sources and objectives of stigma stem from two different concepts: feeling stigma and releasing stigma. Feeling stigma is related to the feelings of those who have a socially undesirable trait, in contrast. Releasing stigma is related to discrimination against those who have stigma, and releasing stigma reproduces through social hierarchies (Veroni, 2019).

Robinson et al., (2016) point out that stigma is a set of counter-attitudes, stereotypes, discriminatory behaviors, and prejudiced social groupings that are endorsed by a large group over a subgroup. It includes three types:

- **1. Public stigma:** It is the most well-known, and it focuses on the attitudes of the general community towards the stigmatized person.
- **2. Self-stigma:** It focuses on the assimilation and adoption of the negative views and evaluations of society by individuals.
- **3. Family stigma** refers to the stigma that an individual experiences as a result of being related to relatives who have stigmatizing characteristics.

The stigma consists of three components, or dimensions, which, as mentioned by Werner et al., (2015), are the following:

- 1. **Cognitive**, defined as stigmatized stereotypes or stereotypical beliefs that are widely known and circulated among members of a single culture, and then these stereotypes become the basis upon which any member of the categorical templates is built.
- 2.Emotionality, which is intolerance, is a concept based on inflexible and false discrimination.
- 3.**Behavioral**, which is discrimination, where the term discrimination refers to the distinction between things and people, and everything that is tainted by difference, deficiency, or defect in the eyes of society is exposed to it.

Dehnavi et al. (2011) indicated that there are six main social dimensions of stigma that have special effects on the emergence of stigma in everyday interactions, as follows: concealment,

internalization, stigma destruction, and traits, aesthetics, origin, and danger. Concealment refers to the ability to see the stigma situation and to control the way it is observed, which is one of the main dimensions that determine the degree of stigma. Goffman focused on the observer's awareness of the situation, which can vary based on people's knowledge or experience about the stigmatized person. Internalization refers to the pattern of stigma that sets over time. Some cases of stigma may disappear over time, but others are permanent.

#### 2.7 Health related Stigma among Children with Type 1 Diabetes

T1D is a hereditary condition, hence it is essentially uncontrollable. Thus, why is diabetes still stigmatized in some ways? It could be because patients with diabetes need insulin from outside sources to avoid complications; this presents a distinct likelihood of devaluation, as dependency on medical care for survival is a stigmatizing trait. It could also be related to the treatment regimens that are typically visible to others, such as insulin administration, eating at specific times, and so on. Also, hypoglycemic symptoms are very evident. All of these factors may add to the possibility of stigmatization. (Ottersen et al., 2012).

Stigmatization is defined as being excluded from society, discriminated against, and accused of wrongdoing (Browne et al., 2014). The goal of a related review study was to describe stigmatizing characteristics of diabetes. A search of CINAHL, PubMed, and Web of Science for qualitative research published between 2007 and 2017 (n = 18) indicated that people with diabetes saw themselves as "patients" and "drunks," and that having diabetes "reminds them of mortality." They see themselves as "rejected suitors" and "drug addicts," and they believe they have a "dangerous" and "contagious" sickness that "needs dietary adjustments" (Abdoli et al., 2018).

Fear of stigma is common among adolescents with type 1 diabetes. The rationale for this is that stigmatization has a negative impact on these patients' emotional, behavioral, and social states, as well as their medical care (Browne et al., 2014). A descriptive correlational study conducted in Turkey to examine adolescent social anxiety and related factors among youth aged 12-15 years with T1D (N = 140) found that fear of stigmatization makes patients with T1D to feel anger, stress, and social anxiety, to delay blood glucose measurements and insulin injections, and experiences diet problems (Ceylan et al., 2017; Jeong et al., 2018). Brazeau et al., (2018) revealed that among patients with type 1 diabetes, those with A1C > 9% were three times as likely to be exposed to stigmatization and that patients with serious hypoglycemia were 1.8 times more likely to suffer from stigmatization (Brazeau et al., 2018).

In a study by Sürücü et al. (2018) The study used cross-sectional and relational research designs (n=80), The purpose of this study was to investigate stigmatization, sociodemographic/ diabetes-related characteristics and parents-related characteristics as predictors of a negative perception of insulin treatment in adolescents with T1Din Turkey, it was found that the negative perception of insulin treatment among adolescents with T1D has increased as their fear of stigmatization increased. It has been claimed that stigma causes people with T1D to hold off checking their blood glucose, ignore their insulin dosages, and feel anger and stress (Jeong et al., 2018).

To explore the experiences of everyday life in children with T1D and their parents living in the West Bank of Palestine, a qualitative study using thematic interviews was conducted with 10 children with T1D and their parents (n=10), revealed that children with T1D did not tell others about their diabetes due to their fear of stigmatization and rejection, and The

overall theme was "facing the social reality of diabetes." Two ideas underlie this: "stigmatization" and "social restrictions" (Elissa et al., 2017).

According to the findings of the Sürücü et al. (2018) study, adolescents did not disclose others about their diabetes in order to avoid being rejected or regarded differently in terms of their health owing to social anxiety, and as a result, their negative perception of insulin treatment rose. It was also discovered that when adolescents' inclination to only use insulin when alone in public or crowded locations increased, so did their negative view of insulin treatment. Similar qualitative research found that people with diabetes went to the washroom alone to inject insulin when they were out with their friends (Browne et al., 2014; Elissa et al., 2017; Haugvik et al., 2016).

#### 2.8 Self-Adherence to treatment among Children with T1D

The term 'adherence' is used in contemporary medical literature because it communicates the importance of viewing people with diabetes as empowered and active participants in their own healthcare. It is preferred over 'compliance,' a term dating from a more paternalistic era of medicine in which people were expected to obey or accede to prescribers' directions (Aronson, 2007). 'Self-management' is a related neutral term representing the processes by which people execute health behavior recommendations (Modi, 2012).

The World Health Organization defines adherence as "the extent to which a patient's behavior—taking medication, following a prescribed diet, and/or executing lifestyle changes—corresponds with agreed recommendations from the health care provider (WHO, 2018). Adherence refers to "the extent to which a person's behavior coincides with medical or health advice" (Modi et al., 2012).

Among youth with T1D, such advice or treatment recommendations include a combination of frequent blood glucose monitoring (BGM), calculating insulin requirements,

administering insulin and/or glucose as needed, possible medication administration, careful attention to diet (e.g., counting carbohydrates for insulin carbohydrate ratios), exercise, clinic attendance, obtaining prescribed laboratory studies, and maintaining medical supplies. (American Diabetes Association, 2015).

The burden of adhering to these various behaviors is carried by adolescents and their families, and it affects nearly every aspect of daily life. Barriers to optimal treatment adherence are common and include competing demands for time and attention, miscommunication or misunderstandings about what to do (among family members and between families and healthcare providers), and financial or insurance-related barriers to obtaining needed care or supplies. It also includes insufficient adult involvement or monitoring of adolescent self-management and emotional or behavioral difficulties, among others (Patton, 2016).

Notably, children with T1D face numerous daily challenges associated with adherence to diabetes care recommendations due to adolescent, child, and family factors mentioned above —including challenges in adhering to intensive therapeutic insulin regimes (daily injections or pump adjustments), dietary restrictions, regular exercise, and frequent monitoring of biochemical markers. In addition, even with the availability of effective treatment, children with T1D have been reported to have challenges regarding adherence to treatment regimens compared with other age groups with diabetes (Borus et al., 2010).

Gandhi et al. (2015) focuses on the issue of adherence to treatment among adolescents with Type 1 diabetes. The study aims to explore the various strategies and considerations for assessing adherence in research and practice. The researcher conducted a comprehensive literature review and found that adherence to treatment among adolescents with T1Dis a major challenge. They identified several factors that contribute to poor adherence, such as

psychological and social factors, family and peer support, and health care provider communication.

The study suggests that effective interventions for improving adherence in adolescents with T1Dshould be multifaceted and include education, behavioral and psychological support, and social support. The researchers also recommend the use of validated assessment tools for measuring adherence in research and clinical practice, such as self-reported measures, biological measures, and electronic monitoring devices.

The results of the study demonstrate the importance of addressing the issue of adherence in adolescents with Type 1 diabetes. Poor adherence to treatment can have serious consequences, including poor glycemic control, increased risk of complications, and decreased quality of life. Therefore, it is essential to develop effective interventions and assessment strategies to improve adherence in this population.

Certainly, the consequences of no adherence to recommendations in T1D are concerning and can be potentially life-threatening. However, given that some of the previous studies have consistently shown an association between poor adherence and worsening glycemic control (Noorani et al., 2016).

### 2.9 Factors associated with adherence to diabetes care among children

Diabetes is a chronic disease that requires continuous medical management to prevent complications. Adherence to diabetes care is essential to ensure effective diabetes management, particularly among children who are at risk of long-term complications. This literature review examines the factors associated with adherence to diabetes care among children.

One study by Noser et al. (2016) investigated the relationship between self-efficacy and adherence to diabetes care among children. The study found that children who had higher

levels of self-efficacy were more likely to adhere to diabetes care compared to those with lower levels of self-efficacy. This highlights the importance of self-efficacy as a determinant of adherence to diabetes care.

Another study by Mehta et al. (2017) examined the role of parental involvement in diabetes care adherence among children. The study found that parents who were actively involved in their child's diabetes management were more likely to have children who adhered to diabetes care. This study emphasizes the crucial role that parents play in promoting adherence to diabetes care among children.

In a study by Winkley et al. (2015), the relationship between depression and adherence to diabetes care was examined among adolescents. The study found that adolescents with depression were less likely to adhere to diabetes care compared to those without depression. This suggests that psychological factors, such as depression, may be a barrier to adherence to diabetes care among adolescents.

Finally, a study by Rausch et al. (2017) investigated the relationship between family conflict and adherence to diabetes care among children. The study found that children who experienced high levels of family conflict were less likely to adhere to diabetes care. This study highlights the importance of addressing family dynamics and conflict as potential barriers to adherence to diabetes care among children.

Adherence among T1D individuals is a complex process that takes place within the social settings and usually involves alterations of social dynamics (Rosland et al., 2008). Patients who have family and friend support have higher degree of optimism and self-esteem to manage their disease as they will be less depressed about their condition (DiMatteo et al., 2012).

Assessing and monitoring adherence are important parts of routine diabetes clinical practice, especially among children, but several unique features of T1D present challenges. In contrast to conditions requiring a single care behavior (e.g., once- or twice-daily injections of insulin), the complexity of T1D management recommendations requires that adherence to multiple behaviors be considered. There may be distinct facilitators of or barriers to each self-management behavior and children tend to be less uniformly adherent to all behaviors (Quick et al., 2014). Indeed, adherence to simple tasks such as pill taking tends to be higher than adherence to more complex tasks, such as blood glucose monitoring (BGM) or insulin calculations, which are central to T1D management. Little evidence exists on the comparative clinical consequences of nonadherence to particular behaviors (Quittner et al., 2008).

Strict adherence to particular behaviors of a typical T1D regimen may not be feasible for some children, requiring modifications. Additionally, insulin routines or delivery methods may need to be tailored depending on individual needs (e.g., higher insulin requirement due to illness or puberty), activities (e.g., sedentary days versus sports activities), abilities of different caregivers (e.g., school nurses), or changing schedules (e.g., traveling, attending summer camp). These may be long-term changes that occur gradually over months or years or short-term adjustments to address a temporary (hours, days, or weeks) need, adding to the challenge of monitoring adherence over time. Because the determination of adherence rates requires a mathematical calculation of the frequency of behaviors that are executed compared with the frequency of behaviors prescribed (Hood et al., 2009), changing recommendations make it difficult to establish a denominator (i.e., the recommended behavior frequency) and accurately calculate an adherence rate (Gandhi et al., 2016).

Furthermore, children generally are not the sole managers of their diabetes. Primarily parents, but also other family members, teachers, coaches, school nurses, and friends,

provide support and execute many diabetes management tasks. This shows a need to evaluate the adherence behaviors of multiple caregivers. As children's capacities and desire for autonomy grow, responsibility for diabetes management tasks may shift between parents and youth. However, the timing, pace, and success of this process vary (Karlsson et al., 2008) and are influenced by many factors, including children's' cognitive development, emotional well-being, attitudes and beliefs about self-management, and the emotional tone and degree of collaboration in parent–child interactions around diabetes management (Wiebe et al., 2014).

The siblings offer more time and are more available to their fellow siblings than their parents, who sometimes leave them for work or go on other engagements. Evidence has suggested that there are higher levels of adolescent–parent conflicts in scenarios where most of the treatment responsibility belongs to adolescents, which may result in nonadherence to treatment (Miller et al., 2013). There is usually a shared responsibility for diabetes management and self-care activities between both parents and the child, which may lead to improved adherence outcomes (Almeida et al., 2013).

In a study done in Uganda to determine the level of adherence and the factors associated with adherence to diabetes care recommendations among type 1 diabetic children and adolescents by Kyokunzire et al. (2018), using a cross-sectional design (N=200), it was found that the caretakers or adolescents with poor knowledge about diabetes had children who were less adherent (or were themselves less adherent) to diabetes recommendations. Low diabetes knowledge was found to be positively associated with nonadherence in a study done by Riaz et al. (2014) with only 30.5% (61 of 200) of the adolescents (or children's caretakers).

So, the researcher came to the conclusion that kids with diabetes will be better able to control their blood sugar if their parents or caregivers have more time to watch them while they do things like give insulin shots and check their blood sugar.

Supporting successful transition to self-management is a major goal of the care for children with diabetes (American Diabetes Association, 2015), so clinically relevant measures of adherence ideally should help clinicians understand youth and families' experiences as they move toward achieving self-management milestones (Gandhi et al., 2016).

#### 2.10 enhancing self-adherence to treatment and reducing daily burden

Enhancing and improving adherence among children is very important to insure more glycemic control; parents of children diagnosed with T1Dnaturally lead the management routine until the child can take on some of the management for themselves (Pierce et al., 2019). When children reach adolescence, they start to transition into taking a more active role in their diabetes management (Datye et al., 2015). During this time, researchers have seen a low level of parental oversight, which has further been linked with reduced adherence rates in adolescents (Datye et al., 2015). Family functioning and adherence are strongly related to metabolic control, and negative family functioning processes negatively impact adherence in children and teenagers (Lewin et al., 2006).

Likewise, more cohesion and agreement were experienced between the adolescent and the caregiver, and the prevalence of diabetes-related conflict was lower with lower HbA1c levels (Rybak et al., 2017). Additionally, Mackey et al. (2011) found that youth with positive functioning had better metabolic control. These findings suggest that family functioning may influence adherence outcomes in adolescents.

Also, peer support has been found to provide more emotional support compared to the family, which provides more support for diabetes medical management (Datye et al., 2015).

#### 2.10.1 Continues glucose monitoring (CGM)

Continuous glucose monitoring (CGM) has been shown to enhance self-adherence to treatment among adolescents with type 1 diabetes. This technology allows for real-time monitoring of glucose levels and alerts individuals of impending hypoglycemia or hyperglycemia, which can help prevent complications and improve adherence to diabetes care.

One study by DeSalvo et al. (2017) examined the effect of CGM on self-adherence to treatment among adolescents with type 1 diabetes. The study found that adolescents who used CGM had significantly better adherence to self-care tasks, such as checking blood glucose levels and adjusting insulin doses, compared to those who used traditional blood glucose monitoring methods. The authors concluded that CGM can enhance self-adherence to treatment among adolescents with type 1 diabetes.

Another study by Peters et al. (2016) investigated the impact of CGM on diabetes self-management among adolescents. The study found that adolescents who used CGM had improved glycemic control, decreased hypoglycemic events, and better adherence to diabetes self-management compared to those who used traditional blood glucose monitoring methods. The authors suggested that CGM can be an effective tool to promote adherence to diabetes care among adolescents.

A systematic review by Lawton et al. (2019) also examined the impact of CGM on adherence to diabetes care among children and adolescents. The review found that CGM was associated with improved glycemic control and reduced hypoglycemic events, and that the use of CGM was associated with increased adherence to self-care tasks, such as checking blood glucose levels and adjusting insulin doses. The authors concluded that CGM can enhance adherence to diabetes care among children and adolescents.

In conclusion, CGM is a useful tool to enhance self-adherence to treatment among adolescents with type 1 diabetes. Studies have consistently shown that CGM can improve glycemic control, decrease hypoglycemic events, and promote adherence to diabetes self-management tasks. Healthcare professionals should consider incorporating CGM into diabetes care plans for adolescents with type 1 diabetes.

#### 2.11 Health related stigma and self-adherence to treatment

Diabetes is a chronic condition that requires consistent management, and non-adherence to treatment can lead to significant health consequences. Adolescents with T1Dface unique challenges related to their age, social and emotional development, and the complexities of managing their condition while navigating their adolescence. One factor that has been identified as a potential barrier to self-adherence to treatment among adolescents with T1Dis health-related stigma. In this review, we draw upon four relevant articles to examine the relationship between health-related stigma and self-adherence to treatment among adolescents with type 1 diabetes.

Kichler et al. (2017) conducted a cross-sectional survey of 162 adolescents with T1Dto investigate the impact of stigma on self-adherence to treatment. The study found that stigma was a significant predictor of lower self-adherence to treatment, even after controlling for other factors such as age, gender, and diabetes-related distress. The authors suggest that health care providers should be aware of the potential impact of stigma on self-adherence to treatment and should develop strategies to address it.

Similarly, Viner et al. (2018) conducted a qualitative study to explore the experiences of adolescents with T1Dwho reported feeling stigmatized. The study found that stigma was associated with poorer self-adherence to treatment, as well as a range of negative emotional

and social consequences. The authors suggest that addressing stigma in diabetes care should be a priority, and that interventions should focus on improving self-management skills and empowering adolescents to better manage their condition.

Markowitz et al. (2020) conducted a systematic review of studies on individuals with type 1 and type 2 diabetes to examine the relationship between stigma and self-management behaviors. The review found that stigma was consistently associated with lower self-management behaviors, such as medication adherence and blood glucose monitoring. The authors suggest that addressing stigma may be an essential strategy to improve self-management behaviors among individuals with diabetes, and that interventions should focus on reducing social isolation and improving social support.

Finally, Lim et al. (2016) conducted a cross-sectional study of 104 adolescents with T1Din Korea to investigate the impact of stigma on self-care behaviors. The study found that stigma was a significant predictor of lower self-care behaviors, such as medication adherence and dietary management. The authors suggest that addressing stigma is essential to improving self-care behaviors among adolescents with type 1 diabetes, and that interventions should focus on reducing stigma and increasing social support.

Taken together, these studies suggest that health-related stigma is a significant barrier to self-adherence to treatment among adolescents with type 1 diabetes. Stigma can lead to negative emotional and social consequences, as well as poorer self-management behaviors. Addressing stigma is vital in improving self-adherence to treatment and self-care behaviors among adolescents with type 1 diabetes. Interventions may include increasing social support, empowering adolescents to better manage their condition, and reducing social isolation. Health care providers should also be aware of the potential impact of stigma on self-

adherence to treatment and develop strategies to address it in their care of adolescents with type 1 diabetes.

In conclusion, health-related stigma is a critical factor that impacts the self-adherence to treatment among adolescents with type 1 diabetes. The review demonstrates that addressing stigma is essential to improving self-care behaviors among adolescents with type 1 diabetes. By understanding the relationship between stigma and self-adherence to treatment, health care providers can develop strategies to reduce stigma and improve diabetes management among adolescents. Future research should explore the effectiveness of interventions aimed at reducing stigma and improving self-care behaviors among adolescents with type 1 diabetes.

#### 2.10 Summary

Type 1 diabetes (T1D) is a chronic condition that affects many adolescents worldwide. Self-adherence to treatment is a critical component of managing T1D and preventing long-term complications. However, adolescents with T1D often face unique challenges related to adherence, one of which is the stigma associated with the condition.

Health-related stigma can manifest in different forms, such as negative attitudes, discrimination, and social isolation. These experiences can have a profound impact on adolescents' mental health, self-esteem, and motivation to adhere to their treatment regimen. Studies have shown that health-related stigma can interfere with self-care activities, such as blood glucose monitoring, insulin administration, and diet and exercise management, leading to poor glycemic control and long-term complications.

Adolescents with T1D who experience stigma may feel embarrassed or ashamed of their condition, leading them to hide their diabetes or avoid self-care activities. This avoidance

behavior can further exacerbate their symptoms and negatively impact their health outcomes. Furthermore, stigma can affect how others perceive and interact with individuals with T1D, potentially leading to discrimination or social rejection.

Given the negative impact of health-related stigma on adolescents with T1D, healthcare providers and stakeholders need to prioritize comprehensive education and support programs that address the psychosocial challenges of living with the condition. Such interventions should focus on promoting resilience, reducing the impact of stigma on adolescents' health behaviors and outcomes, and enhancing their self-esteem and motivation to adhere to their treatment regimens.

One potential strategy to reduce health-related stigma is to increase public awareness and education about T1D. Educating individuals and communities about T1D can help dispel myths and stereotypes and foster a more supportive and inclusive environment for individuals with the condition. This can include educational campaigns, school-based programs, and community outreach initiatives that promote understanding and empathy for individuals with T1D.

In conclusion, health-related stigma is a significant challenge for adolescents with T1D, affecting their mental health and self-adherence to treatment. Healthcare providers and stakeholders need to prioritize comprehensive education and support programs that promote resilience and reduce the impact of stigma on adolescents' health behaviors and outcomes. By working together to address the psychosocial challenges of T1D, we can help adolescents with the condition live healthier, more fulfilling lives.

# Chapter Three Conceptual Framework

#### 3.1 Introduction

This chapter provides the framework for this study. It assessed health-related stigma and self-adherence to treatment among adolescents with T1D in the West Bank, Palestine. The conceptual framework of this study is based on the results of the literature reviews regarding how experience of stigma acts as a barrier to adherence and examined factors in children with T1D.

#### 3.2 Dependent Variables

#### 3.2.1 Health related stigma and self-adherence to treatment

When children develop chronic illnesses like T1D, denying, refusing, or not complying with treatment are common reactions. Factors that contribute to noncompliance with insulin treatment include the perception that it is complicated and restrictive, fear of stigmatization, and the belief that it is ineffective or harmful. Stigmatization is a significant concern for children with T1D, as it can negatively impact their emotional, behavioral, social, and medical treatment outcomes. It is therefore important to understand the level of stigma among these children. In addition, managing T1D requires adherence to a complex regimen that includes frequent blood glucose monitoring, insulin administration, dietary regulation, and exercise. Self-adherence can be challenging for children, and studies have shown that stigma can act as a barrier to adherence.

3.3 Study independent Variables

This study will display the association between the independent variables represented by the

socio demographic characteristic such as age, gender, place of residence, family income,

parents educational level, parents' employment, and Medical data such as Child's illnesses

besides diabetes, child's diabetes chronic complications, informing others about his or her

diabetes, postponing insulin injection in public/crowded places, preferring insulin use when

alone in public, level of HbA1c and route of insulin administration.

3.3.1 Socio demographic variable

**Gender:** This refers to male and female respondents.

**Age:** This refers to the age of the respondent.

Place of residence: This refers to the patient's place of residence. It was categorized into

three groups: City, Village, Camp.

**School grade:** This refers to the patient school grade.

**Family income:** This refers to the patient's family income from the father's or the mother's

work or from both. It was categorized into four groups: less than 1000 Shekel; 1000 -2000

Shekel; 2001-3000 Shekel; More than 3000.

Mother Level of education: This refers to the patient's mother education level. It was

categorized into: no education, primary school, middle school, diploma, bachelor, master

degree/ Phd.

Father level of education: This refers to the patient's father education level. It was

categorized into: no education, primary school, middle school, diploma, bachelor, master

degree/ Phd.

**Mother's employment:** This refers to the patient's mother employment. It was

categorized into two groups: employed; Unemployed.

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**Father's employment:** This refers to the patient's father employment. It was categorized into two groups: employed; Unemployed .

**Postponing insulin injection in public/crowded places:** This refers to children's with diabetes postponing insulin injection in public/crowded places. It was categorized into two groups: Yes; No.

this refers to whether the child tell others about his/her :Telling others about having illness .illness. it was categorized into two groups : Yes,No

**Preferring insulin use when alone in public:** This refers to the children with diabetes preferring insulin use when alone in public. It was categorized into two groups: Yes; No.

#### 3.3.2 Medical variable

**Child's illnesses besides diabetes:** this refers to whether the child has another illness other than diabetes. It was categorized into two categories: Yes; No.

Child's diabetes chronic complications: This refers to child's complications due to T1D. It was categorized into two groups: Yes; No.

Date of diagnosis: This refers to the child's first date when diagnosed with diabetes

**HbA1c level:** This refers to the level of HbA1c.

**Route of medication administration:** This refers to the route of medication administration: It was categorized into three categories: insulin pen, S/C (insulin); Subdermal device (Insulin).

#### 3.6 Definition of terms

### 3.6.1 Operational definition

**Stigma**: "refers to negative beliefs and attitudes that lead people to reject, avoid, or fear and those perceived as being different" (Goffman, 1963)

**Perceived stigma**: "is the fear of being discriminated against or the fear of enacted stigma, which arises from the society's belief" (LeBel, 2008).

**Adherence**: "is defined as the ability to follow a healthcare professional's recommendations on treatment regimens" (Deaton, 2000)

#### 3.6.2 Conceptual definition

**Type 1 diabetes:** it's an autoimmune destruction of the beta cells which consequently leads to an increase in blood and urine sugar levels resulting in impaired glucose tolerance as described earlier (Long and Bingley, 2013).

Health related stigma: "Health related stigma is typically characterized by social disqualification of individuals and populations who are identified with particular health problems. Another aspect is characterized by social disqualification targeting other features of a person's identity—such as ethnicity, sexual preferences or socio-economic status—which through limited access to services and other social disadvantages result in adverse effects on health" (Weiss, Ramakrishna, & Somma, 2006)

**Self-adherence to treatment :** "how well patients carry out the disease management behaviors recommended by their health care providers" (Zolnierek & DiMatteo, 2009).

**Self-image**: "is how you see yourself. This may be how you see yourself physically or your opinion of who and what you are which is normally called self-concept. It is important as it affects your self-esteem and confidence. Self-image includes: What you think you look like, how you see your personality, what kind of person you think you are, What you believe others think of you, How much you like yourself or you think others like you, and the status you feel you have". (Nair, 2016)

Concern with public attitude: referred to what `most people" think about a person with illness or what `most people" with illness can expect when others learn they have illness (Berger et al., 2001)

**Disclosure concern:** "related to controlling information, keeping one's illness status secret or worrying that others who knew the respondent's illness status would tell" (Berger et al., 2001).

### 3.7 Framework of the study

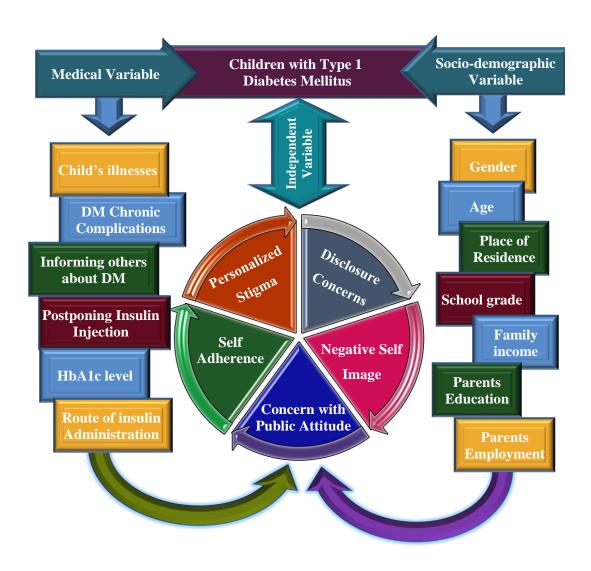


Figure 3.1: Conceptual framework model of the study

### Chapter four Methodology

#### 4.1 Introduction

This chapter describes the methodology to assess perceived stigma and self-adherence to treatment among children with T1D. The study depended on the descriptive analysis methodology so as to answer the research aims and objectives. It describes the study design, study setting, study population, sampling frame, sample criteria, sampling process and data collection procedures. It also reviews the selection of the study tool and how it was built, the amendments made and procedures used to verify the validity and consistency of the questionnaire.

#### 4.2 Research Design

A quantitative cross-sectional research design was used to assess the level of health-related stigma and level of self-adherence to treatment among adolescents with T1D. The type of information collected and analyzed will be quantitative in order to study the relationship between variables in numerical and statistical form. Research information is collected from the study sample through a semi-structured questionnaire.

#### 4.3 Study population

The study population comprises adolescents between the ages of 12 to 18 years old who have been diagnosed with T1D who attended outpatient clinics in Al-ahli hospital and Palestine diabetes institution in Hebron, Ramallah and Nablus. This age group is selected due to their unique health needs, including the physical, psychological, and social changes they undergo during this period of development. Adolescents with type 1 diabetes often face significant challenges in managing their illness, such as maintaining a strict treatment regimen and

dealing with the stigma associated with their condition. Children aged 10 years old or older are capable of answering research questionnaire (Fuchs, 2005). Also children in this group age reached the stage of formal operation (Piaget, 1948).

#### 4.4 Study setting

Study settings included Al-ahli hospital and Palestine diabetes institution in Hebron, some were face to face and some were reached by phone calls. The information of adolescents where obtained from the Palestine diabetes institution in Hebron, Ramallah and Nablus.

- Palestine diabetes institution: "is a non-profit organization based in Al-Bireh city, Palestine. The institute was established in 1995 with the aim of providing comprehensive diabetes care, education, and research services to the Palestinian community. main objectives is to raise awareness about diabetes and its prevention through education campaigns and advocacy efforts. They also work to promote healthy lifestyle choices and provide support to people living with diabetes".
- Al-Ahli hospital: "Al-Ahli Hospital is a non-profit medical facility located in Hebron, Palestine. offers a wide range of medical services, including general surgery, internal medicine, pediatrics, obstetrics and gynecology, and emergency care. The hospital also provides specialized services such as ophthalmology, urology, and radiology. In addition to its medical services, Al-Ahli Hospital is committed to community outreach programs and works to promote health education and disease prevention in the local community".

#### 4.5 Sample size and selection method

A convinced sample method was used to recruit participate in the study. It depends on data collection from members who are conveniently available in the settings. Using this method simplify data collection, shorten the time of it, and lower the costs, but also it has a level of sampling error and selection bias (Saunders et al., 2009).

The sample size is (200) subjects as calculated according to Cohen's Formula (1988) to achieve the goal of the study. The study sample size identified based on level of significant (0.05), effect size as a medium and power analysis 90%. Additional (20) will be added as a non-response rate. The total sample size of the study was 192.

#### 4.6 Eligibility Criteria

#### **Inclusion Criteria**

- **1.** Patients who are between ages: 12–18 years of age and had a, diagnosis of T1D with duration of greater than six months .
- 2. Patients from the West Bank.

#### **Exclusion criteria**

- 1. Patients with intellectual impairments and patients who have additional chronic illnesses.
- 2. Patients who refused to participate in the study.
- 3. Patients whose ages less than 12 or above 18 years.
- 4. Patients who had a diagnosis of T1D with a duration of less than 6 months.

#### 4.7 Study Instruments

**Part one**: includes questions related to socio-demographic characteristics: age, gender, school grade, education of parents, economic status and place of residence.

**Part two**: includes questions related to medical characteristics which contain duration of illness, route of insulin administration, recent HbA1c level, complications of the illness, informing others about the illness and postponing injections in public.

Part three: The Berger HIV Stigma Scale is a 40 item questionnaire used to assess level of perceived stigma in patients with HIV (Berger et al., 2001), and has been validated cross culturally (Berger et al., 2001). For the current study, the Stigma Scale was adapted to fit cultural, as well as diabetes related context. Statements were left out if there was not a proper translation or not related to diabetes, and all statements were changed to inquire about diabetes rather than HIV. The adapted version Contained 31 questions. Participants answered on a Likert Scale (1= strongly disagree, 2= disagree, 3= agree and 4= strongly agree), was translated into Arabic. Regarding the scoring system, the mean score was calculated for each item, each domain and for all items, the maximum score is 4 and the minimum score is 1. Higher mean score means higher stigma. The median score is considered as a cut-off point which is 2.5. A score <2.5 means lower stigma and ≥ 2.5 means higher stigma.

**Part four**: The Adherence in Chronic Diseases Scale (ACDS), the questionnaire was included 7 items about self-adherence to treatment that best reflects the patient's behaviour, situation, and opinion on the treatment. Also was adopted and adapted to fit the study participants. Regarding the scoring system, each item has five choses range from 0-4. The maximum score is 28 and the minimum score is 0. The cut-off point for the scale as follow;

<20 means low adherence, 21-26 means medium adherence and ≥27 means higher adherence (Kubica A et al., 2017).

#### 4.8 Validity and reliability

Content and face validity of the adopted and adapted questionnaire were assessed by a panel of 3 experts. The experts were chosen for their knowledge of stigma and treatment adherence among children with T1D. The panel was asked to indicate if each item adequately represented the topic. Comments of the experts were considered and modified accordingly. Regarding reliability, the reliability was assessed by Cronbach alpha which was as follow; 0.834 and 0.764 for stigma and adherence scales respectively (Table 4.1).

Table (4.1): Results of confirmatory factor analysis of the instrument

Correlation coefficients

Scores	No. of items	Cronbach's Alpha
Stigma scale	31	0.834
Adherence scale	7	0.764

### 4.9 Pilot Study

A pilot study was conducted in July 2021 on (10) children who possess the same inclusion criteria of the potential sample. The pilot study had these purposes; to assess the practicality and feasibility of the whole study process, to assess the level of the subjects' ability of understanding the measurement tools, to evaluate any ambiguous or incomprehensible questions and to estimate the typical time needed for data collection. The results and data of the pilot study were not included in the main study.

#### 4.10 Data Collection

A self-administered questionnaire was used to assess the health related stigma and self-adherence to treatment level among adolescents with T1D. The participants were approached by the researcher after obtaining their assent and consent from their parents to participate. Adolescents filled out a self-administer questionnaires in an isolated room on their own under the supervision of the researcher. In hospital settings such as Al-Ahli hospital, children filled out the questionnaires in a quiet room under the supervision of the researcher independently after obtaining consent from their parents.

Participants were selected by the researcher with the aid of the secretary in the outpatient clinics in Palestine diabetes institution and information's were collected from them, also some participant were approached by phone calls to answer the questionnaire by the aid and consent of their parents.

#### 4.11 Data Analysis

The collected data was analyzed by the Statistical Package for Social Sciences (SPSS) Version (28). Data entry was performed and double-checked for outliers or errors. Data was tested for normality using the Shapiro-Wilk tests. If the total mean score is <0.05, this means that the data is not normally distributed. Table 4.2 presents the Shapiro-Wilk test, which show that Adherence and Stigma mean scores have not normally distributed (p=< 0.05).

Data analysis of descriptive and inferential statistics was conducted. Regarding descriptive statistics, frequency, percentages, mean score and Standard Deviation (SD) were used to describe the study variables.

Regarding inferential statistics, a non-parametric test was conducted included Mann-Whitney U test, which used to assess the differences between dichotomous variables and Kruskal Wallis H test, which used to assess the differences between three or more variables. These tests used to assess the differences between socio-demographic variables such as age, gender, marital status and other variables as well as the medical data of the participants.

**Table (4.2): Shapiro-Wilk Test for Normal Distribution** 

#### **Test of normality**

	Sł	Shapiro-Wilk		
	Statistic	df	Sig.	
Adherence	.867	192	<.001	
Stigma	.965	192	<.001	

#### **4.11 Ethical Consideration**

Letters were sent to Palestine diabetes institutions in Hebron, Ramallah, and Nablus, which and to al-Ahli hospital contain study information and asking their permission of participation in the study. Permissions from selected hospitals and diabetes clinics administration were obtained to conduct this study and this made it easier for the researcher to distribute the questionnaire to children and review their medical records. In addition, adolescents assent and a consent form was filled out by parents and child to participate was obtained was obtained prior to the questionnaire distribution. The participants and their parents were also informed about the study purpose and its nature and confirmed the anonymity and confidentiality of information. All of the outpatient clinics and hospitals, parents and children who participated in the study, agreed to be part of the study. An Ethical approval was obtained from the Ethical Committee at Al-Quds University in Palestine (Annex 1).

#### **Chapter five: Results**

#### **5.1 Results**

This chapter I shows the frequency and percentages of the participant's characteristics, mean score for each item, each domains as well as the percentages of the stigma and adherence among participants. Furthermore, the differences and the relationships between variables.

#### **5.1.1** Characteristics of the participants

Table 5.1 illustrates the socio-demographic characteristics of the participants. Out of 200 participants, 192 were enrolled given a response rate of 96%. The mean age of participants was 15.1 years old, the Min age was 12 years old and the Max age was 18 years old. More than half of the participants were female 54.2%, while 45.8% were male. Closely, half of them lived in a village. The highest percentages of school grades were 10th and 12th with 24.5% and 19.3% respectively. Regarding the educational level among participants' fathers and mothers, 44.8% of their fathers held a Bachelor's Degree compared with 30.7% of their mothers. In addition, more than half of the participants did not inform others about their diabetes with 52.6%. Furthermore, the vast majority of participants Prefer insulin use when the participant is alone in public and postpone their insulin injection public/crowded places also they don't inform others about their T1D. More details are shown in table 5.1.

**Table 5.1: Socio-demographic characteristics of the participants (n=192)** 

Socio-demographic characteristics		n	%
Gender	Male	88	45.8%
	Female	104	54.2%
Place of residence	City	50	26.0%
	Village	98	51.0%
	Camp	44	22.9%

in public	No	9	4.7%
Preferring insulin use when you are alone in public	Yes	183	95.3%
public/crowded places	No	133	69.3%
Postponing insulin injection in	Yes	59	30.7%
	110	101	32.0%
imorning others about his or her diabetes	No	91 101	47.4% 52.6%
Informing others about his or her diabetes	Yes	01	47 40/
	No	83	43.2%
Father's employed	Yes	109	56.8%
	No	129	67.2%
Mother's employed	Yes	63	32.8%
		7	2.1 /0
	Master degree or PhD	86 4	44.8% 2.1%
	Bachelor's Degree	35 86	18.2% 44.8%
	Secondary education Diploma	12 25	6.3%
Level of education of father	Primary education	55	28.6%
Tanalagalarakkan aggalar	Deline and a decid		
	Master degree or PhD	0	0
	Bachelor's Degree	59	30.7%
	Diploma	30	15.6%
	Secondary education	33	17.2%
Level of education of mother	Primary education	70	36.5%
		07	15.570
	>3000 Shekel	92 87	45.3%
	2001- 3000 Shekel	92	0.8% 47.9%
runny niconic	1000 Shekel	13	0 6.8%
Family income	< 1000 Shekel	0	0
	University	16	8.3%
	12 <sup>th</sup> (Tawjihi)	37	19.3%
	11 <sup>th</sup>	24	12.5%
	10 <sup>th</sup>	47	24.5%
	9 <sup>th</sup>	30	15.6%
	8 <sup>th</sup>	4	2.1%
	7 <sup>th</sup>	10	5.2%
School grade	6 <sup>th</sup>	24	12.5%

#### **5.1.2** The medical data of the participants

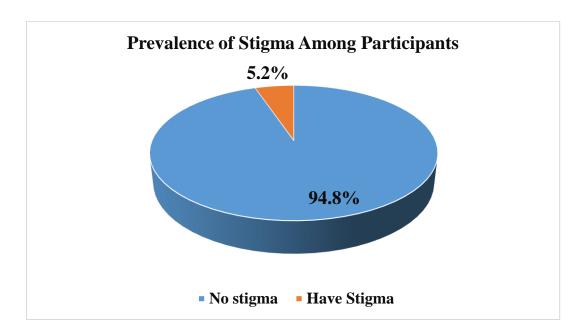
Table 5.2 presents the medical data of the participants. All participants have no complications and illnesses besides diabetes. The mean HbA1c level was 7.67% with a Min level was 6% and a Max level was 11.7%. In addition to that, 96.4% of participants have a high level (>6.5%) of HbA1c, while 3.6% have a normal level. The vast majority of participants were diagnosed with diabetes between 2010 to 2019. More than two-thirds of participants used an insulin pen as a way of insulin administration.

Table (5.2): Medical data of the participants (n=192)

Medical data of the participants		n	%
Child's diabetes chronic complications	Yes	0	0
	No	192	100.0%
Do you have any illness beside diabetes	Yes	0	0
	No	192	100.0%
Date of diagnosis	2004-2009	15	7.8%
	2010-2019	156	81.3%
	2020-2022	21	10.9%
HbA1c	Normal (≤6.5%)	7	3.6%
	High (>6.5%)	185	96.4%
Way of insulin administration	Insulin pen	161	83.9%
	Insulin pumps	5	2.6%
	Insulin syringe	26	13.5%

## **5.2** Prevalence of stigma among participants

Figure 5.1 presents the prevalence of stigma among participants. 5.2% of participants have stigma toward type 1 diabetes mellitus, while the vast majority of them have no stigma.



**Figure 5.1.** *Prevalence of stigma among participants* 

# 5.3 Mean Score for Each Item and the Total Mean Score for Personalized Domain

Table 5.3 shows the mean score for each item toward personalized stigma. Overall, the total mean score toward personalized stigma was 1.90 over 4, SD =0.299. Which means that participants have no stigma toward personalized domain. However, the highest mean score was the participants regret telling some people about my type 1 diabetes diagnosis and it was a mistake to inform people about my type 1 diabetes diagnosis with M=2.79, SD=0.675, and M=2.73, SD=0.808 respectively. More details are shown in table 3.

Table (5.3): Mean score for each item toward personalized stigma (n=192)

Item	Mean	SD
1. Some people distance themselves from me when they found out about my type 1 diabetes diagnosis.	1.81	.616
2. I regret telling some people about my type 1 diabetes diagnosis.	2.79	.675
3. It was a mistake to inform people about my type 1 diabetes diagnosis.	2.73	.808
4. People who used to care about me stopped talking or contacting me when they found out that I have type 1 diabetes.	2.28	.859
5. People don't want me around their children or to play with them when they find out that I have type 1 diabetes.	1.75	.454
6. Some people physically withdraw from me when they learn that I am diagnosed with type 1 diabetes.	1.55	.518
7. Some people act as if it is my fault that I have type 1 diabetes.	1.46	.604
8. I stopped talking to some people because of their reaction to my type 1 diabetes diagnosis.	1.48	.541
9. I lost a friend when I told them that I have type 1 diabetes.	2.21	.862
10. People show fear towards me when they find out that I have type 1 diabetes.	1.55	.557
11. When people find out that I have type 1 diabetes, they look for negative traits in my personality.	1.47	.510
12. I regret telling some people about my type 1 diabetes diagnosis.	1.57	.618
13. I avoid new relationships because of the anxiety I feel about telling someone that I have type 1 diabetes.	2.01	.785
Total Mean Score (13 items)	1.90	.299

Mean out of 4

SD: Standard Deviation

# 5.4 Mean Score for Each Item and the Total Mean Score for Disclosure Domain

Table 5.4 shows the mean score for each item toward disclosure concerns. Overall, the total mean score toward disclosure concerns was 2.49 over 4, SD =0.411. Which means that participants have no stigma toward disclosure domain. The highest mean score was the participants did not want those who know that I have diabetes to tell anyone else and nobody knows that I have Type 1 diabetes with M=3.21, SD=0.666, and M=2.92, SD=0.789 respectively. However, the lowest mean score was informing someone that I have Type 1 diabetes makes me feel somewhat vulnerable with M=1.80, SD= 0.540. More details are shown in table 4.

Table (5.4): Mean score for each item toward disclosure concerns (n=192)

	Item	Mean	SD
1.	I am extremely cautious about not disclosing to anyone that I have Type 1 diabetes.	2.31	.735
2.	Informing someone that I have Type 1 diabetes makes me feel somewhat vulnerable.	1.80	.540
3.	I make a great effort to keep my Type 1 diabetes diagnosis a secret.	2.28	.713
4.	In many areas of my life, nobody knows that I have Type 1 diabetes.	2.92	.789
5.	I am worried about being judged by people when they find out about my condition.	2.69	.761
6.	I do not want those who know that I have diabetes to tell anyone else.	3.21	.666
7.	I never feel like I need to hide my Type 1 diabetes diagnosis.*	2.19	.703
	Total Mean Score (7 items)	2.49	.411

Mean out of 4

# **5.5** Mean Score for Each Item and the Total Mean Score for Negative Self-image Domain

Table 5.5 shows the mean score for each item toward negative self-image. Overall, the total mean score toward negative self-image was 2.25 over 4, SD =0.402. Which means that

<sup>\*</sup>Reversed item

participants have no stigma toward negative self-image domain. The highest mean score was the participants felt lonely and isolated when they first found out about their type 1 diabetes with M=2.95, SD=0.703. However, the lowest mean score was participants considered themselves as bad people because of their diabetes with M=1.55, SD= 0.611. More details are shown in table 5.

Table (1.5): Mean score for each item toward negative self-image (n=192)

Item	Mean	SD
1. I feel different from others because of my type 1 diabetes.	2.48	.758
2. I consider myself a bad person because of my diabetes.	1.55	.611
3. People's behavior towards my condition makes me feel bad about myself.	2.28	.742
4. I felt lonely and isolated when I first found out about my type 1 diabetes.	2.95	.703
5. I do not feel ashamed of having diabetes.*	1.89	.544
6. I do not feel attractive due to my condition.	2.35	.897
Total Mean Score (6 items)	2.25	.402

Mean out of 4

# 5.6 Mean Score for Each Item and the Total Mean Score for Public Attitude Domain

Table 5.6 shows the mean score for each item toward concern with public attitude. Overall, the total mean score toward concern with public attitude was 1.72 over 4, SD =0.510. Which means that participants have no stigma toward concern and public attitude.

Table (5.6): Mean score for each item toward concern with public attitude (n=192)

	Item	Mean	SD
1.	Individuals with diabetes are not welcomed by society.	1.43	.546
2.	People with diabetes are often rejected by others.	1.45	.576
3.	I feel anxious about not being treated kindly by society due to my condition.	1.98	.943
4.	Others do not feel comfortable when a diabetic patient is around them.	1.63	.681
5.	I feel tense when interacting with others because of my diabetes.	2.11	.862
	Total Mean Score (5 items)	1.72	.510

Mean out of 4

<sup>\*</sup>Reversed item

#### 5.7 Prevalence of Adherence among Participants

Figure 5.2 shows the level of adherence among participants. More than half of participants 57% have moderate adherence, 36% have high level, while 7% have low level.

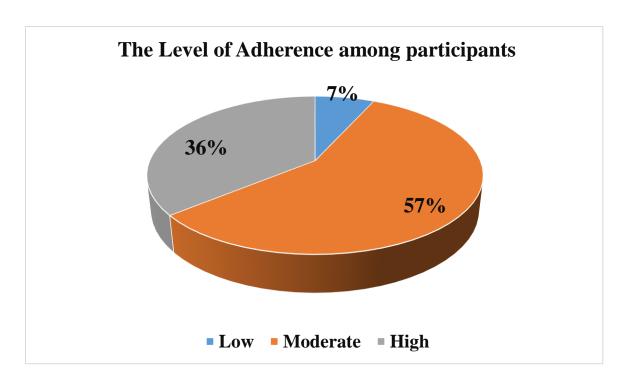


Figure 5.2: The level of adherence among participants (n=192)

# 5.7.1 Differences between socio-demographic characteristics in terms of the stigma total mean score

Table 5.7 shows the Mann-Whitney U and Kruskal Wallis H tests that were used to assess the difference between socio-demographic characteristics in terms of stigma score. The tests indicated that there is no significant difference between gender (p= 0.486), family income

(p= 0.051) and father's employed (p= 0.431) in terms of stigma total mean score. However, a significant difference was found in the following variables in terms of stigma; place of residence (p=<0.001), school grade (p=<0.001), mother education (p=<0.001), father education (p=<0.001), mother's employee (p=0.007), Postponing insulin injection in public/crowded places (p=0.001) and preferring insulin use when alone in public (p=0.022). Regarding the place of residence, a Bonferroni post-hoc test indicated that participants who were live in city M=70.18, have perceived lower stigma than who live in village M=108.46 and camp M=99.76 (P=0.010).

Regarding the school grades, a Bonferroni post-hoc test indicated that participants who in 6<sup>th</sup> grade have perceived higher stigma M=135.92 more than all other grades (P=<0.001). Regarding the mother's education of the participants, a Bonferroni post-hoc test indicated that participant's mothers who have secondary education M=126.67 have perceived higher stigma than participant's mothers held Bachelor's Degree and Master Degree M=81.43 and M= 81.69 respectively (P=0.002).

Regarding the father's education of the participants, a Bonferroni post-hoc test indicated that participant's fathers who have diploma M=131.71 have perceived higher stigma than participants father who have primary education and Bachelor's degree M=89.14 and M=86.94 respectively (P=0.001).

Table (5.7): Differences between socio-demographic characteristics of the participants in terms of stigma (n=192)

Socio-demographic	c characteristics	n	Mean Rank	Statistical value	p-value
Gender	Male	88	99.53	U=4309	
	Female	104	93.93	Z=697	.486
Place of residence	City	50	70.18		
	Village	98	108.46	H=15.959	. 001*
	Camp	44	99.76	df=2	<.001*

School grade	$6^{ ext{th}}$	24	135.92		
8	$7^{\mathrm{th}}$	10	97.80		
	8 <sup>th</sup>	4	83.13		
	9 <sup>th</sup>	30	89.00		
	$10^{\mathrm{th}}$	47	75.46	H=35.046	<.001*
	$11^{th}$	24	82.17	df=7	\.UU1
	12 <sup>th</sup> (Tawjihi)	37	67.58		
	University	16	76.32		
	<b>3</b>	10	70.52		
Family income	< 1000 Shekel	0	_		
	1000 -2000 Shekel	13	104.85	II 5.076	
	2001- 3000 Shekel	92	105.49	H=5.976	.051
	>3000 Shekel	87	85.75	df=2	
Level of	Primary education	70	101.22		
education of	Secondary education	33	126.67		
mother	Diploma	30	81.43	H=16.679	0014
	Bachelor's Degree	59	81.69	df=3	<.001*
	Master degree or PhD	0	-		
Level of	Primary education	55	89.14		
education of father	Secondary education	12	90.58		
rauter	Diploma	35	131.71	H=18.111	.001*
	Bachelor's Degree	86	86.94	df=4	.001
	Master degree or PhD	4	113.00		
Mother's	Yes	63	81.12		
employed	No	129	104.01	U=3094.5	.007*
1 0	110	129	104.01	Z=-2.684	.007
Father's	Yes	109	93.75	11 1000 5	
employed	No	83	100.11	U=4223.5	.431
				Z=788	
<b>Informing others</b>	Yes	91	84.41	U=3495	
about his or her	No	101	107.40	Z=-2.867	.004*
diabetes	*7			2-2.007	
Postponing insulin injection	Yes	59	116.18		
insulin injection in	No	133	87.77	U=2762.5	.001*
public/crowded				Z=-3.273	.001
places					
Preferring	Yes	183	94.47	U=452	
insulin use when	No	9	137.78	Z=-2.286	.022*
alone in public			-	<i>L</i> 2.200	

U=Mann-Whitney U test, H=Kruskal-Wallis H test, Z=Z score, df= degree of freedom \*Significant at p=<0.05

# 5.8 Differences between medical data variables in terms of the stigma total mean score

Table 5.8 shows the Mann-Whitney U and Kruskal Wallis H tests that were used to assess the difference between medical characteristics in terms of stigma score. The tests indicated that there is no significant difference between date of diagnosed (p=0.316) in terms of stigma total mean score. However, a significant difference was found in HbA1c level (p=<0.001) and way of insulin administration (p=0.009) in terms of the stigma total mean score. Regarding the way of insulin administration, a Bonferroni post-hoc test indicated that participants who use insulin syringe M=121.92 have perceived higher stigma than other ways (P=<0.001).

Table (5.8): Differences between medical data of the participants in terms of stigma (n=192)

Medical data of the	e participants	n	Mean Rank	Statistical value	p-value
Date of diagnosis	2004-2009 2010-2019 2020-2022	15 156 21	81.47 96.16 109.76	H=2.307 df=2	.316
HbA1c	Normal (≤6.5%) High (>6.5%)	7 185	18.43 99.45	U=101 Z=-3.792	<.001*
Way of insulin administration	Insulin pen Insulin pumps Insulin syringe	161 5 26	93.84 50.10 121.92	H=9.326 df=2	.009*

U=Mann-Whitney U, H=Kruskal-Wallis H test, Z=Z score, df=degree of freedom \*Significant at p=<0.05

# 5.9 Differences between Socio-Demographic Characteristics in Terms of the Adherence Total Mean Score

Table 5.9 shows the Mann-Whitney U and Kruskal Wallis H tests that were used to assess the difference between socio-demographic characteristics in terms of adherence score. The tests indicated that there is no significant difference has shown between gender (p= 0.910), informing others about his or her diabetes (p= 0.412) and preferring insulin use when alone in public (p= 0.799) in terms of the adherence total mean score. However, a significant difference was found in the following variables in terms of adherence; place of residence (p=<0.001), school grade (p=<0.001), family income (p=<0.001), mother education (p=<0.001) and Postponing insulin injection in public/crowded places (p=0.001) in terms of adherence total mean score.

Regarding the place of residence, a Bonferroni post-hoc test indicated that participants who were live in camp M=66.83, have perceived lower adherence than who live in city M=109.14 and village M=103.37 (P=0.001).

Regarding the school grades, a Bonferroni post-hoc test indicated that participants who in 7<sup>th</sup> grade have perceived lower adherence than other grades (P=<0.001).

Regarding the family income, a Bonferroni post-hoc test indicated that participants who have >3000 Shekil M=115.91 have perceived higher adherence than others incomes (P=<0.001). Regarding the mother's education of the participants, a Bonferroni post-hoc test indicated that participant's mothers who have secondary education M=70.88 have perceived lower adherence than participant's mothers held Diploma and Bachelor's Degree M=117.47 and M= 112.21 respectively (P=0.020).

Regarding the father's education of the participants, a Bonferroni post-hoc test indicated that participant's fathers who have Bachelor's Degree M=118.99 have perceived higher adherence than participants father who have primary education and secondary education M=75.75 and M=31.96 respectively (P=0.025).

Table (5.9): Differences between socio-demographic characteristics of the participants in terms of adherence (n=192)

Socio-demographic char	racteristics	n	Mean Rank	Statistical value	p-value
Gender	Male	88	96.99	U=4533	.910
	Female	104	96.09	Z=113	
Place of residence	City	50	109.14	H=17.028	<.001*
	Village	98	103.37	df=2	
	Camp	44	66.83		
School grade	$6^{th}$	24	77.06	H=31.202	<.001*
<u> </u>	$7^{\text{th}}$	10	16.10	df=7	
	$8^{\text{th}}$	4	96.88		
	9 <sup>th</sup>	30	86.63		
	10 <sup>th</sup>	47	112.07		
	11 <sup>th</sup>	24	113.22		
	12 <sup>th</sup> (Tawjihi)	37	97.08		
	University	16	102.54		
Family income	< 1000 Shekel	0	_	H=31.313	<.001*
	1000 -2000 Shekel	13	32.19	df=2	
	2001-3000 Shekel	92	87.23		
	>3000 Shekel	87	115.91		
Level of education of	Primary education	70	86.35	H=18.777	<.001*
mother	Secondary education	33	70.88	df=3	
	Diploma	30	117.47		
	Bachelor's Degree	59	112.21		
	Master degree or PhD	0	-		
	Primary education	55	75.75	H=39.186	<.001*

Level of education of	Secondary	10	21.06	10. 4	
father	education	12	31.96	df=4	
	Diploma	35	94.30		
	Bachelor's Degree	86	118.99		
	Master degree or PhD	4	111.13		
Mother's employed	Yes	63	118.02	U=2708	<.001*
	No	129	85.99	Z=-3.794	
Father's employed	Yes	109	117.20	U=2267.5	<.001*
	No	83	69.32	Z=-5.985	
Informing others about	Yes	91	99.93	U=4283.5	.412
his or her diabetes	No	101	93.41	Z=821	
Postponing insulin	Yes	59	75.94	U=2710.5	<.001*
injection in public/crowded places	No	133	105.62	Z=-3.455	
Preferring insulin use	Yes	183	96.28	U=782.5	.799
when alone in public	No	9	101.06	Z=255	

U= Mann-Whitney U, H=Kruskal-Wallis H test, Z= Z score, df= degree of freedom \*Significant at p=<0.05

# 5.10 Differences between Medical Data of the Participants in Terms of the Adherence Total Mean Score

Table 5.10 shows the Mann-Whitney U and Kruskal Wallis H tests that were used to assess the difference between medical characteristics in terms of adherence score. The tests indicated that there is no significant difference between HbA1c level (p=0.280). However, a significant difference was found in date of diagnosis (p=<0.001) and way of insulin administration (p=<0.001).

Regarding the date of diagnosis, a Bonferroni post-hoc test indicated that participants who were diagnosed between 2020-2022 M=45.17 have perceived lower adherence than others (P=<0.001).

Regarding the way of insulin administration, a Bonferroni post-hoc test indicated that participants who use insulin pump M=164.60 have perceived higher adherence than other ways (P=<0.001).

Table (5.10): Differences between medical data of the participants in terms of adherence (n=192)

Medical data of the	e participants	n	Mean Rank	Statistical value	p-value
Date of diagnosis	2004-2009 2010-2019 2020-2022	15 156 21	106.47 102.45 45.17	H=20.676 df=2	<.001*
HbA1c	Normal (≤6.5%) High (>6.5%)	7 185	118.50 95.67	U=493.5 Z=-1.080	.280
Way of insulin administration	Insulin pen Insulin pumps Insulin syringe	161 5 26	99.12 164.60 67.19	H=15.460 df=2	<.001*

U= Mann-Whitney U, H=Kruskal-Wallis H test, Z= Z score, df= degree of freedom \*Significant at p=<0.05

#### **5.11 Relationship between Adherence and Stigma Scores**

Table 5.11 presents the correlation coefficient between stigma and adherence scores. A negative small correlation was found (r=-0.153, p=0.034). This means when stigma increase, adherence will decrease.

Table (2): Spearman's Correlation between stigma and adherence (n=192)

Spearman's Correlation	Stigma score	
Adherence score	r	153*
	P-value	.034

R= Correlation Coefficient Spearman's Correlation

#### **Chapter six: Discussion and limitation**

#### 6.1 Discussion

In the following chapter, the researcher went through the findings of a study that assessed health-related stigma and self-adherence to treatment among adolescents with T1D in the West Bank and investigated the relation between health-related stigma and self-adherence to treatment in adolescents who have T1D. Furthermore, this section will discuss the relation of demographic data and medical data with health related stigma and self-adherence to treatment among adolescents with T1D in west bank, Palestine.

An adapted stigma scale with four answers was used; 1 strongly disagree, 2 disagree, 3 agree and 4 strongly agree. According to the scale a higher mean score means higher level of stigma, and lower mean score means low level of stigma.

The findings in this study shows that 5.2% of participants have stigma which indicate a lower level of stigma in adolescents who have T1D and the majority of participants have no stigma.

There is evidence to support that the stigma associated with T1D among adolescents has reduced in recent years. According to a 2015 study published in the Journal of Pediatric Psychology, adolescents with Type 1 diabetes reported experiencing low level of stigma than those before them. The study found that "adolescents with diabetes did not perceive stigma as a significant problem in their daily lives, and stigma did not appear to have a negative impact on their quality of life". Also a study found that adolescents with T1D do not want to be defined by their illness and prefer to be treated normally (Freeborn et al., 2017). And

some adolescents view their illness as manageable and as their responsibility (Jonker et al., 2018).

the study revealed that the participants regret telling others about the illness and it was a mistake telling them and do not want who knows about their illness to tell anyone, because adolescents do not want to be labeled by their illness, and feeling defined by their diabetes may contribute to a sense of alienation, which may lead to a refusal to participate in diabetes management when with peers (Freeborn et al., 2017).

Although the study found that adolescents have no stigma towards negative self-image, however the highest mean score in the items was that they felt lonely and isolated when they first found about the illness. In a qualitative research, adolescents with type 1 diabetes highlighted feeling different and lonely as the disease's greatest challenge (Momani et al., 2022). Also they now think there is a problem with them that they don't know how to manage and make them feel inferior and "now i am different". Parents and healthcare professionals can help children and adolescents realize that effective diabetes management can prevent the health issues that set them apart from their peers (Jonker et al., 2018).

This study findings shows that participants who live in the city perceived lower level of stigma than in the village. Sociocultural beliefs in villages can contribute to stigma (Ran et al., 2021). A study done in Jordan found that cultural and religious beliefs influenced diabetes self-management among adolescents and their parents (Momani, A et al., 2022). also In a study done by (Ingersgaard et al., 2021) suggest that adolescents with T1D living in the urban areas perceived lower level of stigma because living in the cities give access to more resources and support systems. Also people living in cities have greater exposure to individuals with diverse health conditions, including T1D, which could lead to more acceptance and understanding of the condition.

The study also shows that participant's mother and father with lower education perceived more stigma than participant parents with higher educational level. Adolescents with parents who had lower educational levels experienced more diabetes-related stigma than those with parents who had higher educational levels, according to a study published in the Journal of Pediatric Psychology (Ingerski et al., 2010). The study also discovered that adolescents with parents who had less education were more likely to feel ashamed or embarrassed about having diabetes, and that this stigma was linked to less effective diabetic self-care practices.

In addition the study results also show that adolescents with higher HBA1C levels have more level of stigma. According to one study in the Journal of Pediatric Psychology, adolescents with type 1 diabetes who had greater HbA1c levels than those who had lower levels did not experience as much diabetes-related stigma, such as feeling excluded or different from their friends (Kichler et al., 2018). Additionally, the study discovered that adolescents who had greater HbA1c levels were prone to express negative perceptions regarding their diabetes care, such as guilt or frustration over blood glucose control.

A study that was published in Pediatric Diabetes indicated that children who used insulin syringes to control their diabetes experienced higher stigma connected to the illness, such as feeling awkward or ashamed about having it (Hagger et al., 2014). The study also discovered that adolescents with use of syringes had lower levels of diabetic self-care practices and were more likely to report having poor attitudes of their diabetes management. And those result were constitutes with this study results as it shows that participants who used insulin syringe perceived higher levels of health related stigma.

However adhering to treatment is very important. So the study investigated self-adherence to treatment among adolescents with T1D using an adapted 7 items questionnaire. The study results show moderate level of adherence among the participants.

Socio-demographic characteristics are associated with adherence to diabetes management. The results found no significant differences in adherence based on gender, informing others about diabetes, and preferring insulin use when alone in public. However, significant differences were found in adherence based on place of residence, school grade, family income, mother's education, father's education, mother's employment, father's employment, and postponing insulin injection in public/crowded places.

Place of residence, participants who lived in the camp had lower adherence scores compared to those who lived in the city or village. This finding may be due to differences in access to healthcare facilities or socioeconomic status. Living in a camp may disrupt a child's or adolescent's daily routine, which could make it harder for them to remember to take medication or follow other treatment regimens. Also Children and adolescents living in a camp may experience psychological stress due to factors such as overcrowding, lack of privacy, and exposure to traumatic events. This stress could impact their ability to adhere to treatment regimens.

School grade, participants in the 7th grade had lower adherence scores compared to other grades. Higher-grade children may struggle to manage their diabetes owing to academic pressure. The transition from elementary to middle school brings new routines, social dynamics, and expectations for children. This adjustment can be stressful and difficult, decreasing motivation to control diabetes. 7th-graders may undergo physical, emotional, and social changes. These changes may cause them to neglect their diabetes control in favor of socializing, trying new things, or managing emotional stress. Peer pressure may cause 7th-graders to miss meals, overeat, or not take medication. Peer pressure can potentially make diabetes management seem embarrassing, resulting in non-adherence.

**Family income**, participants with higher income levels (>3000 Shekil) had higher adherence scores compared to those with lower income levels. This finding may be due to the increased ability of families with higher incomes to access healthcare and afford diabetes management supplies. As the study results find that children or adolescents using insulin pump have higher adherence levels.

**Mother's and father's education level**, participants whose mothers and fathers had primary or secondary education had lower adherence scores compared to those whose mothers had a diploma or bachelor's degree. This finding may be due to differences in health literacy or the ability of mothers and fathers with higher education levels to better support their children's diabetes management.

#### Medical characteristics in terms of adherence

The results suggest that there is no significant difference in HbA1c level. This means that the medical characteristic of HbA1c level is not related to the adherence score. However, there are significant differences in the date of diagnosis and way of insulin administration.

A recent diagnosis may have affected a patient's ability to adhere to therapy since those diagnosed between (2020-2022) have poorer perceived adherence than others. The COVID-19 pandemic, which began in 2020, may have contributed to the disruptions in healthcare services, including the availability of prescription drugs, appointments, and assistance, as one explanation. As a result, those who received a diagnosis at this time may have had more difficulty controlling their condition and following their treatment plan. The study's findings indicate that the participants reported feeling lonely and alone when they first learned they had T1D, which might damage a person's capacity to manage their condition and comply with treatment. In addition, a recent diagnosis may create sadness, anxiety, and loneliness.

Those who have recently been diagnosed might also not be as familiar with their treatment plan and need extra instruction and help to follow it.

#### The correlation between stigma and self-adherence

According to the findings that have been provided, there is an inverse relationship between the scores of stigma and adherence. This indicates that when stigma increases, there will be deterioration in adherence. This may be because of the fact that personalized stigma may act as a barrier to efficient diabetic management, which may result in adverse outcomes for children or adolescents health. Which is constitutes with a study published in Diabetes Care, adolescents with type 1 diabetes who said they felt more stigma connected to their condition had poorer levels of confidence for managing their condition and lower levels of diabetic self-adherence to treatment. The study also discovered a link between stigma and worse glycemic control (Huang et al., 2017). It is possible for it to lead to adverse feelings, e.g. shame or embarrassment, which can have a poor effect on the individual's adherence to diabetic self-care activities, which can be detrimental to the individual's health. Those who are stigmatized may report feelings of being misunderstood, judged, and devalued, which can result in decreased motivation and involvement in diabetes control activities. For instance, a person who is concerned about being stigmatized because of their diabetes may be less likely to monitor their blood sugar on a regular basis or take their insulin as directed by their doctor. It's possible that they'll go to great lengths to conceal the fact that they have diabetes in public and avoid discussing their health with others, which can make their sense of social isolation and distress even worse. As a result, the fact that stigma is negatively correlated with adherence scores implies that stigma can be a significant obstacle in the way of good diabetes care.

#### **6.2 Conclusion**

Children and adolescents with T1D in West Bank, Palestine have a moderate level of adherence to treatment 57% and no stigma. Also the results shows a small correlation between health related stigma and self-adherence to treatment among adolescents with T1D, which means that the higher level of stigma, the less is the adherence.

#### **6.3 Limitations**

the study is cross-sectional, it only gives an overview of participants' experiences at one specific time. Uses a quantitative approach might not adequately represent the complex nature of the experiences of young people with T1D. It may be possible to gain a deeper knowledge of the social, cultural, and psychological aspects that affect stigma and treatment adherence in this population by using qualitative research techniques like focus groups and interviews.

Moreover, the study did not examine how cultural norms and beliefs affect treatment compliance and stigma health - related issues. Family and community norms are highly valued in Palestinian culture, and this may have an impact on how stigmatized adolescents feel about their illnesses. Future studies would benefit from examining how cultural attitudes and norms affect the lives of Palestinian adolescents and children with T1D.

Also the Israeli occupation in Palestine limits the access to medication and made reaching health care facilities more difficult. And the Palestinian society is fragmented and split to parts due to occupation.

#### **6.4 recommendations**

This is the first study done in Palestine about health-related stigma and self-adherence to treatment among adolescents with T1D. So this study can be a fundamental to other studies and may help health care to better understand stigma and adherence.

In addition to allowing for a more refined understanding of the factors that contribute to health outcomes among adolescents with T1D in the Palestinian context, a longitudinal study that follows participants over time might offer a more dynamic understanding of the relationship between stigma and adherence to treatment.

Furthermore, qualitative research should be conducted to gain a deeper picture about how T1D affects adolescents in terms of stigma and self-adherence to treatment.

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## **Appendices:**

### Appendix 1: Type 1 diabetes stigma scale

## Part One: Socio-demographic Characteristic's

1. Gender: 1. Male 2. Female						
1. Gender: 1. Male 2. Female						
2. Age:						
3. Place of Residence: 1. City 2. Village 3. Camp						
4. School grade:						
5. Family income: 1. less than 1000 Shekel 2. 1000 -2000 Shekel 3. 2001- 3000 Shekel						
4. More than 3000						
6. Level of education for mother						
7. Level of education for father						
8. Mother's employed: 1. yes 2. no						
9. Father's employed: 1. yes 2. No						
10. Informing others about his or her diabetes: 1. Yes 2. No						
11. Postponing insulin injection in public/crowded places: : 1. Yes 2. No						
12. Preferring insulin use when alone in public: 1. Yes 2. No						

## Part Two: Medical data

Way of insulin administration: 1. Insulin pen	2. Insulin pumps	3. Insulin syringe
HbA1c level:		
Date of diabetes diagnose:		
If yes mention them:		
Do you have any illness beside diabetes: 1.yes	2.No	
Child's diabetes chronic complications: 1. Yes	2. No	

## Part Three: 31 items related to Stigma

## Please answer the following items by placing (X) in the blank.

Item	Strongly Disagree	Disagree	Agree	Strongly Agree
Personalized Stigma				
<ol> <li>Some people distance themselves from me when they found out about my type 1 diabetes diagnosis.</li> </ol>	1	2	3	4
<ol> <li>I regret telling some people about my type 1 diabetes diagnosis.</li> </ol>	1	2	3	4
<ol> <li>It was a mistake to inform people about my type 1 diabetes diagnosis.</li> </ol>	1	2	3	4
<ol> <li>People who used to care about me stopped talking or contacting me when they found out that I have type 1 diabetes.</li> </ol>	1	2	3	4
<ol><li>People don't want me around their children or to play with them when they find out that I have type 1 diabetes.</li></ol>	1	2	3	4
<ol> <li>Some people physically withdraw from me when they learn that I am diagnosed with type 1 diabetes.</li> </ol>	1	2	3	4
<ol><li>Some people act as if it is my fault that I have type 1 diabetes.</li></ol>	1	2	3	4
I stopped talking to some people because of their reaction to my type 1 diabetes diagnosis.	1	2	3	4
9. I lost a friend when I told them that I have type 1 diabetes.	1	2	3	4
<ol> <li>People show fear towards me when they find out that I have type 1 diabetes.</li> </ol>	1	2	3	4
11. When people find out that I have type 1 diabetes, they look for negative traits in my personality.	1	2	3	4
12. I regret telling some people about my type 1 diabetes diagnosis.	1	2	3	4
13. I avoid new relationships because of the anxiety I feel about telling someone that I have type 1 diabetes.	1	2	3	4

Disclosure concerns				
I am extremely cautious about not disclosing to anyone that I have Type 1 diabetes.				
Informing someone that I have Type 1 diabetes makes me feel somewhat vulnerable.				
<ol> <li>I make a great effort to keep my Type 1 diabetes diagnosis a secret.</li> </ol>				
In many areas of my life, nobody knows that I have Type 1 diabetes.				
<ol><li>I am worried about being judged by people when they find out about my condition.</li></ol>				
<ol><li>I do not want those who know that I have diabetes to tell anyone else.</li></ol>				
<ol> <li>I never feel like I need to hide my Type 1 diabetes diagnosis.</li> </ol>				
Negative Self Image				
I feel different from others because of my type     I diabetes.				
<ol><li>I consider myself a bad person because of my diabetes.</li></ol>				
<ol> <li>People's behavior towards my condition makes me feel bad about myself.</li> </ol>				
<ol> <li>I felt lonely and isolated when I first found out about my type 1 diabetes.</li> </ol>				
5. I do not feel ashamed of having diabetes.				
6. I do not feel attractive due to my condition.				
Concern with Public Attitude		•		
Individuals with diabetes are not welcomed by society.	1	2	3	4
2. People with diabetes are often rejected by others.	1	2	3	4
<ol><li>I feel anxious about not being treated kindly by society due to my condition.</li></ol>	1	2	3	4
<ol> <li>Others do not feel comfortable when a diabetic patient is around them.</li> </ol>	1	2	3	4
I feel tense when interacting with others because of my diabetes.	1	2	3	4

#### **Appendix 2: The Adherence in Chronic Diseases Scale (ACDS)**

Part four: Level of Compliance with Treatment Plan and Medical Recommendations Below are a set of 7 questions, please answer with the best response that reflects your behavior, opinions, and abilities.

#### 1. Do you always remember to take all of your medications as directed by your doctor?

- 1. Always
- 2. Sometimes
- 3. Occasionally
- 4. Rarely
- 5. Never

#### 2. Have you ever changed your medication doses without consulting your doctor?

- 1. Never
- Only sometimes
- 3. Occasionally
- 4. Often
- 5. I never follow my doctor's recommendations

#### 3. Do you adjust your medication doses based on how you feel?

- 1. No, I strictly follow the prescribed doses regardless of how I feel
- 2. Yes, I lower the dose of some medications when I feel good
- 3. Yes, I skip doses of some medications when I feel good
- 4. Yes, I temporarily stop some medications when I feel good
- 5. Yes, I stop taking all medications when I feel good

## 4. When experiencing medication-related side effects (such as stomach pain, liver pain, rash, loss of appetite, bloating):

- 1. I seek medical attention immediately
- I lower the medication dose and try to schedule an appointment with my doctor sooner
- 3. I stop the medication and try to schedule an appointment with my doctor sooner
- 4. I stop the medication and wait for my next scheduled appointment with my doctor
- I stop taking all my medications and wait for my next scheduled appointment with my doctor

#### 5. Do you find all of your medications necessary for your health?

- 1. Yes, I do
- 2. I find most of the medications I take helpful for my health
- 3. I only find some of the medications I take helpful for my health
- 4. I find some medications I take helpful for my health, while others are harmful to me
- 5. I find most of the long-term medications I take harmful to me
- 6. Does your doctor inquire about medication-related issues that you may encounter?"
- 1. Yes, at every appointment.
- 2. Yes, they usually do.
- Yes, but only sometimes.
- 4. No, never.
- 7. "Do you tell the truth when your doctor asks about medication-related issues?"
- Yes, always.
- Almost always.
- I try to be honest, but sometimes it's hard to admit to not following the doctor's recommendations.
- 4. Sometimes yes, other times no.
- 5. No, I find it to be a personal matter.

#### Thank you

#### Appendix 3: الاستبانة

# الوصمة التي تصيب الأطفال الذين يحملون مرض السكري من النوع الأول ومدى قدرتهم على الالتزام بالخطة العلاجية

رقم:	ىتبيان ر	اس
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#### الجزء الاول: المعلومات الديموغرافية & العامة (يعبا من قبل الاهل)

1) الجنس: أ- ذكر ب- انثى 2) مكان السكن: 1. مدينة 2. قرية 3. مخيم 3) العمر (بالسنوات؟): 4) المرحلة الدراسية (الصف المدرسي): 4.اکثر 5) دخل الاسرة: 1. اقل من 1000 شيكل 2. 1000-2000 شيكل 3. 2001-3000 من 3000 شيكل 6) المستوى التعليمي للأم: 1. امية 2. ابتدائي 3. اعدادي 4. دبلوم 5. بكالوريس 6. ماجستير/ دكتوراة 7) المستوى التعليمي للاب: 1. امي 2. ابتدائي 3. اعدادي 4. دبلوم 5. بكالوريس 6. ماجستير/ دكتوراة 8) هل الام موظفة ؟ 1. نعم 2. لا 9) هل الاب موظف ؟ 1. نعم 2. لا 10) هل تخبر الاخرين عن ان لديك مرض السكري النوع الاول ؟ 1. نعم 2. لا 11) هل تؤجل جرعة الانسولين اذا كنت تأخذه في حال التواجد في الاماكن العامة او المزدحمة ؟ 1. نعم 2. لا 12) هل تفضل اخذ جرعة الانسولين في مكان بعيد عن تواجد الناس في حال التواجد في اماكن عامة ؟ 1. نعم 2. لا

### الجزء الثاني: المعلومات الطبية: الرجاء الاجابة بنعم او لا مقابل الاسئلة التالية

نعم 2. لا	1. هل يوجد لديك امراض اخرى غير السكري النوع الاول ؟ 1.
	اذا كانت الاجابة نعم ، اذكرها /اذكريها:
3. مضخة	2. طريقة اخذ الإنسولين 1. قلم الانسولين 2. ابرة الانسولين
	3. معدل السكر التراكمي (HbA1c ):

	•••••	- تاريخ التشخيص بالمرض	.4
ሂ.2	1. نعم	هل لديك مضاعفات مزمنة من مرض السكري ؟	.5
	••••	كانت الاجابة نعم ، اذكرها /اذكريها:	اذا :

## الجزء الثالث: الاسئلة التي تخص الوصمة الاجتماعية

## ارجو منكم الاجابة عن الاسئلة التالية بوضع علامة (X) داخل المربع الفارغ الذي يعبر عن اجابتك

غیر موافق بشدة	غیر موافق	اوافق بشدة	اوافق	الوصمة الاجتماعية	
				ابتعد عني بعض الناس حين عرفوا باصابتي بمرض السكري النوع الاول	.1
				اشعر بالسوء من ردة فعل الناس حين معرفتهم انني مريض بالسكري النوع الاول	.2
				اشعر بالندم انني أخبرت بعض الناس انني مصاب بمرض السكري النوع الأول.	.3
				كان من الخطأ اخبار الناس انني مصاب بمرض السكري	.4
				الاشخاص الذي اهتم إليهم توقفوا عن التحدث او الاتصال بي حين معرفتهم انني مريض سكري النوع الأول	.5
				الناس لا يريدونني ان اتواجد مع أطفالهم او اللعب معهم عند معرفتهم اننى مريض سكري النوع الأول	.6
				قام بعض الناس بالابتعاد جسديا عني حين معرفتهم انني مصاب سكري النوع الأول	.7
				بعض الناس يتصرفون على انه خطأي انني مصاب بمرض السكري النوع الأول	.8
				لقد توقفت عن الحديث مع بعض الناس بسبب ردة فعلهم اتجاه انني مصاب بمرض السكري النوع الأول	.9
				لقد خسرت احد أصدقائي حين اخبرته انني مصاب بمرض السكري النوع الأول	.10
				الناس يظهرون الخوف مني حين معرفتهم انني مصاب بمرض السكري النوع الأول	.11

12. حين يعلم الناس انني مصاب بمرض السكري النوع الأول يقومون
بالبحث عن المزايا السيئة في شخصيتي
13. أتجنب العلاقات الجديدة بسبب شعور القلق الذي ينتابني من أن اخبر
احدهم انني مصاب بمرض السكري النوع الأول

غیر موافق بشدة	غير موافق	ا <u>وفق</u> بشدة	اوافق	الخوف من الافصاح عن المرض	
,		•		انني حريص جدا ان لا اخبر أي احد انني	.1
				مصاب بمرض السكري النوع الأول	
				اخبار احد انني مصاب بمرض السكري النوع الأمل دين عن النوع الن	.2
				الأول يشعرني ببعض من الخطر انني ابذل جهدا كبيرا لإبقاء إصابتي بمرض	.3
					.5
				السكري النوع الأول سرا في الكثير من مجالات حياتي التي امارسها لا	.4
				أحد يعرف اننى مصاب بمرض السكري النوع	
				الأول	
				اقلق من احكام الناس علي عند معرفتهم	.5
				بالمرض	
				لا اريد من اللذين يعلمون انني مريض	.6
				بالسكري اخبار احد	
				لا اشعر ابدا انني احتاج الى اخفاء اصابتي	.7
				بمرض السكري	
				السلبية عن الذات	الصورة
					.1
				بمرض السكري	
				انا شخص سيئ لانني مصاب بمرض السكري	.2
				سلوك الناس اتجاه المرض تجعلني اشعر	.3
				بالسوء اتجاه نفسي	
				شعرت بالوحدة والأنعزال عندما علمت بانني	.4
				مريض بالسكري النوع الاول	
				لا اشعر بالخجل لانني مصاب بمرض السكري	
				لا اشعر ان لدي جاذبية بسبب مرضي	.6
				سلوك الناس	القلق من
				المصابون بمرض السكري لا يريدهم المجتمع	.1
				المصابين بمرض السكري يكونون مرفوضين من قبل الآخرين	.2
				من عبن ، ه حرین	

		اشعر بالقلق من عدم معاملتي بطريقة لطيفة من قبل المجتمع	.3
		لا يشعر الاخرون بالراحة عند تواجد مريض سكري حولهم	.4
		اشعر بالتوتر لدى التعامل مع الاخرين بسبب مرضي بالسكري	.5

القدرة على الالتزام بالخطة العلاجية : Appendix 4:

#### الجزء الثالث: مستوى القدرة على الالتزام بالخطة والتوصيات الطبية للعلاج والرعاية

يوجد أدناه مجموعة من 7 أسئلة الرجاء الاجابة بأفضل رد يعكس سلوكك وآرائك و مقدرتك

- 1. هل تتذكر دائمًا تناول جميع أدويتك وفقًا لتعليمات طبيبك؟
  - 1. دائما
  - 2. احياناً
  - 3. في بعض الأحيان
    - 4. نادر ا
      - 5. أبدا
- 2. هل قمت بتغيير جرعات الأدوية الخاصة بك دون استشارة طبيبك؟
  - ً أبدأ
  - 2. في بعض الأحيان فقط
    - 3. في بعض الأحيان
    - 4. في كثير من الأحيان
  - 5. لا ألتزم بتوصيات طبيبي على الإطلاق
  - هل تقوم بتعديل جرعات الأدوية الخاصة بك وفقًا لما تشعر به؟
- 1. لا ، أنا أتبع بدقة الجرعات الموصوفة ، بغض النظر عن شعوري
- 2. نعم، أقوم بتقليل جرعة بعض الأدوية عندما أشعر أنني بحالة جيدة
- 3. نعم، أتخطى جرعات بعض الأدوية عندما أشعر أننى بحالة جيدة
  - 4. نعم ، أوقف بعض الأدوية مؤقتًا عندما أشعر أنني بحالة جيدة
- 5. نعم ، أتوقف عن تناول جميع الأدوية عندما أشعر أنني بحالة جيدة
- 4. عند ظهور الأعراض الجانبية المرتبطة بالأدوية (مثل آلام المعدة ، آلام الكبد ، الطفح الجلدي ، قلة الشهية ، الانتفاخ):
  - 1. أطلب العناية الطبية على الفور
  - 2. أقوم بتقليل جرعة الدواء ومحاولة الإسراع في الموعد الاختياري مع طبيبي
    - أوقف الدواء وأحاول تسريع الموعد الاختياري مع طبيبي
    - أوقف الدواء وانتظر الموعد الاختياري التالي مع طبيبي
  - أوقف جميع الأدوية الخاصة بي وانتظر الموعد الاختياري التالي مع طبيبي

#### 5. هل تجد كل أدويتك ضرورية لصحتك ؟

- 1. نعم، أفعل
- 2. أجد أن معظم الأدوية التي أتناولها مفيدة لصحتي
- 3. أجد فقط بعض الأدوية التي أتناولها مفيدة لصحتي
- 4. أجد أن بعض الأدوية التي أتناولها مفيدة لصحتى ، في حين أن بعضها الآخر ضار بي
  - 5. أجد أن غالبية الأدوية طويلة الأمد التي أتناولها ضارة بالنسبة لي

#### 6. هل يستفسر طبيبك عن المشاكل المتعلقة بالأدوية التي قد تواجهها؟

- 1. نعم، في كل موعد
- 2. نعم ، يفعل ذلك عادة
- 3. نعم ، ولكن في بعض الأحيان فقط
  - 4 لا، أبدا

#### 7. هل تقول الحقيقة عندما يسأل طبيبك عن المشاكل المتعلقة بالأدوية؟

- 1. نعم دائما
- 2. دائما تقريبا
- 3. أحاول أن أكون صادقًا ، لكن في بعض الأحيان يصعب الاعتراف بعدم الامتثال لتوصيات الطبيب
  - 4. أحيانًا نعم ، مرة أخرى لا
  - 5. لا ، أنا لا أجدها شان خاص بي

#### **Annex 1: letter of approval**



Al Quds University
Faculty of Health Professions
Jerusalem –Abu Dis

## aalth Professions

جامعة القدس

كلية المهن الصحية

القدس – أبو ديس

#### Research Ethics Subcommittee of Faculty of Health Professions Letter of approval

Dec., 18, 2021

Ref. No.: RESC/2021-25

Dear Applicants, (Dr. Kawther Alayasa, Mr. Hammam Yaghi)

Program: MSc Nursing Department

The Research Ethics subcommittee of Faculty of Health Professions has recently reviewed your proposal entitled (Stigma and Self-Adherence among Children with Type 1 Diabetes Mellitus: Cross Sectional Study, West Bank, Palestine) submitted by (Dr. Kawther Alayasa). Your proposal is deemed to meet the requirements of research ethics at Al-Quds University, but further assessment is required by the Central Research Ethics Committee of Al-Quds University. We wish you all best for the conduct of the project.

Hussein ALMasri Research Ethics Subcommittee Chair Faculty of Health Professions

CC: File

CC: Committee members

Hussein AlMassi

تلفاكس: Tel. Fax: 02 2791243 Email: dean@hpro.alquds.edu 02 2791243