QATAR UNIVERSITY

COLLEGE OF PHARMACY

ASSESSMENT OF ADHERENCE, BARRIERS AND STRENGTHS TO ADHERENCE AMONG ADOLESCENTS WITH TYPE 1 DIABETES IN QATAR: PERSPECTIVES OF PATIENTS AND THEIR CAREGIVERS

BY

SOHAYLA ASHRAF IBRAHIM

A Thesis Submitted to
the College of Pharmacy
in Partial Fulfillment of the Requirements for the Degree of
Masters of Science in Pharmacy

June 2021

COMMITTEE PAGE

The members of the Committee approve the Thesis of
Sohayla Ibrahim defended on [Defense Date].

Dr. Ahmed Awaisu
Thesis/Dissertation Supervisor

Dr. Maguy ElHajj
Committee Member

Dr. Yaw Owusu
Committee Member

Dr. Maryam Khaja
Committee Member

Approved:

Dr. Mohammad Diab, Dean, College of Pharmacy

ABSTRACT

IBRAHIM, SOHAYLA, A, Masters: [June]: [2021], Clinical Pharmacy and Practice

Title: Assessment of Adherence, Barriers and Strengths to adherence among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and Their Caregivers

Supervisor of Thesis: Ahmed, Awaisu.

Background: Metabolic control among adolescents with type 1 diabetes mellitus (T1DM) is generally poor. Non-adherence is one of the contributors to this poor glycemic control, leading to high complication rates. The objective of this study was to assess the level of adherence among adolescents with T1DM in Qatar and to identify the barriers and strengths to adherence from the perspective of patients and caregivers.

Methods: Average blood glucose monitoring frequency (BGMF) was used to assess adherence level among adolescents with T1DM. Adolescents who had an average of ≥4 checks/day were considered adherent. A qualitative approach was used to identify barriers and strengths to adherence through semi-structured, online interviews with adolescents and their caregivers.

Results: The level of adherence among adolescents with T1DM in Qatar was found to be 40%. Ten adolescents and 14 caregivers described factors that are associated with adherence including patient-related factors/influencers, societal influence, medication and device-related factors, healthcare system-related factors, and lifestyle, school, and environment-related factors.

Conclusion: Poor adherence is common among adolescents with T1DM in Qatar. Factors impacting adherence are multifactorial in nature, requiring comprehensive interventions aimed at improving adherence and ultimately optimizing glycemic control.

DEDICATION

I dedicate this thesis to my precious family who believed in me …

Without you, I would have never been here.

ACKNOWLEDGMENTS

Praises is to Allah SWT by whose grace, good deeds are completed. Alhamdulillah for the strength, courage and determination throughout this journey.

This long journey had come to an end, and I would not have completed this master's degree without the blessings of Allah SWT, and the kind support of many people whose names may not all be enumerated.

Beginning with special thanks of gratitude to my primary supervisor, Prof. Ahmed Awaisu, who has been always supportive, helpful and provided me with guidance and encouragement throughout my MSc journey. Thanks a lot for imparting his knowledge, expertise and valuable comments and suggestions in this thesis. I appreciate his kindness, patience and generosity to achieve the best throughout my MSc journey. I would like also to express my gratitude to my co-supervisors, Dr. Maguy and Dr. Yaw for their valuable expertise, knowledge in the area of research, and precious time and effort.

Special thanks to our collaborators from Sidra Medicine, Dr. Amal Khalifa, Dr. Maryam Khaja and Dr. Dalia Ahmed, for their continues support and for providing me with the resources needed from Sidra to conduct this project, including ethical approvals, data collection and logistic facilitation. I would like to extend my thanks to all patients and caregivers who have participated in this study for their great input.

I would also like to express my sincere gratitude and appreciation to my dear parents, husband, sisters and my son Khalid, who have been my main source of inspiration. They have been a constant source of support and they were there whenever I needed them throughout my MSc journey. I give them credit after Allah, without whom it would not have been impossible to complete my thesis, especially through looking after Khalid while I am trying to complete thesis work. I would like also to

thank my friends and colleagues who kept motivating me and provide support whenever needed.

Finally, I would like to acknowledge the College of Pharmacy and Qatar University for the endless professional support and for facilitating the completion of this work with two grants.

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CHAPTER 1: INTRODUCTION

1.1. Background

Type 1 diabetes mellitus (T1DM) is an autoimmune disease that is usually characterized by absolute deficiency or lack of insulin. The autoimmune destruction of pancreatic β-cells is mediated by type IV hypersensitivity through T lymphocytes and leads to irreversible failure of insulin secretion (1, 2). It is usually diagnosed at a young age and classified as juvenile onset diabetes or insulin-dependent diabetes (3, 4). T1DM is a chronic and complex disease that constitutes multiple facets for successful management (5). It is the most prevalent metabolic noncommunicable chronic disease in children, accounting for 5-10% of all diabetes cases, and increasing at a rate of about 3% each year (4, 6). In general, the incidence of T1DM is increasing worldwide (7). The incidence of T1DM is highly variable among different populations (6, 8), which is partially explained by genetic variabilities among diverse ethnicities, climates, geographical locations, and socioeconomic backgrounds (9). In the Middle East and North Africa (MENA) region, predominantly Arabs, epidemiological data have reported a wide variation in the incidence of T1DM, ranging from 2.54/100,000 population in Oman to 29/100,000 population in Saudi Arabia (6).

Relative to other countries in the region, the incidence of T1DM is considered to be comparatively high in Qatar (7, 10). According to the International Diabetes Federation's (IDF) Diabetes Atlas, Qatar ranked the fourth highest among 89 countries in terms of T1DM incidence rate among children and adolescent populations in 2011(11). The reported incidence in Qatar in 2011 was 23.64 cases per 100,000 children population (10). However, the incidence increased to 28.39 cases per 100,000 children population between 2012-2016 (11). In 2018, a study conducted in Qatar stated that overall, more than 900 children with diabetes received care at Sidra Medicine, which is currently the only governmental tertiary hospital that treats children with diabetes under the age of 18 years (12). The economic burden of T1DM is not well studied especially among adolescent population however, a study published in the United States (U.S.) in 2017 estimated the average annual direct cost per person with diabetes of patients less than 18 years old to be $7510. This value was slightly higher than the average cost among adults likely due to a higher proportion of patient less than 18 years being type 1 (13).

In diabetes management, achieving and maintaining adequate glycemic control is critical as it reduces the risk of potential diabetes-related complications (14). Lower hemoglobin A1c (HbA1c) levels have been linked to a lower incidence of micro- and macrovascular complications (15). However, only 21% of adolescents with T1DM meet the HbA1c targets of less than 7%, set by the American Diabetes Association (ADA) (16). Adolescence is a transitional phase between childhood and adulthood during which a number of changes occur, including hormonal, cognitive, and psychosocial changes associated with puberty (17, 18). These changes may be attributed to the poor glycemic control that occurs during adolescence (18). Particularly, hormonal changes and worsening insulin resistance, can result in higher blood glucose levels, compromising diabetes management (18, 19). Adherence in T1DM requires a set of cognitive processes including monitoring, planning, initiating, and organizing. Those processes are referred to as executive function (20).Incomplete development in the cognitive and executive functioning could lead to poor glycemic control due to worsened adherence (19-21). In addition, psychosocial and behavioural factors have the greatest effect on glycemic control, where the adolescent starts having more autonomy and independence. Adolescents spend more time away from home, and their peers begin to have a greater influence on their lives as their parent’s authority fades (18, 19). Similarly, the responsibility of diabetes management starts to shift from parents to adolescents themselves, potentially resulting in family conflicts related to self-care tasks (19). In the Diabetes Control and Complications Trial (DCCT), adolescents clearly had poor glycemic control measured as higher HbA1c levels compared to adults (22). Collectively, during adolescence, glycemic control is typically at its lowest levels, and the rates of acute complications including hypoglycemia and diabetic ketoacidosis (DKA) are the highest (23).

Several targeted efforts have been made to address this poor glycemic control problem among adolescents. However, understanding the causes of poor glycemic control is a vital first step towards successful management and improved health outcomes (17). One of the reported suggested causes for uncontrolled T1DM is the worsening in adherence observed as children with diabetes reach puberty (14). Adherence is defined as "the extent to which person's behavior (including medication-taking) corresponds with agreed recommendations from a healthcare provider to which patients comply to medical advices" (24). In T1DM, those recommendations include monitoring blood glucose frequently, correcting insulin doses relative to glucose readings, administering doses of insulin, attending appointments regularly, performing carbohydrates counting, modifying lifestyle and obtaining medical supplies (17, 23, 25). Adherence to those multiple tasks is extremely challenging among adolescents, especially that those tasks are highly demanding in frequency and in nature (25). Adolescents with T1DM have a high rate of non-adherence reaching up to 93%, which can lead to complications and hospitalizations adding to the medical costs of the disease (26, 27). Non-adherence is expected to cost the United States $300 billion a year (27).

Adherence measurement in T1DM is challenging since it is defined by multiple factors and there are several recommendations offered to patients which they have to comply to; therefore, patients can have different levels of adherence to different components (17). Another challenge is that children and adolescents are not solely responsible for the management of their diabetes; they largely rely on caregivers as children and this role shifts partly to them as adolescents. This shift in responsibilities can cause conflicts that indirectly affects adherence and self-care. Furthermore, there are no objective biological measures of adherence in T1DM, such as serum drug concentration measurement, that clinicians could rely upon when assessing adherence (23). Although, there are multiple measures for assessing adherence, there is no gold standard measurement approach in adolescents with T1DM (28).

The methods used for adherence assessment in adolescents with T1DM can be broadly classified into objective and subjective measures. Objective measures include direct methods such as blood glucose monitoring frequency (BGMF), in addition to other indirect proxy methods that are rarely used such as HbA1c. Subjective measures include the utilization of self-reported assessment tools such as questionnaires, structured interviews, and logbooks (23). BGMF is a well-recognized measure of adherence in adolescents with T1DM. Studies have shown that this measure is one of the best markers of adherence to therapy (14). BGMF is a direct objective method that utilizes data stored in glucose meters to reflect the adherence of patients to the recommendations of their healthcare provider. It also provides a summary report of glycemic control that can show patterns of glucose levels (23). Its major drawback is that it only focuses on self-care aspects related to blood glucose monitoring without touching upon other important factors such as exercise, diet, carbohydrate counting, and insulin administration (29).

The association between glycemic control and adherence was assessed in many studies among adolescents with T1DM that found conflicting conclusions. Some studies have found that there is a link between improved adherence (measured as higher BGMF) and reduced HbA1c (8, 30, 31). Those studies had a common feature were reporting was mainly done based on patient's charts, data from logbook or parent's records, and were not based on self-reported by the adolescents. Moreover, a meta-analysis of 2492 Adolescents with T1DM reported that there is an adherence-glycemic control link with a mean effect size of -0.28 (95% confidence interval: -0.32 to -0.24) across 21 studies (22). In contrast, some studies have not found a link between BGMF and glycemic control, but those studies measured adherence exclusively by self-reports from diaries or logbooks (32, 33). Therefore, whether or not there is an association between adherence and glycemic control among adolescents with T1DM is still controversial.

In order to improve glycemic control through enhancing adherence, an initial step of identifying barriers to adherence and strengths/facilitators of adherence should be done and those identified should be addressed by reducing barriers and promoting facilitators. This step will help in developing holistic interventions aimed at maximizing adherence, improving glycemic control, and consequently minimizing diabetes-related complications (27). Previous studies have assessed factors affecting adherence among adolescents with T1DM (17, 23). These include psychosocial factors such as family functioning, parental supervision, friend's support, mood disorders, and eating disorders. Other barriers include medication, healthcare provider and cost-related factors (17, 23). Studies usually tend to focus on identifying barriers and/or challenges to overcome them instead of focusing on strengths to be promoted; however, strength-based research has started gaining more interest recently (34, 35). Strengths are defined as "adaptive processes, behaviors, and attitudes that facilitate achievement of resilient outcomes when faced with disease-related challenges" (36).

For T1DM in adolescents, these could include supportive and cooperative family environment, enhanced problem-solving skills and self-efficacy with diabetes management (35, 37, 38). The reported factors and barriers are highly variable among cultures and societies, particularly when it comes to parenting styles, which in this case plays a significant role on adherence. Therefore, it is essential to investigate barriers specific to Qatar, which may ultimately mirror the MENA region.

Previous studies have assessed the use of various interventions in order to improve adherence in adolescents with T1DM. Those interventions could be classified into health services delivery, group education and peer support, technological advancements to influence self-care behaviours, and diabetes devices. However, there is an inconclusive evidence about the impact of such interventions on clinical, behavioural, and psychosocial outcomes (39).

1.2.Study Rationale

During the transition from childhood to adulthood, many changes occur as a result of puberty including hormonal, cognitive and psychosocial changes which collectively lead to poor glycemic control. Consequently, only about 21% of adolescents with T1DM achieve their target HbA1c levels set by ADA, leading to high complication rates among this population (16). This poor glycemic control is associated with poor adherence that is noted during adolescence (14).

Multiple interventions were directed towards improving adherence of adolescents with T1DM, yet, those interventions showed inconsistent results with regards to their effect on glycemic control (39). Therefore, in order to improve glycemic control through maximizing adherence, barriers and facilitators of adherence should be identified to tailor interventions that improve adherence more effectively. Those barriers/facilitators are highly variable among different populations due to differences in cultures, climate, geographical location and ethnicities. Therefore, interventions cannot be generalized and should be culturally sensitive and based on factors that are unique to each specific environment or population.

In addition, Qatar has a very high incidence of T1DM (10), but no previous studies have assessed adherence levels among adolescents with T1DM and the barriers/facilitators of adherence among this population from the perspective of adolescents and their caregivers.

1.3. Study Objectives

1.3.1. General objective

The overall objective of the study was to assess the level of adherence of adolescents with TIDM in Qatar and to identify the barriers/strengths to adherence from the perspectives of patients and their caregivers.

1.3.2. Specific objectives for Phase I: Assessment of adherence and its association with glycemic control

The specific objectives of Phase I of the study were to:

- assess the level of adherence among adolescents with T1DM in Qatar using BGMF approach.
- investigate the relationship between the level of adherence of adolescents with T1DM in Qatar and their glycemic control measured via HbA1c

1.3.3. Specific objectives for Phase II: Barriers and strengths to adherence from the perspectives of adolescents and their caregivers

On the other hand, the specific objectives of Phase II of the study were to explore the:

- barriers/challenges to adherence from the perspectives of adolescents with T1DM in Qatar and their caregivers.
- strengths/facilitators to adherence from the perspective of adolescents with

T1DM in Qatar and their caregivers.

1.4. Study Significance

There is a lack of data regarding the level of adherence and the factors associated with it among adolescents with T1DM in Qatar. Therefore, this study will provide data that can be utilized by healthcare providers and policymakers to optimize adherence and improve health outcomes.

This research is expected to be of a great benefit since identifying barriers and strengths to diabetes adherence among adolescents with T1DM will help in developing holistic interventions targeting those barriers and strengths. Hence, it will help in improving glycemic control and diabetes related complications in this vulnerable population.

This study is in alignment with the Qatar National Health Strategy 2018-2022, given that diabetes is one of the priority themes under the biomedical and health pillar section of the strategy (40). The National Diabetes Strategy 2016-2022 stated that diabetes is a major health challenge worldwide and particularly in Qatar since the prevalence of diabetes in Qatar is relatively high. Diabetes is forecasted to contribute to 7% of the disease burden in the country and 10% of the death burden in 2020 (41). In addition, children and adolescents are set under the population priorities (40). Therefore, this study aligns well with major health and development strategies in the State of Qatar.

CHAPTER 2: LITERATURE REVIEW

This chapter provides an overview of the available literature about adherence among adolescents with T1DM and barriers/strengths to adherence. It starts with a definition for adherence followed by challenges and methods to adherence assessment. It also includes a section on the relationship between adherence and glycemic and finally concluding with a section on available evidence about factors associated with adherence

2.1.Defining adherence in type 1 diabetes

The World Health Organization (WHO) defines adherence as “the extent to which person’s behavior (including medication-taking) corresponds with agreed recommendations from a healthcare provider (24). The term “adherence” is preferentially used over the term “compliance” to describe a medication-taking behavior as it indicates that the patient is actively involved in developing the treatment plan rather than blindly following recommendations (42). Adherence shows the extent to which the patient complies to medical advices (23). When it comes to T1DM, those advices include monitoring blood glucose frequently, correcting insulin doses relative to glucose readings, administering doses of insulin, attending appointments regularly, performing carbohydrates counting, modifying lifestyle and obtaining medical supplies (17, 23, 25). Non-adherence is sometimes classified further into primary and secondary non-adherence. Primary non-adherence is related to problems in the frequency of refilling or obtaining prescribed medications, whereas secondary non-adherence refers to not taking the medications as intended after filling the prescription (43).

2.2. Assessment of adherence among adolescents with type 1 diabetes

2.2.1. Challenges

Adherence assessment and monitoring are crucial aspects of diabetes management. However, assessing adherence is inherently challenging especially among adolescents with T1DM due to many reasons. First, adherence among adolescents with T1DM has multiple facets with varying complexities and does not rely on a single self-care behavior. Adolescents tend to have distinct levels of adherence to different self-care behaviors, making it difficult to assess comprehensively (23, 44). Second, it is challenged further by the fact that there is no objective biological measure for adherence, such as serum drug levels, necessitating clinicians and researchers to rely on diabetes self-care behaviors as a measure for adherence (23, 28). Moreover, as the child grows up to adolescence, the responsibility of adherence to different self-care activities gradually shifts from the parents to the adolescents (23). In other words, the adolescent patient is not yet the sole manager of his/her diabetes. This shared responsibility means that different adherence measures do not necessarily reflect the adherence of the adolescent. Hence, the adherence behavior of the caregivers should be also considered. Finally, there is not a single protocol for T1DM management. The regimens and advices are tailored based on multiple factors including insulin delivery methods, glucose monitoring tools, level of activity, and glycemic control which makes it difficult to establish an adherence rate (22). The recommendations are not static even for an individual patient and this adds up to the challenge of identifying or measuring adherence in adolescents with T1DM.

2.2.2. Methods

There are multiple reported methods for the assessment of adherence among adolescents with T1DM, each method assesses adherence from a different aspect and have its merits and drawbacks. The adherence assessment methods can be broadly divided into objective and subjective methods. Objective adherence measures assess the occurrence of a specific behavior, whereas subjective adherence measures assess the report of the patient on whether he/she has performed the behavior or not (23). The objective methods are summarized in Table 1, while the subjective methods are presented in Table 2 below.

Table 1. Objective Measures for Adherence Assessment in Adolescents with Type 1 Diabetes Mellitus (23)

Direct objective methods	
Adherence measure	Description
Blood glucose monitoring (BGM) adherence via meter download	• Provides data on BGMF • Glucometers store data on BGMF for a couple of weeks • Provides better and more reliable predictions to glycemic control than self-reports
Insulin adherence via pump download	• The timings and the doses of rapid and long-acting insulin taken are saved which can be used in adherence assessment • Other aspects of adherence are also potentially assessed including incorrect dosing, timing, or administration technique • Dietary adherence could be subjectively assessed through carbohydrate intake entries into the pump
Indirect objective methods	
Adherence measure	Description
Pharmacy claims data	• Provides data regarding prescription filling of insulin or other diabetes-related supplies which can be used to assess medication-taking behavior
Hemoglobin A1c (HbA1c)	• Many researchers and clinicians rely on HbA1c data to assess adherence as the association between BGMF and HbA1c is well established • Currently, HbA1c is not used in adherence assessment as it is affected by many other factors not related to adherence.

Table 2. Subjective Measures for Adherence Assessment in Adolescents with Type 1 Diabetes Mellitus

Structured interviews

Instrument (Author)	Age range (years)	Description	Psychometric properties
Diabetes Self-Management Profile (DSMP) (Harris et. al.) (45)	6-15	• Interviewer administered • Assesses how frequently a patient performs 23 different self-care tasks in the last 3 months by interviewing patient/caregiver. • It includes 5 domains; exercise, hypoglycemia management, diet, blood glucose monitoring and insulin administration and dose adjustment.	• Internal consistency of 0.76 • Moderate adolescent-caregiver agreement • Showed strong association with measures of quality of life and HbA1c (validity) • Commonly used in research context and in validation of newer adherence tools
Diabetes 24h Recall Interview (Freund et. al.) (23, 46)	6-17	• Interviewer administered through face-to-face or telephone interviews • The patient is required to state all self-care activities performed during the past day with the interviewer prompting to ensure sufficient details and descriptions are provided • Adolescents and their caregivers are interviewed separately • The interview is repeated on 3 separate days and the average is used for the analysis	Adolescent-caregiver agreement is acceptable

Youth-, parent- and provider-report questionnaires

Instrument (Author)	Age range (years)	Description	Psychometric properties
Self Care Inventory (La Greca et. al.) (26, 47)	4-18	• Includes 14 items • Assesses how frequently a patient follows 14 recommendations in one month • Recommendations are rated on a 5-point Likert scale, ranging from ‘never do it’ to ‘always do this as recommended without fail’ • Different versions exist for adolescents and caregivers	• Internal consistency above 0.7 • Moderate adolescent-caregiver agreement • Strong test–retest reliability • Showed strong association with adherence scores (validity)

Table 2. Subjective Measures for Adherence Assessment in Adolescents with Type 1 Diabetes Mellitus

Youth-, parent- and provider-report questionnaires continued			
Instrument (Author)	Age range (years)	Description	Psychometric properties
Diabetes Self-Management Profile – Self Report (Wysocki et.al.) (48)	8-18	• A tool summarizing Diabetes Self-Management Profile interview minimizing its burden • Includes 24 items • Assesses how frequently self-care tasks were performed or missed • Each question has 3–6 response options not fixed for the whole tool	• Internal consistency was high (>0.8) • Moderate adolescent-caregiver agreement • Showed strong association with quality of life scores and glycemic control (validity)
Diabetes Self-Management Questionnaire (Markowitz et.al.) (49)	9-15	• A tool summarizing Diabetes Self-Management Profile interview minimizing its burden • Includes 9 items • Assesses how frequently a patient performed self-care tasks in response to common scenarios in one month • Response options range from 'never' to 'always' with an additional 'not applicable' option	• Internal consistency was relatively low (0.5-0.6) • Good adolescent-caregiver agreement • Showed strong association with adherence scores and glycemic control (validity)
Provider report (23)	-	• Estimates of adherence provided by healthcare providers • Those estimates are usually based on HbA1c levels and overall glycemic control of patients which makes it inaccurate	-

Table 2. Subjective Measures for Adherence Assessment in Adolescents with Type 1 Diabetes Mellitus

Diaries and logbooks			
Instrument (Author)	Age range (years)	Description	Psychometric properties
Diary method (23)	-	• Diary methods include daily handwritten or electronic documentation of self-care tasks • Advantages include the ability to assess multiple tasks at once and the short recall period • Disadvantages include the possible nonadherence to documentation and white-coat adherence where entries are made prior to the appointment. It also requires high literacy level	-

2.3. Association between adherence and glycemic control

The relationship between adherence and glycemic control was assumed long ago. This assumption was initially supported by findings of the DCCT (50). In addition, this assumption also reflects in clinical practice guidelines in terms of the strong emphasis on the importance of adherence as part of a treatment plan (51, 52). As previously mentioned, the adherence required from patients with T1DM is comprehensive and it includes the integration of multiple self-care tasks such as diet, exercise, insulin, and blood glucose monitoring. However, few limitations were that the DCCT recruited only 195 adolescents, it did not include a correlation analysis between adherence and glycemic control, and it did not measure adherence comprehensively (22).

Later, the association between glycemic control and adherence was investigated in several studies involving adolescents with T1DM with conflicting conclusions. Some studies have found that there was an association between improved adherence (measured as higher BGMF) and reduced HbA1c (8, 30, 31). These studies had a common feature were reporting was mainly done based on patient's charts, data from logbook or parent's records, and were not self-reported by the adolescents. In contrast, some studies have not found an association between BGMF and glycemic control, but those studies measured adherence exclusively by self-reports from diaries or logbooks (32, 33). A meta-analysis of 2492 youths with T1DM, published in 2009, reported that there was an adherence-glycemic control link with a mean effect size of -0.28 (95% confidence interval: -0.32 to -0.24) across 21 studies (22).

Additionally, a study published in 2010 aimed to correlate BGMF with HbA1c and to identify whether this relationship was affected by other demographic or clinical factors such as age and insulin regimen (53). This study found that BGMF was significantly associated with HbA1c particularly with a drop of 0.2% for each additional glucose check per day ($p<0.001$) after adjusting for confounders. However, this increase was only up to five checks per day and any additional check did not result in further reduction in HbA1c. The effect was even more pronounced in age group older than 12 years (0.30% ± 0.011, $p < 0.001$) (53).

Moreover, another study was conducted to assess the relationship between three different BGMF indices and glycemic control (54). Those indices were meter downloads, caregiver-reported BGMF, and adolescent-reported BGMF. This study concluded that HbA1c was significantly correlated with BGMF from meter downloads, caregiver-reported, and adolescent-reported frequencies with the meter downloads being the most robust in predicting glycemic control (54).

A 5-year longitudinal study also published in 2011 aimed at determining the relationship between BGMF and glycemic control (55). This study examined the relationship between self-reports of other self-care tasks and HbA1c independent of BGMF. This study concluded that higher BGMF was related to lower HbA1c and that both BGMF and self-care tasks predicted glycemic control independently, suggesting that all other aspects of self-care tasks affect glycemic control (55).

Furthermore, a study in 2012 examined the interrelation between four different methods of adherence assessment among adolescents with T1DM: self-report, diary measure, electronic monitoring, and provider rating (56). Following the analyses, the different methods of adherence assessment appeared to be interrelated. The association analyses between all different measures of BGMF assessment and HbA1c revealed a statistically significant association with an effect size ranging from 0.27 to 0.75. Moreover, regression analysis found that the strongest significant predictor of glycemic control was the score of the self-reported Self-Care Inventory tool accounting for an additional 17.3% of the variance (56).

A more recent study aimed to assess the relationship between BGMF and glycemic control was conducted among Korean adolescents with T1DM (57). The study found a negative correlation between BGMF and HbA1c with an average drop of 0.42% of HbA1c. It also showed that adolescents who check more than four times per day tend to have significantly more controlled blood glucose levels opposing to those who had four or less checks per day (57).

In general, most of the available evidence supports the presence of an association between adherence (specifically measured as BGMF) and glycemic control among the population of adolescents with T1DM.

2.4.Current evidence on factors affecting adherence among adolescents with type 1 diabetes

According to WHO, there are multiple factors that affect medication adherence (24). Those can be classified into five categories: socioeconomic factors, therapy-related factors, patient-related factors, condition-related factors, and health system/healthcare team-related factors (24, 43).

2.4.1. Socioeconomic factors

Parental influence

The influence of family on adherence of adolescents with T1DM was examined in many studies focusing on aspects related to parental involvement, parenting style and family conflict. Parental involvement in diabetes care and shared responsibility have been associated with improved adherence (58, 59). The direction of the relationship between parental involvement and adherence in adolescents with T1DM is not clear. Some studies have reported that among adolescents, parental involvement was associated with worse adherence (60), whereas other studies have proven positive relations (59, 61, 62). This disparity is partly explained by the lack of information on how ready the kids were to take over the responsibility as well as the various ways by which parental involvement was assessed (58).

Parenting style was also associated with treatment adherence. Parenting styles are parents' constant attitudes, behaviors and values towards their kids (63). There are four main parenting styles: authoritative, authoritarian, permissive, and uninvolved (64). The parenting style tends to be constant regardless of the encounter (58). Authoritative parenting style, which is characterized by warmth and behavioral control, was associated with better adherence (63, 65-67). Authoritarian and permissive parenting styles were associated with worse adherence (65). It was also found that the parenting style is a confounding factor in the relation between parental involvement and adherence (58).

Family conflicts in relation to diabetes-related tasks is one of the major barriers to adherence reported in the literature. Many studies have found that higher level of family conflict leads to poor adherence (68-72). Conflicts about diabetes-related tasks results in lower parental ability for involvement or supervision. It creates unhealthy environment for the adolescent to the extent that he/she might intentionally avoid all the tasks just to prevent family conflict and the end result is poorer adherence and glycemic control (73).

Peer influence

Peer influence on adherence level was less studied among adolescent population. However, in some studies it was perceived as a barrier to adherence (5, 17, 74, 75). The main challenge was that the adolescents fear bullying and being put at the center of attention as a result of performing diabetes-related tasks (74). Other studies showed that peers provide the emotional support, whereas parents provide diabetes-care support (5, 17, 75). Overall, peer influence needs more attention as it can play both positive and negative roles in terms of adolescent's adherence.

2.4.2. *Therapy-related factors*

Fear of needles was documented as one of the barriers to adherence in relation to self-injections and self-monitoring blood glucose. As a fact, the needles used nowadays for insulin injections or glucose monitoring are much finer (76). Despite this, fear of injections and pain are still major factors impacting adherence. Studies have proven that patients with fear of injections have lower BGMF and higher HbA1c (76, 77).

Insulin delivery method was also found to impact adherence to treatment. Research has shown that adolescents using continuous subcutaneous insulin infusion (CSII) report higher levels of adherence compared to patients using multiple daily injections (MDI) (5, 78, 79).

2.4.3. *Patient-related factors*

Some demographics and clinical characteristics were associated with adherence. These characteristics include age, gender, and diabetes duration. Age was found to have a negative relationship with adherence, so as patients get older, their adherence becomes worse (5, 80-82). Gender was also found to impact adherence of adolescents with males reporting higher adherence to self-care tasks compared to females (5, 79, 82, 83). Furthermore, the duration of diabetes was also proven to have an impact on adherence, such that as the duration of diabetes increases, the adherence to treatment worsens (5, 79, 82).

2.4.4. *Health system/health care team-related factors*

Patient-provider relationship plays an important role in promoting adherence to treatment. Studies have shown that communication skills between patients, their caregivers, and health-care providers can positively or negatively influence the experience of attending appointments which is a major aspect of diabetes adherence (84, 85). Effective communication can facilitate the provider's understanding of the attitudes, knowledge, behaviors and preferences of the adolescent which will help in tailoring his/her treatment plan based on those issues and that will collectively help in optimizing adherence given the complexity of the treatment plan (85). Inclusion in the decision-making and considering patient's autonomy is also critical in adherence improvement, especially among this population of newly autonomous adolescents (85-87).

CHAPTER 3: METHODS

This chapter presents the methods used in this study. This research was a multi-method research which was performed in two phases. The first phase was a retrospective cross-sectional observational study through which quantitative data were collected to assess the levels of adherence among adolescents with T1DM in addition to other demographic and clinical data. The adherence level was assessed objectively using BGMF. The data obtained were then used to find the relationship between the level of adherence and glycemic control. The second phase of the study was a phenomenological qualitative study using one-to-one interviews. Data were collected to assess barriers and strengths towards diabetes adherence among adolescents with T1DM from the perspectives of the patients and their caregivers (in this case, parents). Qualitative data were collected through interviewing the adolescents and their parents. Those two separate methods were used to achieve the overall objective of the research which is to assess the level of adherence of adolescents with TIDM in Qatar and to identify the barriers/strengths to adherence from the perspectives of patients and their caregivers.

3.1. Phase I: Assessment of adherence and its association with glycemic control

3.1.1. Study design

Phase I of the study was a retrospective, cross-sectional observational study. Quantitative data were collected to assess the levels of adherence among adolescents with T1DM using the mean BGMF through glucometers or other flash glucose monitoring (FGM) devices.

3.1.2. Study Setting

This phase of the study was conducted at Sidra Medicine. Sidra Medicine is a quasi-governmental institution that provides tertiary healthcare services to children, young people and women (12). It has an Endocrinology and Diabetes outpatient clinic were all children and adolescents with T1DM in Qatar receive their treatment. The Endocrinology and Diabetes outpatient clinic operates 8 hours on weekdays (Sunday-Thursday) from 7 am to 3 pm. It provides interdisciplinary and comprehensive care for children and adolescents with endocrine disorders such as diabetes mellitus, thyroid disorders, and growth disorders. Follow up appointment are usually scheduled every 3 months. It includes 4 physician clinics and separate rooms for diabetes education, dietitians, and pump school. Diabetes educators and dieticians run their own clinics with separate appointments for patients referred to them by clinicians.

3.1.3. Participants

Participants were adolescents with T1DM aged from 12 to 18 years. A list of all patients with T1DM attending Endocrinology and Diabetes outpatient clinic at Sidra Medicine was obtained. Patients were assessed against the predefined inclusion criteria and the medical records for eligible patients were reviewed to obtain demographic and clinical data. This specific population was chosen due to the multiple challenges that arise as children transition to adolescence phase including hormonal and psychosocial factors.

3.1.4. Inclusion criteria

Participants were included in the study if they satisfied the following inclusion criteria:

- Adolescents aged from 12 to <18 years old
- Diagnosed with T1DM
- Taking insulin through MDI or CSII
- With a duration of diabetes of at least one year

3.1.5. Exclusion criteria

Participants who failed to satisfy any of the inclusion criteria or who satisfied any of the following exclusion criteria were excluded from the study:

- Diagnosed with multiple chronic conditions
- Diagnosed with mental illness

3.1.6. Sample size calculation

Raosoft® sample size calculator was used to calculate the sample size using the parameters below:

- Margin of error 5%
- Confidence level 95%
- Response distribution 50%
- The population size was estimated as 500 patients:

  This value was not obtainable as a statistic from the clinic; therefore, it was estimated based on a study conducted in Sidra Medicine that stated that more than 900 kids (under 18 years) were treated at their institution (12). According to the distribution of children: adolescents in Qatar in 2019, the ratio was around 2.5:1 so we overestimated the population size to be 500.

The overall sample size using the parameters and assumption above was determined as 218 patients.

3.1.7. Sampling

Convenient or opportunity sampling technique was used for inclusion in this study since the identification of a sampling frame was not feasible.

3.1.8. Data collection tool

The data collection tool was designed to incorporate all relevant demographic data to be extracted from the medical records including gender, nationality, and age. It also included relevant clinical data such as comorbidities, duration of illness, and type of diabetes. Data on adherence were also collected using this data collection tool through

BGMF collected from saved reports produced by glucometers or the frequency of sensor scanning of FGM devices.

3.1.9. Data collection procedure

The researcher obtained the list of patients with T1DM attending Endocrinology and Diabetes outpatient clinic at Sidra Medicine. Each patient profile was assessed for eligibility. Clinical and demographic data were collected from the patient's electronic medical record (Cerner Millennium, North Kansas City, USA) once they were identified as eligible. Data on BGMF per day were also collected from the saved reports previously downloaded from glucometers (OneTouch®) or other FGM devices (FreeStyle® Libre™; Abbott Diabetes Care Inc., Alameda, CA, USA).

The FGM system works by measuring actual interstitial glucose concentration once the patient scans the sensor with the reader device. Unlike continues glucose monitoring (CGM) devices, they do not have alarm systems, do not require calibration, and do not provide continuous data on glucose level unless the patient scans the sensor every 8 hours (88, 89). The sensors should be changed every two weeks and these devices have shown to produce accurate results compared to glucometers (88) and CGM devices (89).

If objective data on BGMF were not available, clinical notes were reviewed and data were extracted based on adolescent/caregiver report (if documented). Previous studies have shown that adolescent/caregiver report was significantly correlated with BGMF from meter downloads with a correlation coefficient of around 0.6 ($p < 0.0001$) (54). An average of 30 days was collected and if not available, the average of 14 days was documented. Thirty days were chosen because previous studies have proven the influence of white coat adherence where the frequency of monitoring increases as a clinical visit approaches (90).

3.1.10. Data analysis

Descriptive statistics were used to describe the demographic and clinical characteristics of the patients. Frequencies and percentages were used to report categorical variables, while median and inter-quartile range (IQR) were used to summarize continuous variables. Pearson Chi square and Fishers Exact tests were used to identify the effects of demographic and clinical characteristics on adherence and glycemic control as categorical variables. In addition, Mann-Whitney U and Kruskal-Wallis tests were used to assess the effect of demographic and clinical characteristics on adherence (BGMF) and glycemic control (HbA1c) as continuous variables. Spearman’s rho test was used to assess the correlation between adherence and glycemic control among adolescents with T1DM in Qatar.

Univariate Binary Logistic Regression test was used to assess the relationship between adherence (BGMF) and glycemic control (HbA1c levels). It was also used to assess the relationships between other covariates (insulin delivery methods, nationality, duration of diabetes, gender…etc.) and glycemic control. Multivariate Binary Logistic Regression test was then used to incorporate those covariates into the model. Entry of variables into the model was less restrictive ($p<0.25$) and then for the multiple regression model, $p<0.05$ was considered significant. Statistical Package for the Social Sciences (SPSS) version 25 was used for data analysis.

3.2. Phase II: Barriers and strengths to adherence from the perspectives of adolescents and their caregivers

3.2.1. Study design

This was a qualitative phenomenological study (91) involving adolescent with T1DM and their caregivers using a social constructivism interpretative framework (91, 92). Face-to-face semi-structured interviews were utilized in this phase for further exploration of factors that influence the adherence of adolescents with T1DM. A phenomenological approach was used because our aim was to gain a deep understanding and insight from several patients and their caregivers sharing their lived experiences with T1DM management and self-care.

Social constructivism interpretative framework was the most appropriate framework to represent the knowledge and the perceptions of the researcher. Creswell and Winit-Watjan defines the social constructivism interpretative framework as the development of a subjective meaning of individual experiences in a complex manner taking into consideration the multiple realities present (91, 92). In this study, there were multiple realities since patients and their caregivers had different perspectives about barriers/strengths to adherence, and those realities were built through discussions with patients and their caregivers. Inductive method was used for the qualitative data analysis.

3.2.2. Study Setting

The study setting where the participants (i.e. the adolescent and their caregivers) were recruited (Sidra Medicines) was described in detail under section 3.1.2.

3.2.3. Participants

Participants included adolescents with T1DM aged from 12 to 18 years and their caregivers. Caregivers were included in this phase due to the significant impact and influence they have on the adherence of adolescents as they share the responsibility with them. This was well-documented in previous study as presented in Chapter 2.

3.2.4. Inclusion criteria

Adolescents were included in the study if they satisfied the following inclusion criteria:

- Adolescents aged from 12 to 18 years old
- Diagnosed with T1DM
- Taking insulin
- With a duration of diabetes of at least one year

- Speaks Arabic and/or English

Caregivers were included in the study if they satisfied the following inclusion criteria:

- Parents of adolescents who fulfilled the above mentioned inclusion criteria (aged from 12 to 18 years old, diagnosed with T1DM, taking insulin, and with a duration of diabetes of at least one year)
- Speaks Arabic and/or English

3.2.5. Exclusion criteria

Participants who failed to satisfy any of the inclusion criteria or who satisfied any of the following exclusion criteria were excluded from the study with their caregivers:

- Diagnosed with multiple chronic conditions
- Diagnosed with mental illnesses
- Adolescents with language or communication problems

3.2.6. Sample size calculation

Participants were consecutively enrolled in the study until data saturation was reached. Data saturation is the point where data analysis would not result in the identification of new information and it indicates that the researcher could stop the data collection (93). In this study, saturation was reached after interviewing 14 caregivers and 10 adolescents.

3.2.7. Sampling

Purposive sampling of participants who were interested to participate was used in recruiting adolescents and their caregivers. Maximum variation in participant characteristics was targeted to make sure that the study captured the true experiences regardless of age, nationality, duration of diabetes and any other confounding variables.

3.2.8. Interview guide

The interview guide was developed following a thorough literature review of previous studies on barriers/strengths to adherence in adolescents with T1DM. The interview guide included mainly open-ended questions to generate discussions. The guide was independently reviewed by the team members and validated by researchers in the field of diabetes and qualitative research to ensure the comprehensiveness and coverage of the interview. Pilot interviews were conducted with the target population to ensure the comprehensiveness of all interview questions and to assess the interview burden including the time needed to complete the interview. Pilot interviews were included in the analysis because of the richness of the information provided by those participants.

3.2.9. Interview setting

Face-to-face interviews were conducted online through Adobe Connect™. Adobe Connect™ software facilitates web conferencing upon subscription. This software is commonly used in research studies as it is password-protected which increases its protection for confidentiality. This software also allows recordings that are also password-protected and saved within the software securing its access (94). In case the participant requested to use other platforms such as Zoom, Skype, or Microsoft (MS) Teams, we clearly stated to the participant that the confidentiality of the interview was not guaranteed.

To facilitate online interviews and to ensure all logistic, methodological, and ethical considerations were met, some strategies were followed as presented below:

- Participants were given the right to choose whether they prefer video or audio conferencing and they also chose whether they allow for audio recording or otherwise notes were taken.
- We discussed each participant's setting and ensured that it was convenient for an interview setting. We also planned for the interview schedule to be as feasible and convenient to the participant as possible.

- We gathered information from participants about their previous use of online platforms and we shared instructions with participants in advance of the interview on how to establish the connection.
- In case of video interviews, notes were taken about the setting of the participant and whether other people were present in the setting. Facial expressions or hand gestures were also documented as those help in interpreting confusion or confidence.
- To enhance the privacy of the conversation, participants were encouraged to use earphones.

3.2.10. Interviews

Semi-structured interviews were conducted with adolescent patients and their caregivers separately to avoid any possible sensitivities and pressures that may be caused by the presence of the parents with their adolescents. Caregivers of adolescents identified were called on their phone numbers and were informed about the study. Those who accepted to take part were invited for an online interview through Adobe Connect™ at a time of their convenience. We asked the caregiver's parental permission to interview their adolescent child and in case they both agreed, they were included in the study. In case the participant requested to use other platforms such as Zoom, Skype, or MS Teams, we clearly stated that we could not guarantee the confidentiality of the conversations. We shared instructions with participants in advance of the interview on how to establish the connection. On the day of the interview, participants were provided with an information sheet describing the study and its procedures as well as a consent form that they had to sign.

For interviews with adolescents, the interviewer started by a brief introduction about the study followed by reflections on adherence in T1DM management and self-care. Open-ended questions and discussions then followed to allow them to express their views, perceptions, and lived experiences in more details. For interviews with caregivers, the interviewer started by a brief introduction about the study followed by open-ended questions and discussions to explore their detailed views, perceptions, and lived experiences. The interview sessions took an average of 40-60 minutes. The interviews were recorded as part of the software and were password-protected. If the participant refused that their responses/voices to be recorded, handwritten notes were used as alternatives. The interviews were conducted either in English or in Arabic based on each participant's preference to better express their thoughts. New participants were interviewed until saturation point was reached.

3.2.11. Transcribing

The interviews were audio-recorded for transcribing purposes. Each session was transcribed verbatim by the interviewer. Interviews that were conducted in Arabic were translated and transcribed simultaneously to ensure that the English translation reflected the intended meaning.

3.2.12. Data analysis

Using thematic analysis, text that were considered relevant to the research questions were coded. Codes were then categorized based on the key concepts of the study, and themes or subthemes were identified. The interview transcripts were reviewed and coded, and the main themes and subthemes were discussed with the team members through face-to-face discussions to resolve discrepancies.

3.2.13. Quality measures

Quality measure in qualitative studies include credibility, dependability, confirmability, transferability, and reflexivity (95). Credibility confirms the validity and the confidence of the conclusion. This measure was ensured by interviewing different categories (adolescent and his/her caregiver) and by using the proper analysis strategy (inductive approach). Dependability confirms the reliability of the findings making sure that they are consistent and repeatable. This was ensured by having a detailed methodology written, saving all transcripts and relevant data in one folder and peer reviewing the transcripts. Confirmability reflects that the perspectives of the interviewees were presented and not interviewer perspectives and this ensures the objectivity of the data presented. It also ensures that the bias of the researcher does not affect the results, and this was maintained by reflecting upon the researcher's biases and acknowledging them and trying to keep them away during the interview. Transferability represents the external validity of the findings and that its applicable to similar scenarios. This was achieved by providing detailed information about the whole context and by providing detailed justifications for interpretations that should be published. Finally, reflexivity which is approving the researcher's bias and reporting it when relevant and this was maintained by reporting biases available during interpretations of the data. We followed Consolidated Criteria for Reporting Qualitative Research (COREQ) quality reporting tool for reporting. COREQ is a 32-item checklist that aids researcher in reporting essential aspects of qualitative research (96).

3.3.Ethical considerations

Ethical approvals were obtained from the Institutional Review Board (IRB) of Sidra Medicine (IRB number: 1500792), and Qatar University IRB (QU-IRB 1103-EA/19). Adolescent's assents were obtained in addition to parental permissions prior to the enrolment of the adolescents in the study. Caregivers consents were also obtained prior to the interview sessions.

The informed consent/assent/parental permission forms included an information sheet with a statement about the background and the purpose of the research, the expected duration, the procedures expected, and the possible risks and benefits. It also included information on confidentiality, voluntary participation, and policy for withdrawal from the study. Finally, it included consent with the signature of the caregiver or both the caregiver and the adolescent in case of the assent form.

All members of the research team have completed the CITI Collaborative Institutional training required to conduct research involving human subjects.

CHAPTER 4: RESULTS

This chapter presents the results of the research project with the objectives of: I) assessing the level of adherence among adolescents with T1DM in Qatar and its relationship with glycemic control and, II) exploring the barriers/strengths to adherence from the perspectives of adolescents and their caregivers. The results are presented separately for the two phases of the study as in the methods section above.

4.1. Phase I: Assessment of adherence and its association with glycemic control

4.1.1. Demographic and clinical characteristics of the study population

A total of 216 patients were included in the study. The demographic characteristics of adolescents are presented in Table 3. The median age of adolescents was 14.2 years and most of them were in the age category of 12-15 years (71.8%). The gender distribution was almost equal with a slightly higher percentage of female patients (52.3%). The majority were Qatari nationals (60.2%) and did not have a family history of diabetes (71.8%). The median body mass index (BMI) of adolescents was 22.2 kg/m^2 and most of them were within the normal BMI range of 18.5-24.9 kg/m^2.

The clinical characteristics of participants are summarized in Table 4 below. The median duration of diabetes was 5.0 years with the majority ranging from 1-5 years (60.3%). The majority of patients were using multiple daily injections as the insulin delivery method (75.8%) and only few had other comorbidities, with 8.3% having thyroid disease. In terms of diabetes complications, eight patients had nephropathy and two patients had retinopathy.

The median HbA1c was 9.3% with only 14 patients (7.3%) achieving the HbA1c target of <7% (Table 4).

Table 3. Demographic Characteristics of Adolescents with Type 1 Diabetes Mellitus in Qatar (N=216)

Variable	**Total n**	**n (%)**	**Median (IQR)**
Age (years)	216		14.2 (3.0)
Age category (years)	216		
12-15		155 (71.8)	
16-18		61 (28.2)	
Gender	216		
Male		103 (47.7)	
Female		113 (52.3)	
Nationality	216		
National		130 (60.2)	
Non-National		86 (39.8)	
Family history of diabetes	216		
Yes		61 (28.2)	
No		155 (71.8)	
Weight (kg)	216		58.4 (21.0)
Height (cm)	214		159.0 (12.5)
BMI (kg/m^2)	214		22.2 (7.0)
BMI category (kg/m^2)	214		
Underweight <18.5		44 (20.6)	
Normal weight 18.5-24.9		104 (48.6)	
Overweight 25-29.9		44 (20.6)	
Obese ≥30		22 (10.3)	

BMI: Body Mass Index

4.1.2. Adherence assessment

Data on BGMF were available for 193 patients. The median of the average BGMF per day was 3.0 (checks/day), and the majority of adolescents (59.1%) checked less than four times per day, those who checked less than 4 times/day were considered to be non-adherent. Adherence rate (adolescents who checked ≥4 times/day) was found to be around 40 % (Table 4).

Table 4. Clinical Characteristics of Adolescents with Type 1 Diabetes Mellitus in Qatar (N=216)

Variable	Total n	n (%)	Median (IQR)
Duration of diabetes (years)	214		5.0 (6.0)
Duration of diabetes category (years)	214		
1-5		129 (60.3)	
6-10		63 (29.4)	
>10		22 (10.3)	
Insulin delivery method	215		
Pump		52 (24.2)	
Injections		163 (75.8)	
Comorbidities*	216		
Thyroid disease		18 (8.3)	
Mental disorder		2 (0.9)	
Epilepsy		2 (0.9)	
Pulmonary disease		1 (0.5)	
Diabetes complications*	216		
Nephropathy		8 (3.7)	
Neuropathy		0 (0)	
Retinopathy		2 (0.9)	
Cardiovascular		0 (0)	
Vitals	216		
Systolic blood pressure (mmHg)			112.0 (15.0)
Diastolic blood pressure (mmHg)			72.0 (12.0)
Heart rate (bpm)			91.0 (20.0)
Lipid profile	147		
Total cholesterol (mmol/L)			4.7 (1.2)
Low-density lipoprotein (mmol/L)			2.7 (0.9)
High-density lipoprotein (mmol/L)			1.5 (0.5)
Triglycerides (mmol/L)			0.8 (0.7)
Thyroid function	211		
Thyroid stimulating hormone (mIU/L)			2.0 (1.6)
Free T4 (pmol/L)			11.5 (2.2)
Kidney function			

Table 4. Clinical Characteristics of Adolescents with Type 1 Diabetes Mellitus in Qatar (N=216)

Variable	**Total n**	**n (%)**	**Median (IQR)**
Creatinine (µmol/L)	190		50.0 (19.3)
Blood urea nitrogen (mmol/L)	194		4.2 (1.7)
Vitamin D (ng/ml)	207		50.0 (28.0)
HbA1c at time of BGMF data collection (%)	192		9.3 (2.8)
HbA1c at time of BGMF data collection category	192		
<7% (controlled)		14 (7.3)	
≥7% (uncontrolled)		178 (92.7)	
Average BGMF/day (checks/day)	193		3.0 (4.5)
Average BGMF/day category (checks/day)	193		
<4 (non-adherent)		114 (59.1)	
≥4 (adherent)		79 (40.9)	

*Multiple option response
HbA1c: Hemoglobin A1c; BGMF: Blood Glucose Monitoring Frequency

4.1.3. Effect of demographic and clinical characteristics on adherence

Table 5 summarizes the effect of demographic and clinical characteristics on adherence. The percentage of non-adherent adolescents was higher in the age group of 16-18 years compared to 12-15 years (65.5% vs 56.5% respectively), however, this difference was not statistically significant (*P*-value=0.255). The median of the average BGMF per day was higher among adolescents aged between 12-15 years compared to those aged between 16-18 years (3.0 checks/day vs 2.0 checks/day respectively), and this difference was statistically significant (*P*-value=0.033).

Females had a slightly higher percentage of non-adherence (64.4%) compared to males (53.3%), however this difference was not significant (*P*-value=0.117). The nationality and the duration of diabetes had almost no effect on adherence. Adolescents using multiple daily injections showed higher percentage of adherence compared to those using an insulin pump (42.8% vs. 36.2% respectively), but this difference was not significant (*P*-value=0.425). Patients who were underweight (BMI<18.5) showed higher levels of adherence (51.4%) compared those who were not underweight (38.8% - 40.0%), but this difference was not significant.

4.1.4. Effect of demographic and clinical characteristics on glycemic control

The effects of demographic and clinical characteristics on glycemic control are presented in Table 6. The age category and the gender had no effect on glycemic control (*P*-value=1.0 and 0.473 respectively). Qatari nationals had a higher median HbA1c of 9.7% compared to non-nationals (9.7% vs 8.9% respectively) and this difference was significant (*P*-value=0.001). Adolescents using insulin pumps had significantly lower median HbA1c of 8.9% compared to patients using multiple daily injections (9.6%) (*P*-value=0.008). As the duration of diabetes increased, the glycemic control worsened but this was not significant statistically (*P*-value=0.243). Moreover, 100% of obese adolescents had uncontrolled diabetes, and this percentage of adolescents with uncontrolled diabetes was lower for lesser BMI categories, but this difference was not significant (*P*-value=0.354).

Table 5. Effect of Demographic and Clinical Characteristics on Adherence among Adolescents with Type 1 Diabetes Mellitus in Qatar

Variable	**Total n***	**Adherent** (≥4 checks/day) **n (%)**	**Non-adherent** (<4 checks/day) **n (%)**	***P*-value** [a]	**Average BGMF/day Median (IQR)**	***P*-value**[b, c]
Age category (years)	193			0.255[a]		**0.033[b]**
12-15		60 (43.5)	78 (56.5)		3.0 (4.0)	
16-18		19 (34.5)	36 (65.5)		2.0 (3.5)	
Gender	193			0.117[a]		0.167[b]
Male		43 (46.7)	49 (53.3)		3.0 (5.1)	
Female		36 (35.6)	65 (64.4)		2.9 (3.2)	
Nationality	193			0.920[a]		0.679[b]
National		47 (41.2)	67 (58.8)		3.0 (4.6)	
Non-national		32 (40.5)	47 (59.5)		2.9 (3.2)	
Family history of diabetes	193			0.535[a]		0.982[b]
Yes		21 (37.5)	35 (62.5)		3.0 (3.0)	
No		58 (42.3)	79 (57.7)		3.0 (4.6)	
Insulin delivery method	192			0.425[a]		0.856[b]
Pump		17 (36.2)	30 (63.8)		3.0 (2.8)	
Injections		62 (42.8)	83 (57.2)		3.0 (4.7)	
Duration of diabetes (years)	191			0.947[a]		0.982[c]
1-5		45 (40.5)	66 (59.5)		3.0 (4.2)	
6-10		26 (41.9)	36 (58.1)		3.0 (3.5)	
>10		8 (44.4)	10 (55.6)		3.0 (4.5)	
BMI category (kg/m^2)	191			0.594[a]		0.457[c]
Underweight <18.5		19 (51.4)	18 (48.6)		4.0 (6.8)	
Normal weight 18.5-24.9		38 (38.8)	60 (61.2)		3.0 (4.1)	
Overweight 25-29.9		14 (38.9)	22 (61.1)		2.6 (3.8)	
Obese ≥30		8 (40.0)	12 (60.0)		2.0 (4.0)	

[a]Pearson Chi-square test, [b]Mann-Whitney U test and [c]Kruskal-Wallis test were used to compute the *p*-values

BGMF: Blood Glucose Monitoring Frequency; BMI: Body Mass Index

*Total n represents participants whom we have data on their BGMF

Table 6. Effect of Demographic and Clinical Characteristics on Glycemic Control among Adolescents with Type 1 Diabetes Mellitus in Qatar

Variable	**Total n***	**Controlled** (<7%) **n (%)**	**Uncontrolled** (≥7%) **n (%)**	***P*-value**[a,b]	**HbA1c Median (IQR)**	***P*-value**[c,d]
Age category (years)	192			1.000[b]		0.633[c]
12-15		10 (7.2)	128 (92.8)		9.3 (2.6)	
16-18		4 (7.4)	50 (92.6)		9.6 (2.8)	
Gender	192			0.473[a]		0.908[c]
Male		8 (8.7)	84 (91.3)		9.5 (2.6)	
Female		6 (6.0)	94 (94.0)		9.2 (2.9)	
Nationality	192			0.075[a]		**0.001**[c]
National		5 (4.5)	107 (95.5)		9.7 (3.3)	
Non-national		9 (11.3)	71 (88.8)		8.9 (2.8)	
Family history of diabetes	192			0.357[b]		0.238[c]
Yes		2 (3.6)	53 (96.4)		9.7 (3.0)	
No		12 (8.8)	125 (91.2)		9.2 (2.7)	
Insulin delivery method	191			0.750[b]		**0.008**[c]
Pump		4 (8.5)	43 (91.5)		8.9 (1.8)	
Injections		10 (6.9)	134 (93.1)		9.6 (3.2)	
Duration of diabetes (years)	191			0.070[b]		0.243[d]
1-5		12 (10.8)	99 (89.2)		9.2 (3.1)	
6-10		1 (1.6)	61 (98.4)		9.3 (2.1)	
>10		1 (5.6)	17 (94.4)		10.6 (2.5)	
BMI category (kg/m^2)	191			0.354[b]		0.354[d]
Underweight <18.5		4 (10.8)	33 (89.2)		9.4 (3.1)	
Normal weight 18.5-24.9		9 (9.1)	90 (90.9)		9.2 (3.0)	
Overweight 25-29.9		1 (2.9)	34 (97.1)		9.3 (2.9)	
Obese ≥30		0 (0)	20 (100)		9.8 (1.7)	

[a]Pearson Chi-square test, [b]Fisher's Exact test, [c]Mann-Whitney U test and [d]Kruskal-Wallis test were used to compute the *p*-values

BMI: Body Mass Index; HbA1c: Hemoglobin A1c

*Total n represents participants whom we have data on their HbA1c

4.1.5. Effect of adherence on glycemic control

Table 7 summarizes the effect of adherence on glycemic control. Among adolescents with T1DM in Qatar, 12.8% of adherent adolescents (≥4 checks/day) had controlled HbA1c levels (<7%) whereas 96.4% of non-adherent adolescents (<4 checks/day) had uncontrolled HbA1c levels (≥7%) (*P*-value=0.016). The median HbA1c for adherent adolescents was 9.7% whereas the median HbA1c of non-adherent adolescents was 9.0%, and this difference was significant (*P*-value=0.002).

Table 7. Effect of Adherence on Glycemic Control among Adolescents with Type 1 Diabetes Mellitus in Qatar

Variable	**Total n***	**Controlled** (<7%) **n (%)**	**Uncontrolled** (≥7%) **n (%)**	***P*-value**^{a}	**HbA1c Median (IQR)**	***P*-value**^{b}
Adherence (Average BGMF/day)	191			**0.016**^{a}		**0.002**^{b}
Adherent (≥4 checks/day)		10 (71.4)	68 (38.4)		9.7 (2.95)	
Non-adherent (<4 checks/day)		4 (28.6)	109 (61.6)		9.0 (2.55)	

^{a}Pearson Chi-square test and ^{b}Mann-Whitney U test were used to compute the *p*-values
HbA1c: Hemoglobin A1c; BGMF: Blood Glucose Monitoring Frequency
*Total n represents participants whom we have data on their HbA1c and BGMF

4.1.6. Relationship between adherence and glycemic control

The association between adherence and glycemic control was assessed using Spearman rho test and the correlation coefficient r_s was -0.325 (*P*-value=0.000) pertaining to a weak significant negative correlation (Table 8).

Table 8. Correlation Between Adherence and Glycemic Control among Adolescents with Type 1 Diabetes Mellitus in Qatar

Variable	**Total n***	**Correlation Coefficient r_s**	***P*-value**[a]
Adherence (Average BGMF/day) **vs** **Glycemic Control (HbA1c)**	191	-0.325	**0.000**[a]

[a] Spearman's rho test was used to compute the *p*-value
HbA1c: Hemoglobin A1c; BGMF: Blood Glucose Monitoring Frequency
*Total n represents participants whom we have data on their HbA1c and BGMF

The results of the univariate binary logistic regression are presented in Table 9. The findings indicate that "adherence" was the only independent variable that had a significant effect on glycemic control. For instance, non-adherent adolescents (<4 checks/day) were 75% less likely to have controlled diabetes (HbA1c <7%) compared to adherent adolescents (≥4 checks/day) (OR=0.25, 95%CI=0.075-0.827, *P*-value=0.023). Some other variables also fulfilled the statistical requirements for inclusion into the multiple regression model including nationality, family history of diabetes, duration of diabetes, and BMI category with *P*-values <0.25.

The combined effects of the determinants of glycemic control among adolescents with T1DM that were included in the multiple regression model were able to explain around 9% of the variances in glycemic control. However, "adherence" was the only variable that had a significant effect on glycemic control such that non-adherent adolescents (<4 checks/day) were 78% less likely to have controlled diabetes (HbA1c <7%) compared to adherent adolescents (≥4 checks/day) (OR=0.221, 95%CI= 0.063-0.778, *P*-value=0.019) (Table 10).

Table 9. Univariate Binary Logistic Regression of the Determinants of Glycemic Control among Adolescents with Type 1 Diabetes Mellitus in Qatar

				95% CI for Exp (B)		
Variable	**Total n***	**B**	**Exp (B)**	**Lower**	**Upper**	***P*-value**
Adherence (Average BGMF/day)	191	-1.388	0.250	0.075	0.827	**0.023**[a,**]
≥4 (adherent)						
<4 (Non-adherent)						
Age category (years)	192	-0.024	0.977	0.293	3.258	0.969[a]
12-15						
16-18						
Gender	192	0.400	1.492	0.497	4.476	0.475[a]
Male						
Female						
Nationality	192	-0.998	0.369	0.119	1.145	0.084[a,**]
National						
Non-national						
Family history of diabetes	192	0.934	2.544	0.550	11.761	0.232[a,**]
Yes						
No						
Insulin delivery method	191	0.220	1.247	0.342	4.177	0.721[a]
Pump						
Injections						
Duration of diabetes (years)	191	1.265	3.544	0.956	13.139	0.058[a,**]
1-5						
> 5						
BMI category (kg/m^2)	191	1.742	5.707	0.728	44.733	0.097[a,**]
< 25 (underweight and normal)						
≥ 25 (overweight and obese)						

[a] Univariate Binary Logistic Regression test was used to compute the *p*-values

BMI: Body Mass Index; BGMF: Blood Glucose Monitoring Frequency

*Total n represents participants whom we have data on their HbA1c

**Significant *P*-values that qualify to the multiple regression model (*P*-value <0.25)

Table 10. Multiple Binary Logistic Regression of the Determinants of Glycemic Control among Adolescents with Type 1 Diabetes Mellitus in Qatar

Variables	Total n*	B	Exp (B)	95% CI for Exp (B) Lower	Upper	*P*-value
Adherence (Average BGMF/day)	189	-1.509	0.221	0.063	0.778	**0.019**
≥4 (adherent)						
<4 (Non-adherent)						
Nationality		-0.981	0.375	0.113	1.248	0.110
National						
Non-national						
Family history of diabetes		-0.766	2.150	0.439	10.538	0.345
Yes						
No						
Duration of diabetes (years)		1.322	3.750	0.959	14.657	0.057
1-5						
> 5						
BMI category (kg/m^2)		1.565	4.783	0.579	39.483	0.146
< 25 (underweight and normal)						
≥ 25 (overweight and obese)						

[a]Multiple Binary Logistic Regression test was used to compute the *p*-values
BMI: Body Mass Index; BGMF: Blood Glucose Monitoring Frequency
*Total n represents participants whom we have data on all the variables
Cox & Snell R Square =0.092

4.2.Phase II: Barriers and strengths to adherence from the perspectives of adolescents and their caregivers

4.2.1. Participants' characteristics

Semi-structured interviews were conducted with adolescents with T1DM and their caregivers in Qatar. A total of 14 caregivers and 10 adolescents with T1DM were interviewed between July and November 2020. Four male adolescents and six female adolescents were interviewed from different nationalities (Table 11). All caregivers were from the mother's category mainly because mothers are usually the primary caregivers in Qatar. Adolescent's age ranged from 12-17 years with an average of 13.95 ± 1.8 years. The average duration of diabetes among the participants was 5.75

± 3.6 years. Table 11 presents the characteristics of adolescents with T1DM and their caregivers who participated in the semi-structured interviews.

Table 11. Characteristics of Adolescents with T1DM and their Caregivers who Participated in the Semi-structured Interviews about Barriers and Strengths to Diabetes Adherence in Qatar.

Caregiver's code	**Caregiver's gender**	**Adolescent's code**	**Adolescent's gender**	**Caregiver's and adolescent's nationality**	**Adolescent's age (years)**	**Duration of diabetes for adolescent (years)**
C1	F	K1.a	F	Egyptian	14	3
		K1.b	F	Egyptian	16	8
C2	F	K2	F	Egyptian	16	6
C3	F	-	-	-	-	-
C4	F	-	-	-	-	-
C5	F	K5	M	Egyptian	13	3
C7	F	K7	M	Egyptian	17	11
C8	F	-	-	-	-	-
C9	F	-	-	-	-	-
C10	F	-	-	-	-	-
C12	F	K12	M	Qatari	12	4
C13	F	K13	M	Qatari	14	12
C14	F	K14	F	Sudanese	12	1
C15	F	K15	F	Qatari	12.5	4.5
C16	F	K16	F	Egyptian	13	5

T1DM: Type 1 Diabetes Mellitus; F: Female; M: Male

4.2.2. Themes generated from the interviews

Five major themes emerged from the interviews: (1) patient-related factors/influencers, (2) societal influence, (3) medication and device-related factors, (4) healthcare system-related factors and, (5) lifestyle, school, and environment-related factors. The themes, subthemes, and codes are summarized and presented in Table 12.

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes	Codes	
Theme 1: Patient-related factors/influencers	Patient's characteristics	*Age*	• Age of diagnosis – older has no effect • Age older the better • Age younger the better
		Gender	• Boys more stubborn and difficult to control
		Duration of diabetes	• Duration has no effect • Duration the longer the better
		Previous lifestyle	• Previous lifestyle impacting adherence to diet • Usual eating style
		Hormones	• Hormonal disturbances
	Patient's perceptions, attitudes, and psychological factors	*Perceptions*	• Not accepting the disease • Feeling of misdiagnosis • Denial about diabetes • Resistant to taking insulin • Denial of adolescence and missing childhood • Feeling "overly normal" • Feeling different • Feeling restricted • Afraid of weight gain • Caring about body shape • Motivation through encouraging good body shape • Thinking about acceptance of the other gender
		Attitudes and attributes	• Laziness • Stubborn • Boredom • Being tired • Being busy

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	**Subthemes**	**Codes**
		• Embarrassment • Forgetting • Forgetting supplies • Ignoring • Strong personality
	Psychological factors	• Bad mood • Psychological stress • Impact of psychological status • Emotional support • Physically and emotionally exhausted • Stress • Previous insecurities in addition to diabetes affecting psychology
	Patient’s knowledge and experiences	• Difficulty in applying knowledge • Lack of knowledge • Lack of experience • Recognizing the risk • Knowledge • Knowledge and experience • Learning through experience • Knowing the complications • Knowing the complications as a deterrent • Understanding insulin • Experience with diabetes
	Coping strategies	• Prioritizing diabetes • Setting alarms

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	**Subthemes**		**Codes**
			• Setting system • Adapting to the situation • Viewing diabetes not as an obstacle • Making self busy • Coping with diabetes • Diabetes as a lifestyle • Knowing the reward • Having fixed routine • Carrying supplies as a source of feeling secured • Controlled diabetes promoting adherence • Seeing other patients with worse cases • Seeing other successful diabetics
Theme 2: Societal influence	Parental and family influence	*Relationship and support*	• Parents' pressure • Parents yelling • Strict follow up • Relationship with father • Parents giving orders • Father unable to help • Family support • Letting go sometimes • Support and motivation • Avoid clashes • Firm and soft • Taking things easy • Follow up without pressure • Share tasks

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes		Codes
			• Parents’ motivation • Motivation by reward • Conflicts solved by discussions • Acceptance and understanding • Trust • Motivational talks • Holding him accountable for his actions • Setting rules • Making available healthy alternatives • Supporting her independence • Involvement of other family members siblings • Respecting privacy • Importance of follow up
		Parent-specific factors	• Busy parents • Being over stressed • Parent’s phobia of injections • Parents tired • Parents worry • Uneducated family members (illiterate) • Parent being a role model • Awareness of family members
	Community influence	*Peer support*	• Friends acting as guardians/special treatment • Going out with friends • Lack of knowledge by family and friends • Feeling burden on friends when they go out • Personal preference about friends’ support

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes		Codes
			• Friends' relationship and its effect • Friends support
		Population awareness and stigmatization	• Showing device • Telling others that she has diabetes • Checking in front of others • Injecting in front of others • People asking questions • Friends asking questions • People unfamiliar with the pump
	Support from other patients with diabetes		• Comparison to other patients with diabetes in the family • Support from parents of other patients with diabetes • Gathering with other patients with diabetes • Influence of camp • Support of other patients with diabetes in the family • Seeing other successful patients with diabetes • Diabetes in common strengthened the relationship between siblings • Seeing other patients with diabetes • Learning with other patients with diabetes • Seeing complications on other patients with diabetes • Recommendations, support group for newly diagnosed • Recommendations, support groups
Theme 3: Medication and	Insulin-related factors		• Injection phobia • Injection frequency

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes	Codes
device-related factors		• Injection site bruises • Injection site pain • Injection site swelling • Insulin acting differently • Insulin causing weight gain • Insulin resistance • Taking injections • Tasks are time consuming • Using insulin pens requires many steps • Lantus causing burning sensation • High insulin doses causing hunger
	Device-related factors	• Pump heavy • Accessories not available in other countries • Adherence to exercise • Sensor falling • CGM alarm at night • Attaching wires • Pump restricting movement • Pump not fixed well • Pump alarm annoying • Pump leaving marks on body • Pump preventing her to wear what she wants • Pump cannula blocked • Pain using glucometer • Sensor causing allergic reaction • Sensor falling out during swimming

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	**Subthemes**	**Codes**
		• Pump attached restricting daily activities • Swimming with the pump • Long process to change the set • Using pump • Finding solutions to carry pump easily • Pump easier than pen • Sensor making adherence easier • Pump alarm
Theme 4: Healthcare system-related factors	Healthcare provider-related factors	• Busy doctors • Busy schedules for counselors • Doctor advices not personalized • Healthcare provider assuming lack of adherence due to carelessness • Healthcare provider communication barrier • No close follow up with case due to long time between appointments • Healthcare provider no relationship • Healthcare providers from a different culture • Healthcare providers not all following the same strategy • Healthcare providers not considering psychological factors • Healthcare providers not providing emotional support • White coat adherence • Healthcare provider-adolescent relationship • Healthcare provider support by reward

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes	Codes
		• Healthcare provider discussing not ordering • Healthcare provider accessible • Healthcare providers including patients/caregivers in decision making • Healthcare providers have positive impact • Healthcare provider having personal experience with diabetes
	Counselling and educational aspects	• Diabetes education • Diabetes education not making use of technology • Diabetes educational not detailed • Strengths diabetes education • Education from experts as a motivation • Recommendations educating adolescents • Recommendations educational videos by SIDRA as a trusted source of information • Recommendations workshops for parents and adolescents • Recommendations practical workshops • Support group in the presence of professionals
	System and administrative factors	• Appointment few • Appointments far • No agents available for devices bought online • Long waiting list for the pump • Lack of support groups • Healthcare system dealing with diabetes emergencies • Different protocols in different countries

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes	Codes
		• Some supplies not available in Qatar (Omnipod) • Healthcare system in Qatar is good • Easy access to healthcare and medications • Appointments enough • Availability of medications • Recommendation, fixed appointments with psychologist and dietician
	Cost associated with care	• Cost exercise • Cost expensive • Expensive healthy alternatives • More than one kid with diabetes in the family • Cost not always affordable • Cost of other illnesses • No insurance coverage • Cost affordable and subsidized • Cost free • Cost insulin subsidized from the country • Subsidized medications and doctor visits
	Sources of information	• Not interested to look for new information • Sources of information • Easy access to information • Sidra as trusted source of information
Theme 5: Lifestyle, school, and environment-related factors	Educational institution-related factors	• Break time spent with the nurse • School friends sharing food • Lack of knowledge about diabetes • Not respecting privacy

Table 12. Themes, Subthemes and Codes Related to Barriers and Strengths to Adherence among Adolescents with T1DM in Qatar

Themes	Subthemes	Codes
		• School nurse not updated • School nurse only follow instructions • School nurse sometimes not available • School preventing her from activities • School teachers lack knowledge • School nurse support • School nurse cooperative • School cooperation • Having a system at school • Healthy society in school
	Environmental and lifestyle-related factors	• Healthy alternatives not readily available • Gym or club do not have medical support in cases of diabetes emergencies • Unhealthy food advertisements everywhere • Hot weather • Options available on food applications are not healthy • Scheduling adolescents with men causing embarrassment for the mothers • Dietary habits of the country • Emergency situations during travel

4.2.2.1. Theme 1: Patient-related factors/influencers

Patient's characteristics: This subtheme emerged widely throughout the interviews and it incorporated several codes related to age, gender, duration of diabetes, previous lifestyle, and hormonal changes.

Age: Age of diagnosis was considered a crucial factor affecting adherence in adolescents with diabetes. Adolescents and caregivers had conflicting opinions about the direction of the effect. Some participants indicated that older age of diagnosis is better in terms of adherence, whereas others indicated that the younger the adolescents, the better their adherence to medication and self-care activities. Conversely, some participants believed that adherence in adolescents is not related to age.

> *"Yes definitely, children who are diagnosed from 1 to 8 years old, all what they think of and want is to eat ice cream and chocolate, they can't understand that eating those things will affect them. Unlike older children at age of 12 for example, they can understand how harmful eating these things would be. So, the age of diagnosis makes a lot of difference in adherence to treatment. Diabetic children under the age of 5, their mothers would be completely responsible of everything which is very difficult for them [mothers]." C4.*

> *"If it is at the adolescence age, 11 years or above, I think adherence to treatment and following up the treatment would be very bad because when she was young, I tell her to take this and not to take*

> *that, she would obey the orders and say ok. “This is good for your health, come and see these videos”, so it affected her. But you know in the teenage years, they are resistant to everything and they don’t consider any other opinion other than their own. So, of course the situation would differ.” C16.*

> *“I don’t think so, because it [adherence] is related to getting used to the treatment. If I was 12 or 13 or 14 years old, after the same 9 months, I would be able to do the tasks like calculating and taking the insulin and testing the glucose level. I was diagnosed at the age of 11 and I did learn how to do the tasks by myself.” K5.*

Gender: One caregiver indicated that gender could have an impact on adherence such that boys are usually more difficult to control compared to girls.

> *“Yes, it is difficult at this age to accept any information even in normal life situations, so how about a health issue? It is even more difficult for families who have a boy with diabetes as they are more stubborn, and it is more difficult to control them.” C2.*

Duration of diabetes: Participants indicated that as the duration of diabetes increases, the knowledge associated with the disease and its management also increases and it becomes a routine. However, they also stated that this longer duration comes with periods of boredom and tiredness, which negatively impacts adherence to treatment and lifestyle modification.

> *“At the beginning, when I was recently diagnosed, I wasn’t used to it [diabetes], but at the same time I was caring about it, as I had no idea about the consequences of not adhering. But now I feel that I’m more adherent because I understand it better, since I’m diabetic for 8 years now, so almost a decade. So I got used to it as a part of my lifestyle. Even now if it went away, I think that I will be confused because I got used to it.” K1.b.*

> *“Mmm both, yes it [adherence] becomes a routine and everything but still he gets bored. Even us as parents we sometimes feel that we got tired and bored and our psychological status is destroyed. So, both are possible as the duration increases, it’s a routine in my life but I got bored from it.” C5.*

Previous lifestyle: Usual dietary habits were perceived to affect adherence to diet. Adolescents who tended to have previous unhealthy dietary habits would have more difficulty adhering to a healthy diet after being diagnosed with diabetes mellitus.

> *“[Daughter] likes to have snacks all the time, and it is not like she likes to eat a lot of food, but rather she likes foods that are high in carbs, and this is kind of a problem.” C3.*

> *“And unlike her siblings, [daughter] did not prefer healthy food, so, we faced many psychological issues during the last period*

> *especially the last couple of months. She was different than her siblings and she did not like healthy food at all." C10.*

> *"For me it is not possible that you find Nutella or Tahini Halawa and eat it with a spoon. This is not acceptable at all even before the diagnosis. But I imagine if no one was diabetic in the house and they were living this [unhealthy] lifestyle, then after the diagnosis it would be extremely difficult. It would be a suffering. She would come saying: 'this is the only thing she eats, she only eats corn flakes on breakfast' 'Nutella sandwich is a must on breakfast' or 'Halawa sandwich is a must on breakfast of course', what would you do then? It would be difficult." C3.*

Hormones: Some caregivers identified hormonal disturbances as a barrier to diabetes adherence with two different dimensions. First, hormonal disturbances upon menstruation were perceived to affect psychology resulting in changes in attitudes towards adherence. Moreover, hormonal disturbances associated with puberty were thought to affect glycemic control requiring more attention.

> *"No, nothing happened, but I associated that [attitude of non-adherence] with the start of her period [menstrual cycle]. Since her period started, her behavior towards everything has changed, not only regarding diabetes."* C14.

> *"For the problems, the adolescence itself comes with difficulties. She is not yet into puberty but up to my knowledge, this phase comes with many hormonal disturbances and this increases the glucose level, so you have to change a bit in the doses, you might need to inject more. Those are the problems that I know about when it comes to diabetics. This hormonal disturbance is a problem and it needs more control."* C10.

Patient's perception, attitude, and psychological factors:

Perceptions: Participants had varying perceptions with regards to disease acceptance, appearance, feeling different, and acceptance of the other gender. Many participants indicated that adolescents pass through phases of denial of the disease, feeling that they are normal, and this impacted adherence negatively. Conversely, others indicated that feeling "overly normal" impacts adherence negatively such that they blend completely to the society forgetting that they are committed to certain tasks.

> *"She [daughter] says, 'I feel I do not have diabetes'. Sometime, and I know this is wrong, I feel that she does not have diabetes. For example, 2 days ago, I was busy with the baby, so, I told her '[daughter], inject 3 units by yourself'. But she did not take it, she said that she forgot, but I think she intentionally did not take insulin. She ate noodles with milk, which has sugar and milk. She ate too much until satiety. I was scared because this was carbs and sugar. When she said that she forgot, I was scared. However, when I*

> *checked the sugar, it gave me 93. I expected it to be 350, but I found it 93. So, she jumped from happiness and said, 'look, didn't I tell you! I do not have diabetes. I ate a lot from it' (laughter). So, I did not know how to respond to her." C14.*

> *"To be completely honest with you, many times [daughter] might say I don't have diabetes, and I discover that she didn't take her insulin dose all day long." C3.*

> *"[Daughter] for example, because we always keep telling her that she is a normal girl, and that the only difference between her and other kids is that she takes insulin and so on, this makes her forget to take the insulin, forget to check before taking the insulin despite reminding her several times. So, while we are trying to blend her with the society, she sometimes forgets, or her gut feeling tells her that she is normal." C16.*

> *"I am not able to accept that treatment at all and there is nothing that can make me happy that I have this disease." K14.*

Many adolescents tend to care about their appearance, weight and body shape. Having said that, participants indicated that caring about maintaining a good body shape was a strength towards improved adherence. However, being afraid of weight gain to the extent of following an extreme diet was perceived as a barrier to adherence among adolescents with diabetes.

> "*As adolescents, [daughter] cares about her look and appearance and what she wears. So, she always wants her appearance to be good. 'I don't want to gain weight and I want to take care of my health through healthy eating and exercising'. She doesn't believe that diabetes could be a barrier for her to live a normal life, but she knows that the lifestyle including the diet and exercise makes a difference." C16.*

> *"… but as she grew up, she became more aware that it is better to adhere to healthy diet, and she started handling her issues to the extent that she sometimes gets ketones due to low carbohydrates. She reaches a stage of diet that she does not want to eat a lot, so that she will not gain weight, so, the amount of carbohydrates [that she takes] is not enough for her body." C2.*

Many caregivers indicated that adolescents feel different among their peers and surroundings and this feeling could lead to worse adherence. Adolescents also admitted feeling different and restricted in performing some daily activities such as eating and taking a shower because of diabetes.

> *"… but many times she [daughter with diabetes] could come to me saying, or [son with diabetes] could come saying: 'my lunch box is different from that of my friends, you are depriving me from…'. He feels that I am the one depriving him from that specific thing." C3.*

“ For example, normal people around us can eat a whole bar of chocolate, for example Galaxy (brand of chocolate), but I’m only able to eat 2 or 3 pieces not the whole bar, and this is not enough for me, I want to eat the whole bar. This was a problem for me during certain period of my life and I could see it in many people around me. Even when I go to the doctor, I also find people with diabetes younger than me facing this problem with their families. They want to eat sweets and their families do not want to them to eat sweets as they worried about them.” K2.

“Yes, because here [at home], he lives with individuals that are different from him. When he goes to school, he is different. When he meets his friends and family, he is different. He does not find anyone like him. Therefore, this fact [going to diabetes camp] was a milestone in his [son] life and his psychology.” C12.

“For example, I do not prefer for her to take a shower while the pump is working, so, she has to wait until the reservoir is empty so that she would be able to take a shower, and it takes 3 or 4 days for the reservoir of the pump to be empty which she does not like. I feel that when we change the cannula, remove the pump, close the cannula, and then she takes a shower, the cannula will be blocked. This makes her feel bored as she feels that she is restricted and unable to even take a shower.” C8.

Furthermore, one caregiver mentioned that teenagers would start thinking about whether they would be accepted by the opposing gender as they are, or diabetes would be a barrier.

> *“As I mentioned before by supporting her and talking to her, everything becomes better. You know that she is a teenager and she will start to think about the other gender and if they would accept her with diabetes or not.” C2.*

Attitudes and attributes: Many participants addressed factors related to various attitudes and attributes including being busy, lazy, ignorant, and forgetfulness. They also discussed how those factors impacted adherence to medications and other self-care tasks negatively.

> *“Yes, I am telling you, being lazy, ‘I forgot’. That’s the answer. All the time she tells ‘sorry I forgot’. That’s the answer for… always when I ask her ‘why didn’t you check?’, she tells me ‘sorry mom I forgot’. ‘Ok eat and after 2 hours check’. I call and ask again ‘did you check?’ she says, ‘no sorry I forgot’. So, that is a barrier to adherence.” C16.*

> *“I don’t have any problem except one problem which is that I always forget, and I always ignore the device [pump] when it alarms. But since I was admitted to the ICU for the second time, I tried to pay more attention to the device.” K13.*

> *“Sometimes I go out with my friends to have lunch or dinner and I forget my insulin at home. I feel lazy to go back home to get it and then come back to my friends. I used to eat my food with them and then take my insulin when I go back home.” K5.*

Additionally, issues related to being tired, stubborn, bored, and embarrassed have emerged widely among caregivers and adolescents. All those factors were perceived as barriers to diabetes adherence.

> *“Lately he has become… like sometimes his glucose level is high, like 150, and usually he has to wait at least 15 minutes after injecting before he eats. So sometimes you know, I do not know is it stubbornness or what at that age, so he asks ‘why do you want me not to eat, no its good 160 or 170, its ok’ I tell him that when he will eat it will become 200 or 250, but he also refuses. So over all dealing with him became more difficult not only with diabetes.” C5.*

With this regard, sometimes adolescents and their caregivers had conflicting views to reasons behind lack of adherence. For example, a caregiver perceived non-adherence to a specific task to be an outcome of being stubborn, whereas the adolescent justified that by being tired.

> *“It [stubbornness] has increased. When she was younger, she was a little stubborn, but now she became very stubborn. She*

> *started hearing from one ear and taking it out from the other one. She said if there is no motivation, she will not adhere. It is impossible that she takes care of herself on her own." C15.*

> *"Maybe I didn't like to measure the glucose because I am tired when I come back from school or any place, I am tired." K15.*

Conversely, in other cases, the adolescent confirmed the thoughts of their caregiver about specific behaviors related to diabetes self-care.

> "*… but once or twice, I noticed when he came back that he turned the pump off. It seems that he gets embarrassed in front of the other boys, or that someone told him something regarding why the pump alarms. I think that, but he as a boy will never tell me what is wrong with him, or why he turned the pump off. I asked him, 'did someone annoy you with his words?' He said, 'No. I just turned it off'. Or he sometimes gives other excuses. This issue made me worried." C12.*

> *"Sometimes I feel embarrassed, but I know they [family and friends] will not say anything. Its ok for me if they see the pump." K12.*

Psychological factors: The impact of psychological status on adherence was expressed among almost all participants such that when they feel happy, their adherence to medications and other self-care tasks improve compared to when they are feeling down or upset. Some also indicated that they notice immediate impact on their glucose levels when they have mood alterations.

> *"Yes, it [psychological status] affects adherence and I have personal experience with that. When I get bored, not necessarily depressed, but at that time I feel that I don't want to eat or take injections, I just want to stay in the bed without doing anything. And also, during this period, my blood glucose level becomes affected whether it increases or drops. So, my glucose level itself is affected by my psychological status. But when I am happy, my blood glucose level becomes stable and in the normal range that it should be. I eat my food and I take my insulin, so, I take care of myself." K2.*

> *"My biggest problem with diabetes, which makes me less caring about it, is my mental status." K1.b.*

> *"Yes, it [psychological status] affects adherence. Of course, when she is happy, she brings the balance, weighs, injects and takes [the insulin]. I feel happy with what she is doing. She adheres to treatment especially when we fulfill her requests. For example, if she wants Nutella, her father brings it and that motivates her to adhere. When she is happy from any reason, whether related to food or anything that happens at home, she becomes [adherent]." C14.*

> *“On some days when I am upset, not because of diabetes but another thing, I would for example ignore testing the glucose level or ignore taking the insulin.” K5.*

Patient’s knowledge and experiences:

Adolescents and caregivers indicated that gaining knowledge about diabetes had a great impact on adherence as it helped adolescents recognize the symptoms and the complications of uncontrolled glucose levels. In fact, one adolescent stated that knowledge is the factor that had the highest impact on improving adherence to medications and other self-care activities.

> *“Of course, it [knowledge] will affect adherence to treatment positively. As much as you support her [daughter] with knowledge and information the better. When she reads more and gains more information about it [diabetes], she will be more aware of the importance of adherence. And I always try to make her read articles about diabetes, so, she would be more knowledgeable about diabetes when she grows up.” C10.*

> *“The thing that made my adherence improve the most was knowing about diabetes. At the beginning, I didn’t know anything about diabetes. I felt like a loser. I had some thoughts that I am a loser because I did not know anything about diabetes. As time passed, I learned more about diabetes, and this was a motivation for me, or like one of the reasons that made me adhere to the*

> *treatment is that I have nothing… I know the information that can help me adhere to the treatment, so I need to adhere because I know this information." K5.*

> *"Yes, because I understand it [diabetes] better and my knowledge is bigger. I became aware of the symptoms of hypoglycemia and hyperglycemia, and [the consequences] if I ate something with too much carbs or fats without correcting and so on." K1.b.*

However, one participant indicated that she faced difficulties in applying the knowledge that she gained.

> *"… but it was difficult to apply these things [knowledge] practically at home and to know when and how to increase or decrease the amount of carbohydrates and so on." C4.*

Learning through experience was reported by many participants. Some participants indicated that with experience, their problem-solving skills have improved and their ability to manage difficult situations enhanced. Moreover, a mother of an adolescent who was born with diabetes emphasized that with time, she became more experienced in all tasks related to diabetes to the extent that she can predict doses without exact calculations.

> *"With experience, we did not reach this level except with experience. Last year when we were in Turkey, her blood ketone*

> *was 0.5, and it was during Eid holidays and there was nowhere to go, and my flight was the next day. But by asking and consulting people like [admin of diabetes WhatsApp group], I was able to treat her at home and her ketone level reached 0 despite the stress that we had. I was packing and I was in a strange country, everything was closed, language was different. You know we gain experience by going through crisis. So, after this crisis, I became able to treat her whenever she has ketones at home." C2.*

> *"You know, diabetes is an experience that the person lives, and based on that experience, he tries to fit things in. So, the doctor will not be able to control everything through an appointment every 3 or 4 months, but with experience and trial and error, we [caregiver and adolescent] figure out what is best for us." C5.*

> *"Yes, as it is their life and they learn without recognizing that they are actually learning. She sometimes reduces her meal without weighing and calculates her exact dose of insulin for it. She is able to decide how much she will eat without using a scale, she just uses her prediction to determine. Diabetes is more like a lifestyle for her as she was born with it." C8.*

One adolescent stated that knowing the complications of diabetes and recognizing its risks made him feel that he is ready to take the responsibility of diabetes management and to adhere better. Moreover, the mother of that adolescent confirmed that when her kid knew about the complications of diabetes, he was able to perceive the risk and to look at things from different viewpoints. She also emphasized that knowing the complications might have both positive and negative impact on adolescents depending on their personalities.

> *"The time that I felt that I am most ready to take the responsibility of my diabetes was when I knew about the danger it causes to the eyes and so on. This was the time when I was motivated, and I wanted my blood sugar level to be just right." K7.*

> *"It [the effect of knowing the complications] actually differs from one child to another. You can't generalize it and say that it will negatively affect all children. Some of them will be stubborn and others will be able to think and recognize and look at the aspects that they were not looking at. It was like this with [son], because when we were following up - but this is lately about 2 years ago - we started to follow up with an ophthalmologist and he honestly was the one who talked to him about it and told him the complications." C7.*

However, sometimes, knowing the complications had a negative impact on the psychological status of the kid as narrated by some of the participants. But at other times it was perceived as a harsh decision, yet a must, in order to enhance adherence to medications and other self-care activities among stubborn adolescents.

> *"One of the things that affected him psychologically was when he heard or somehow, he knew that diabetes causes blindness, and that diabetes can lead to amputations of hands or legs. So, he came once full of tears, I told him, 'this is not about you, this is about poor people who cannot afford treatments or those who do not control their blood sugar, or those who eat a lot. I mean, those who always have their blood sugar high". His words touched my heart. I got affected and my eyes were full of tears when I was talking to him." C12.*

> *"Since she was young, I told her all the information about diabetes to be able to get good understanding as she grows up. I even told her the complications of high glucose levels when I felt that she is not complying. That was harsh from me and her dad, but for her benefit. We showed her YouTube videos and pictures so that she gets afraid and to be more compliant." C2.*

Coping strategies:

Prioritizing diabetes was a common strategy that was perceived as a facilitator to adherence. Adolescents who prioritized diabetes were able to overcome many of the obstacles of adherence and to have better adherence compared to adolescents who underestimated its importance.

> *“She [daughter] is busy, busy, and at the same time she considers it [adherence] as an unimportant issue, ‘Don't worry mom, let me enjoy my time’.” K3.*

> *“No, since she was still a kid, we build in her that her life is the most important thing, and she should always care about herself, and she make herself a priority even during hard situations. I clearly told her ‘when I die or your dad die, in the condolences, cry and do whatever you want, but eat and measure your sugar level’. She told me ‘do not say that’. But I wanted to deliver a message that her health is number one.” C2.*

Some coping strategies were related to trying to find solutions for problems that they face, such as setting reminders and alarms to remind them to take their injections and this will overcome the barrier of forgetting medication times. Additionally, making all the supplies available and easily accessible helped adolescents to avoid feeling lazy or busy, hence, it improved their adherence. Having snacks always available for use in cases of hypoglycemia was also perceived as a source of feeling secured.

> *“The Lantus, we had several problems with it, so we set a reminder for it and we can’t ignore taking it. But with the other one [rapid acting insulin], he takes it with the main meals.” C7.*

> *“When I study, I become completely concentrated, so I feel that I do not want to disrupt my thoughts to check on the sensor, so I put everything I might need beside me. So, when the sensor rings, I just move my hands to grab whatever I need instead of interrupting my studies and wasting my time.” K2.*

> *“… but now when he goes out to play or something, he takes his insulin, water and dates or biscuits to eat in case of hypoglycemia. He feels secured when he has his stuff with him.” C4.*

Other adolescents found it useful to see patients with other worse conditions and this made them feel that their disease is a blessing and that they must not give up. Conversely, seeing example of successful patients with diabetes who were able to achieve important things in life was also a facilitator towards improved adherence. Moreover, when adolescents themselves had their glucose levels controlled for a while, this was a motivation for them to continue and to adhere to their regimens.

> “*I always tell him that diabetes doesn’t prevent him from eating whatever he wants. He eats whatever he wants but with injecting, unlike other people with other diseases who are not able to eat anything, and they are being fed through tubes. One day we were out and he didn’t want to eat or inject himself with insulin, and then God sends us a message, we saw a completely disabled girl and her mother is feeding her, and at that time I started crying*

and I told him 'look at her, she is not able even to feed herself', he immediately told me give me the supplies, I will go take my insulin. Alhamdulilah, he is able to move and eat whatever he wants." C4.

"We always thank god that she can be treated inside her home, not at the hospital like many other people who have diseases which need to be treated at the hospitals, and they are unable to go back to their homes and sleep on their beds , and when she is bored I tell her not be bored as long as she is in her home. She only needs to check on her blood sugar and take insulin to eat, and I remind her that God tests us with things we can bear." C8.

"When I make him read stories about a popular football player who is diabetic, or a doctor who has been diabetic since he was young and decided to become a doctor to treat diabetic people, these stories motivate him and have a positive impact on him. They make him believe that diabetes won't be an obstacle to him and won't prevent him from reaching his goals." C4.

"I think that the thing that motivates him the most is when he controls himself for 1 or 2 days, and then he finds that all the readings are controlled, this motivates him to continue." C7.

4.2.2.2. Theme 2: Societal influence

Parental and family influence:

Relationship and support: Participants in this study recognized that some external factors could have an impact on adolescent’s adherence to treatment. A major contributor of adolescent’s adherence is the parental relationship and support. Caregivers and adolescents agreed that their relationship together should be smooth and should avoid conflict and strict follow up because this tension in the relationship would lead to more clashes and pressure on adolescents, which could affect them psychologically.

> *“She [daughter] started applying the sensor to herself when she was 8 years old. They like to be independent. They think that we are like loads over them in diabetes and being overprotective sometimes bothers them. Many times, she tells me ‘enough mum, I already measured my blood glucose level “. C8.*

> *“I always make sure not to put pressure on her [daughter]. I do not get the mothers who want their kids to always get the full marks, there is no problem if the kids are lazy for a while. I do not blame my daughter when she gets a bad mark, I talk with her quietly. The mother is the only motive in the life of the kid with diabetes, she is the only one who is able to push her kid forward, and she is also able to disappoint her.” C3.*

> *“My mother asks me every 5 minutes ‘did you check your glucose level?’, ‘show me your device, and so on this is stressful. It might be good if said without yelling”. K1.a.*

> *“I do not like any one to keep nagging on me.” K14.*

Furthermore, sharing tasks and responsibilities, continued follow up, and setting rules were factors that facilitated good relationship and avoided conflicts between parents and their kids. However, caregivers stated that it is important to hold adolescents accountable for their actions, to support their independence, and to try to prepare them to take responsibility as they grow up into adulthood.

> *“There are certain rules that we will not talk about because it is not a point of discussion. Those things [taking insulin and checking glucose] are similar to waking up in the morning and dressing up for school. We cannot eat until we check glucose, glucose is high we correct, we will calculate carbs to eat, you get the point?” C1.*

> *“For example, if anything gets disturbed in his blood glucose, I do not take over the responsibilities in front of him, I tell him, ‘No, you are the one who ate this. How many times did the pump alarms with this number and that number? You did not hear it at all? I mean, I hold him accountable. Sometimes we go very seriously*

> *and firmly and then we go softly. I mean we let him know and be aware for the sake of his benefit." C12.*

A consensus among almost all participants was that parental motivation and support have the highest impact on adolescent's adherence. Motivational talks were perceived as an important facilitator to adherence. Moreover, an agreement was that reward is the strongest source of motivation at that age of adolescence. When parents offer rewards upon achievement of short-term targets, adolescents adhered the most.

> *"There are times when I find that she is compliant with applying her sensor, complying with the diet to a great degree and also complying with the injection time, then I encourage her and tell her, 'see how your graph is looking, excellent, bravo, good job, you can do this'." C3.*

> *"Yes, for example my dad tells me, if your glucose is controlled for a specific period of time, I will give you specific amount of money, this makes me motivated. And if it was still not controlled he tells me I will give you one or two months more to control and then I will give you a specific amount of money, and when this amount is high, I become excited the most and I work so hard to keep it controlled, and does not go above 270." K13.*

> *“I have to set her a specific target. For example, I tell her ‘this Thursday, we will go to that place. If you controlled your blood sugar, we would go to that shop, we will order a sweet that you like’. Like this. There should be a reward from my side, so that she adheres to the treatment. Without a reward, she will not adhere. Advices from my sisters or friends or her aunts do not work.” C15.*

> *“In his case, he is still young, and his mind is young, so playing. Allowing him to play, or to do things that he wants, or going out to a place that he likes, this motivates him so much.” C9.*

Additionally, the father’s role was discussed by some participants and it can be outlined by taking part in providing psychological support and in complementing the mother’s role upon conflicts. However, they were not involved directly in performing diabetes related tasks.

> *“We are not talking at all about the other side, which is the father, sharing is important. I share everything with her father and I keep him updated with all the information, but he doesn’t interfere directly except when I ask him, for example when she [daughter] doesn’t eat enough or when she takes advantage of her illness, then we both have to take actions.” C2.*

> *“For sure, my father cares about my health, but I think the mother is the one who cares more about the health and fathers care about the marks and academic stuff that affect my future. My mom also cares about those stuff but father cares more about the future. Because he might be a bit strict but for our benefit.” K1.b.*

> *“Honestly, this was a very sensitive issue for my husband to deal with directly, but he was supporting him psychologically, however he was unable to do any task related to measurement or injection. Yes, so I had to teach my son to be independent even at a young age such that when he was 5 years old, he was able to at least measure his glucose level on his own.” C3.*

Parent-specific factors: Some parent-specific factors were identified as barriers to adherence such caregivers being busy, tired, exhausted, and stressed. Caregivers agreed that they sometimes reach a stage where they feel that they are overly stressed to the extent that they feel that they cannot continue providing the necessary care. At that time, they felt that they needed to have support.

> *“This [non-adherence] could be a result of the father and mother having a busy life, and that their work would be the reason for lesser adherence. It could be a result of their negligence.” C12.*

> *"Ok, this is true. Like during some periods of time when I am going through a mental problem, or if I was mentally stressed. Some mothers might put a lot of pressure on themselves to keep the situation under control, while others might reach a stage where they don't care anymore, because they are tired. She might be not even able to do the carb calculations. It differs [response to mental stress] from one person to the other." C3.*

> *"Sometimes, the mother reaches her top [exhausted and overloaded] and is not able to continue and the boy or girl has low adherence and are being stubborn. This period is very stressful for both the child and the mother, and it always ends with clashes. It doesn't end peacefully." C7.*

Caregivers also expressed the importance of them being role models for their kids by having a healthy lifestyle, and that this helps in promoting adherence of adolescents with diabetes. Additionally, parents' education was also perceived as a factor that might affect adherence because it will be more difficult for them to get the knowledge and awareness needed.

> *"I always show her that I eat little to not feel that she is the only one reducing her food portions, so she tries to act like me. As I mentioned before, it's not logical to advise her to lose her weight and to eat little and at the same time I eat too much. I think this is an important point for mothers to consider." C2.*

> *“Also, I should be a role model. If I am not putting her into consideration or not adhering to a healthy lifestyle, or even her siblings or people around her are non-adherent, then it will make the child non-adherent even if she was adherent before. As long as I and the people around her are on the right path, she will be like us.” C10.*

> *“At the beginning it (diabetes education) was difficult, but with time it became easier. I feel sorry for people who live with families who are not well-educated, I think it is much harder for them.” C2.*

Some parents addressed an important point regarding parents’ phobia of injections. Mothers explained how difficult it was for them to overcome their phobia of injections and to be able to cope with it. One of them mentioned that until then, she was not able to overcome it.

> *“Until now I can’t bear injecting him or even seeing him injecting himself, I feel like you are injecting this needle into my heart. He is also able to change his sensors and his father helps him with that. As you know, he was old enough when he was diagnosed so he learnt how to inject himself with insulin in the hospital since day one of his illness.” C4.*

> *“It took me a long time to pull myself together [after diagnosis] because I have a phobia. I do not like injections at all, and I*

> *couldn't imagine injecting my 4-year-old child with insulin, and why should I inject him with insulin to begin with."* *C3.*

Community influence:

Peer support: Many participants indicated that they received peer support and that this support was mainly during episodes of hypoglycemic events. Some participants also added that their friends play an important role in enhancing their adherence through reminding them and motivating them to go to the nurse or to check their glucose levels and take their insulin doses. They also offered psychological support when adolescents felt down.

> *"Yes, yes. Recently, they took care of her. Because it was a new diagnosis, she was in a period of Honeymoon. So, she experienced a lot of hypoglycemic events. So, I requested them to take care of her, 'if she said anything to you, you go call the nurse. If she experienced a tremor...etc.'. I told them about the symptoms of hypoglycemia. So, I felt that they care about her, and sometimes, they called me from the teacher's phone, and informed me, '[name] experienced this and this.' They were communicating with me." C14.*

> *"Yes, a lot. When my glucose level drops and I feel that I am not able to stand on my foot or to walk, my friends notice this from the look on my face, and they know whether it is a rise or a drop and they inform the teacher, and the teacher asks the nurse to come*

> *and see what is wrong with me. They do not wait to take my opinion; they immediately take me to the nurse." K2.*

> *"Two years ago many bad things happened when I was with my friends which affected my adherence, But this year and last year my friends are so good and they help me with everything, and they cheer me up when I'm not feeling well and they help me a lot with many things not only diabetes." K1.b.*

> *"When they see me bothered because of my high blood glucose level, or when they see me taking the insulin, they keep reminding me not to be sad as it is god's fate, and that makes me feel better. They give me hope." K16.*

However, some adolescents preferred that they do not get any support from friends and they felt that they wanted to keep their privacy. Moreover, many adolescents felt that their friends are treating them in a special way or acting as their guardians, and this bothered them a lot.

> *"They [friends] are not involved because [daughter] doesn't like to have others be involved in her personal issues. Because … excuse me, I remembered something, [son] had one of his friends who was like this, who was acting as his guardian and [son] was bothered, he even refused his friendship. He felt that he doesn't want anyone to be responsible for him, for example he would tell*

> *him, ‘be careful, measure your glucose" or "you forgot your device, take it ". No, he doesn't want anyone to act as his guardian. He doesn't accept this from his friends. Previously, I thought that it would be nice for him to receive support from his friends, but I felt that it wasn't like that for them. They need to protect their privacy.” C3.*

> *“During the break time, when they [friends] are going to run and I am about to run with them, they stop me and tell me not to run, otherwise my blood glucose level would drop.” K16.*

Going out with friends was perceived as a strong barrier to adherence. When adolescents are with their friends, they usually get busy and they do not like to stop their plans to care for their diabetes. They also do not like their parents to keep reminding them, and they feel that they want to be like their friends. Caregivers also found it difficult to estimate the insulin doses for their kids when they are out alone because they do not see them and they do not know how much they ate, or how much activity they did. Additionally, one caregiver noted that her daughter sometimes feels that she is a burden on her friends when they go out as any emergencies can happen at any time.

> *“I think that, yes when I am at home, I take care of my glucose level 100%. I always take care of my glucose level when I am at home. But when I am outside or with my friends and we are going to a restaurant or travelling to another state or city, I am busy with*

them, having fun and playing together, so my attention to my glucose level is lower than when I am at home." K5.

"Yes, this is the reality, if they go out with their friends alone to a mall, this is when what I told you happens. You have to call them and ask … but also you are afraid because they do effort, so you do not know what to tell them exactly. Diabetes has a specific effect on life that is difficult to estimate. What if they went to a playing area? What if they walked a lot? She cannot take the same insulin dose, and you are not there with her, so you do not understand. Look, the reality is that we are always in stress especially that you are not there with them. But still it is important that you agree for them to do that [go out with their friends]." C1.

"I always feel that when she is out with her friends watching a movie, and usually she has something to raise her blood sugar level with her, but sometimes she does not have something to raise her blood sugar level and so she has to leave the place and go to another place in order to buy something to raise her blood sugar level, or send one of her friends to buy her something to eat to raise her blood sugar level which makes her upset. At the same time her friends are still young, and they feel that she is a load on them, so she feels bothered for making them have to wait. Although they are her close friends, but they are still adolescents." C8.

Population awareness and stigmatization: Some adolescents indicated that they preferred not to show their attached devices because they did not feel comfortable showing them. Sometimes they received questions out of curiosity that annoyed them, and other times they just felt embarrassed or they were afraid that they might be stigmatized. Many also mentioned that at the beginning of the diagnosis, they preferred not to show it but later they became more confident. However, only few adolescents stated that they did not have a problem showing the device from the beginning.

> *"Yes, at the beginning of his illness he didn't want to attend the training, because he was shy of showing his sensor and taking medicines in front of people, but I convinced him that it's okay to take medicines in front of people as it's a normal disease, and he shouldn't be ashamed of it, so he started attending the training again." C4.*

> *"He feels shy to take out the device in front of his friends at school to enter values or check for low or high levels. He has to go out of the class. He does not like to show the device and he does not like anyone to know that he is diabetic." C13.*

> *"No, I do not have a problem showing them [devices], because I believe that diabetes is not a disease, it is a lifestyle." K16.*

Similarly, some adolescents felt confident injecting and checking their glucose levels in front of others, whereas others felt that they preferred to inject in a private place. Besides, some adolescents expressed that it depends on the place and the people surrounding them. Therefore, in public they preferred to keep their privacy, but with their families or friends, they do not mind doing injections or checking glucose in front of them.

> *"No. I delivered a message to my kids that diabetes is normal, so we can weigh and inject in front of others, its ok. Maybe my older son [23 years old] is the one who does not like to inject in front of others, because he thinks that he is a grownup now and he got used to it. But [daughter with diabetes] and [other daughter with diabetes] no. And now with the sensor its easier, we measure by the sensor and inject by the pump and life is easy." C1.*

> *"Yes, if we are out in a restaurant or an open-air place, he doesn't like to inject himself in front of people and he goes to bathroom to inject himself. And also, when we go out to visit someone, I do not remind him in front of them, and I do not measure his glucose in front of them or inject him in front of them. I make sure to keep that because he gets upset. Even if we are in an open-air place like parks, we look for a private place to take his injections." C9.*

> *"With the people that I feel comfortable around like telling them that I have diabetes and they won't judge, and they won't change*

> *how they feel about me, I won't mind checking in front of them. But if I was in a public place, for example, if I was in a food court in front of a bunch of people, I definitely would go to the bathroom and check there, but if I am in a restaurant and the table is full of family members I would check my sugar in front of them." K1.a.*

Most adolescents were annoyed by the questions asked by people about diabetes or about the devices they use. Some were annoyed only when questions came from people that they do not know, while others were annoyed even if the questions came from their friends.

> *"Honestly, I used to be annoyed because of these [people asking questions]. Now it still bothers me but not to the same extent as at the beginning. Before, if I was for example in the sports club, and I have the sensor, some people that I don't even know approach me to ask what this device was for, and I didn't like this. I don't like that someone that I don't know, or someone that is not very close to me to ask me about it or how do you take it. I like to take the insulin for example away from everyone, alone, because they are sometimes like 'ooh you are taking an injection [drugs]'. They make it a very big issue for me, and I don't like this." K5.*

> *"Exactly, to add on this point, my friends, they keep asking questions like 'how to do you apply your sensor? does it hurt? how do you feel? how do you sleep with it?', come on, it's just*

> *normal. And the same person keeps asking the same question several times and I answer the same every time which is a little bit bothering, they don't understand that it is a normal thing." K2.*

Support from other patients with diabetes:

Participants discussed the support provided by other family members who have diabetes, and the positive impact of this support on adherence of adolescents with diabetes. However, one caregiver stated that some comparisons might happen which are not in the advantage of the adolescent especially if that family member tends to have lower level of adherence.

> *"Ah I will tell you something, the experience of having a second child with diabetes, [son] was one of people who supported me the most. This is a small thing which I want to share with you, I will tell you about it. When [daughter] was diagnosed with diabetes [son] was the happiest person on earth, because he finally had a partner at home, someone who could share his worries with him. So, having a diabetic person in the family is a supporting factor. He started to deal with her and support her because he felt that this was his responsibility." C3.*

> *"Yes, that's true. When he was diagnosed, his cousin had a great role. They always talk with each other about diabetes and he advises her." C9.*

> *“My brother here is also diabetic so when he sees me being strict about weighing and so on, he looks at me ‘what are you doing, you will make him [son] bored, he will be fed up’. So when he [son] hears that, he stays quiet but later he tells me ‘my uncle has diabetes also similar to me, why isn’t he doing what you are doing?’ C5.*

Furthermore, caregivers and adolescents felt the importance of the diabetes camp on the psychological and educational levels. Adolescents expressed how motivational it is for them to gather with other patients with diabetes and to discuss issues in common with them. They also found it helpful to learn together. Additionally, caregivers valued the knowledge that adolescents were able to gain through those camps.

> *“When he joined the association, and we joined the camp for the first time, they taught him how to inject himself with insulin and I saw this as a great achievement. I mean at age of 6.5 years [son] started to inject himself with insulin under our supervision of course, nothing is done unless we determine the dose for him, and he injects.” C3.*

> *“Yes, he is able to do all of these things [self-care tasks]. We have the balance and the measuring cups, so he knows how many carbs, and he also participated in “Bawasil” camp at Qatar Diabetes Association last December … last year and he has*

> *learnt a lot from it. Also, when he sees other kids with diabetes like him in the camps or in the gatherings, this motivates him a lot." C9.*

> *"When I was young and I had diabetes, there were camps for young patients with diabetes where I was able to learn too many things, and my parents used to make me join these camps. I still remember it and I appreciate the efforts they made." K16.*

The support provided by parents of other patients with diabetes through social media, such as WhatsApp groups, was perceived by caregivers to be of great importance. Receiving support and getting to know other experiences from people who were in the same situation helps caregivers to overcome the stress especially upon recent diagnosis.

> *"It also depends on who provides the information. For example, in our WhatsApp group, when a new parent joins, we provide her with information and support from people who were in the same situation. They know how you feel as they were in your place once. It is better than accepting it from a doctor." C2.*

> *"I also benefited so much from [diabetes] group. I left the hospital with understanding [about the condition], but from the shock and the accumulation of information, I forgot many things so when I*

> *did not know [how to do] the calculations for something, I asked. So, this group helped me a lot." C14.*

Many participants recommended that this kind of support should be official for example through professional support groups at the hospital library where patients and caregivers can meet with other families who have similar cases; hence they can get the needed support.

> *"It would be beneficial to have a support group, and also we should listen to them and know their needs and how we can help them. I mean my appointment is for example every 3 or 4 months, let's say every 4 months. We need each month for example a group with the nutritionist and other children with diabetes, not my daughter only. When I see more than one experience, I can go home with 10 different ideas if I am sitting with 10 people for example." C16.*

> *"Yes. It [adherence] improves significantly. When she hears their experiences, what has happened to them and what has not. I mean, when she hears their stories, she fears for herself more as she does not want that harm to happen to her. From my point of view, I see it [having support groups] as having a positive effect. It will be a quantum leap in this area." C15.*

> *“I will honestly answer you based on my experience. My mother had her friends on Facebook and in groups. They made gatherings. I used to go there and gather with my friends. Some of them I already knew and some I didn’t know. I was making friendships with them. Secondly, I got more knowledge from them. The things they didn’t know sometimes I advise them about it. It was a knowledge exchange and friendship making.” K5.*

4.2.2.3. Theme 3: Medication and device-related factors

Insulin-related factors:

Some adolescents were annoyed by the blue marks that the insulin pens or injections leave on their skin. They also mentioned that the site of injection becomes swollen upon injection and sometimes becomes painful. These factors can lead to non-adherence as they affect appearance.

> *“… but when I used to take insulin by injections, I used to have blue spots on the site of injection as a result of the rupture of the blood capillaries. I was annoyed from their appearance and they were so painful. This used to bother me, but then I calm down myself by saying that these blue spots are going to disappear, and I force myself to take insulin to live my life normally.” K2.*

> *“Sometimes when I take insulin, I notice that the sites of insulin injection swell, especially in my tummy in places where I inject, so places that I do not inject in, they do not have that swelling.*

> *So, when I inject insulin, I feel that it is still inside, and it is clear, and this bothers me." K16.*

A common complaint was that insulin, specifically Lantus® (glargine), causes burning sensation as they are injecting it and this made the adolescent feel that they were not willing to take it.

> "*Every day she says that she feels heat in her body, she feels heat spreading in her body. I do not know the difference [she means the difference between insulin types], maybe she truly feels the difference" C14.*

> *"Lantus for example used to make me feel burning sensation in my arms so I was not willing to take it frequently." K2.*

With regards, to weight gain, some participants indicated that insulin causes weight gain, whereas others justified the weight gain not to be a side effect of insulin, it is rather a consequence of feeling hungry after taking insulin.

> *"Insulin itself does not cause weight gain, but it makes her hungrier, so she eats and hence, gains weight." C2.*

> *"… but of course, like any other girl, she wishes to be fit and she says: 'since I have started taking insulin, I am gaining weight'. She is bothered by that." C3.*

The nature, frequency and time burden of the self-care activities were also factors that could render adherence to insulin. The fact that insulin is taken through injections multiple times a day and requires preparations such as sterilizing the injection site and keeping it in fridge, was considered as a challenge to adherence.

> *"I can't say it [being able to self-inject] is related to knowledge. I think it is more about being afraid. As when I was young, I knew how to inject myself with insulin, but I used to be afraid of injecting myself, so my mother used to inject me. For sure my knowledge has increased as I got older and by experience, but when I was young I wasn't able to inject myself not because I didn't know how, but because I couldn't bear injecting myself and seeing the blood coming out of my body." K2.*

> *"… they will consequently rely on multiple pricks for blood glucose monitoring, and on injecting several times with Lantus and Novorapid, which is too tiring to the kid and his parents. Around 6 times Onetouch [glucometer], three times Novorapid and one time Lantus, that's too much." C2.*

> *"If it was by insulin pen, it would definitely be hard to keep up with, but with the pump, it makes it easier as I just put the number of carbs and the sugar reading, and the insulin goes through the cannula into my body. It is way easier than going to the fridge and*

> *taking the insulin, putting it in the needle, cleaning with the alcohol, then taking the injection, then going back again to the fridge to put the insulin, and doing the same thing each time." K1.a.*

Moreover, profound insulin resistance throughout puberty was perceived as a challenge to optimal glycemic control. One caregiver added that insulin acts differently among different patients, some patients respond immediately to the dose whereas others require some time, and this affects the timing of insulin injection.

> *"We also passed through puberty which is a very difficult period because of insulin resistance, we use huge amounts of insulin without seeing an effect." C1.*

> *"Because [son] is the type of … once he is injected with insulin, it starts working quickly. So, I worry that his reading could be 80 [low] and if he injects himself before eating, this would not be correct. He would need to inject himself during the meal or after it because the reading is 80." C3.*

Device-related factors:

Some adolescents did not prefer having wires attached to their bodies and moving around with it, they preferred insulin injections or pens over the pump (CSII) to avoid moving around with a cannula.

> *"But look, also the cannula for example has problems, it causes psychological problems for adolescents. For example, my son refuses to attach any wires like the cannula. After lots of pressure he agreed to put freestyle [FGM] but walking with a cannula in his stomach and every time he needs to fill the reservoir, he refused that. He finds it much easier to have the pen in his pocket and that's it but do not tell him to attach any wires." C1.*

> *"Yes, I did [ask him if he wants the pump], I personally wanted him to apply the pump at the beginning to avoid injecting several times, but when I asked him he wasn't interested in the idea of applying a device on his tummy and moving around with a canula." C4.*

A common barrier that is related to devices was that the adolescents found it challenging to practice swimming while they have the insulin pump (CSII), or the sensor (FGM) attached. Participants complained that the device keeps falling and getting detached regardless of the efforts they put to secure it in place. Additionally, participants felt restricted as they were not able to practice the sport they liked and this was perceived as a barrier to adherence particularly, to exercise.

> *"It [device] bothers her because [daughter] loves swimming, and she wants to return back to swimming, but unfortunately, keeping*

> *the sensor [FGM] attached to her body and being responsible for that … No, it bothers her when it falls down in the swimming pool, and she needs to put glue, and it might still get detached, yes, it does bother her.” C3.*

> *“He likes swimming very much. One of the challenges that I face is related to the attached accessories to his body. During the swimming time, they get loose and detach. So, he should have a specific time for swimming, he cannot swim every day. I am trying to buy large patches that stick tightly. I am trying to do things for him, but as swimming, he doesn’t do it much.” C12.*

Moreover, some adolescents were annoyed by the fact that the sensor with the insulin pump [CGM] alarms and wakes them up at night, so they preferred not to use it. On the other hand, some caregivers preferred having the sensor applied because it made them feel more safe, hence, they were able to sleep because they know if anything wrong happened, it will alarm.

> *“Yes, she has the freestyle libre sensor [FGM]. She doesn’t like the pump sensor as the calibration wakes her up at night.” C2.*

> *“Now I feel safe. As long as the pump is there, if her blood sugar goes up or down, it will notify and alarm me. Previously, I had problems with syringes that I was not sleeping at night. I had to wake up every 45 minutes at night to check her, maybe she has*

> *a rise or a decline in her blood sugar, maybe she is in a coma, I do not know." C15.*

The pump is also heavy, and adolescents felt that they are restricted while applying the pump. They are not able to wear whatever they want and to move freely. Therefore, adolescents and their caregivers tried to find solutions for those challenges, such as sewing a pocket specifically for the pump to carry the weight and to not be too obvious. Moreover, alternating between injections and pump was another solution to overcome some of those barriers.

> *"Yes, and it [pump] is heavy for her [daughter] as she uses the 640 pump and hang it on her pants, and it shows a bit. So, when we sewed the school uniform, we tried to make a special pocket for the pump." C16.*

> *"I use the pump for 2 months and then I stop using it for 3 months and then I use it again and so on, because it prevents me from wearing whatever I want, and it also obstructs my movement, which is considered a problem to me." K16.*

All participants agreed that the sensor [FGM] made their adherence to blood glucose monitoring improve. However, one caregiver indicated that the sensor causes many allergic reactions to her son, so she decided to stop using it for him. Another barrier was that the accessories of the devices are not available in all countries and going back to glucometers after relying on the sensor (FGM) is more difficult.

> *"The freestyle sensor makes the blood glucose monitoring easier, I only fix it for him for two weeks and that's it." C9.*

> *"[son] had an allergic reaction to the sensor freestyle libre [CGM] and since then, I became unable to use the sensor. For [son], the allergy problem was not solved so I decided to stop using the sensor for [son], while [daughter] was using the sensor." C3.*

> *"Here [the participant was in Egypt for vacation] it is not available to use the sensor. I couldn't buy it because we went to Egypt and couldn't go back, so all of our reliance is on our main device [glucometer] with the lancets." C7.*

4.2.2.4. Theme 4: Healthcare system-related factors

Healthcare provider-related factors:

Healthcare provider-adolescent relationship and support was also discussed. Some participants indicated that the healthcare providers have a supportive role especially upon inclusion of adolescents in decision-making and in discussions. However, some adolescents felt that the providers focus on diabetes management, disregarding issues related to emotional support. One participant also added that she feels that they do not have a close relationship with the physician because they meet them every now and then and this does not allow them to provide the needed support.

> *“Actually, we are following up with Dr. [name], and when I go to visits with [daughter], he talks to her directly, and this is the best thing I like about him. He talks with her to make her feel that she is responsible for her health, and that mom is just a facilitating factor, and this is a nice thing which I like in doctors at Sidra. Of course, not all doctors follow the same strategy, I think it differs from one doctor to another.” C3.*

> *“Everything is by discussion. Even when we meet the diabetes educator, we tell her what we have and she tells us what she has, until we reach an intermediate solution. So, we discuss to reach consensus.” C9.*

> *“Yes, I know that they want to help us to control our sugar level, but what is missing is that they don’t ask why we do that [not adhere], they don’t provide the emotional support that we need.” K1.b.*

> *“No, not at all, because to her, he is just a physician or a person that she meets for 10 or 15 minutes maximum, once every 4 or 5 months. The last time she met the physician was last week, and the one before that was in December or September 2019, almost*

> *a year gap between the two visits. When I need something, I call the doctor and she tells me what to do and that's it." C16.*

Participants expressed that they sometimes face issues that are personalized to their kids which the physicians are not always able to help them with. Participants justified this by expressing that physicians usually deal with patients according to guidelines and not based on a personal experience with diabetes.

> *"The doctor studied and everything and he can tell you diabetes types for example, but he did not see it for 24 hours on a kid. So, the doctor sometimes advises the mother to wait for 10 minutes or 15 minutes [after injection] and then let him eat, so the mother tells him 'no I can't do that' because she tried to do that before, but the kid suffered from hypoglycemia." C1.*

> *"Exactly, they deal with you as the book says. It once happened that my daughter did not take insulin for a week and despite that, her blood sugar was low. The doctor kept insisting that my daughter was taking insulin behind my back, and he kept asking whether I count pens or not, but my daughter is in front of me all day and she was not taking insulin and her sugar was low. I thought that something was going on with her pancreatic alpha cells, so she did a blood analysis. But when I asked people in the WhatsApp group, they told me that this could happen, maybe*

> *insulin was accumulating somewhere and it released, or maybe her diet at that time did not include a lot of carbohydrates, and they told me many reasons and that this happened to their children before. Unlike her doctor that was insisting that it's either she is taking insulin and the glucose sugar is reducing, or she is not taking it and her blood sugar is high." C2.*

One caregiver highlighted that having a healthcare provider from a different culture and speaking a different language is a challenge because when the diabetes educator is from a different culture, he or she does not know the ingredients of dishes for example and this is a major issue in diabetes management.

> *"In addition to that, there is a language barrier, because some people have complained about doctors and the educators. I will not talk about this issue because I have depended on myself primarily in the education, I take the basic information from them and I always try to educate myself through referring to other resources, ok? credible resources of course. The problem that I was talking about is that some people have communication problems. Differences in language or culture causes problems. Like for example if she does not know what the nature of this dish, and what are its effects on blood glucose levels, as she doesn't know this culture to begin with." C3.*

Some participants faced difficulties in scheduling appointments with the diabetes educator at times when they needed instant support. However, other participants indicated that having the phone number of the physician and being able to contact him/her directly was beneficial.

> *“For example, if we changed something in the pump and we need an appointment these days or after a week to check it with the educator, we do not find her available after a week or two, rather, we find her available only after a month or a month and half.” C12.*

> *“In the hospital, they see the suitable appointment for us and for the doctor and they inform us about it, and if it is after a long time or there are no appointments available at Sidra, and I need to see the doctor to adjust the settings of my insulin pump, or I need the doctor’s consultation, we can contact the doctor directly, he gives us his phone number.” K2.*

Moreover, participants confirmed that adherence often improves just before appointments which is also known as white-coat adherence.

> *“I get stressed when I have an appointment with the doctor, I don’t know whether I’ve eaten too much carbs or too little, and whether I’ve checked on my glucose level too much or too little, so I do not know what they will tell me. So I try to make sure that I adjust my glucose levels when the appointments are soon.” K1.a.*

> *"I always tell [daughter], 'Next week you will have an appointment'. I tell her that she has an appointment even though she does not, and she gets concerned about it, and tries to adhere to the physician's recommendations, watch her meals, and weighs correctly. But if no appointments, she will not adhere." C15.*

Counselling and educational aspects:

Participants indicated that diabetes education had significantly improved throughout the years and that diabetes education now is more comprehensive. However, some caregivers felt that this education was not sufficient as it focused on the period just after diagnosis, but it is not sustainable, and it is not utilizing the recent technology.

> *"Previously there was no diabetes education. Diabetes education is not that you go to your appointment and leave, they teach you how to inject but that's easy. Diabetes education is not that after diagnosis you let me go home and whatever happens happens. With diabetes you have to take actions all the time, you get the point?" C1.*

> *"Without them [healthcare providers], I would have never learned anything about diabetes, I wouldn't know how to calculate, and*

> *my mother wouldn't know as well. They sure have the main role like 90% that I learned everything." K5.*

> *"But we were hoping that … of course they organized Zoom meetings for us and things like that, but I was hoping that both the doctors and the educators play their roles in relation to this. I think the contact with the education department needs to be updated using the technology which is currently available for us. But it is not currently used in the way we expect it to be, or in the way that patients with diabetes needs it to be. I mean we need more care; it is not just about appointments." C3.*

Particularly, many caregivers suggested that the role of educating adolescents about diabetes-related self-care should be handled by diabetes educators and dieticians and not solely by parents because usually adolescents at that age would not listen to what their parents say and they would prefer to get instructions from professionals.

> *"In Sidra [hospital] or Hamad [hospital] or any institution, they need to explain to them [adolescents]. It should not be our responsibility to explain. There should be nutrition courses for example. You should educate them on how to eat for example and so on." C1.*

> *"I talked to Ms. [name] from the diabetes association and told her that I would like that the instructions come from your side. That we make a group, for example, they visit you for a week, 4 or 5 days as much they need. I would like him [son] to visit you and take the training and instructions from your side. This way is better, he will take over the responsibility more seriously than if it comes from my side and I will supervise from home, of course." C12.*

System and administrative factors:

Some participants indicated that the appointment system is suitable and that the appointments are sufficient. However, some participants felt that they need more appointments, specifically fixed appointments with the dietitians and psychologists to seek their support.

> *"The appointments and the follow up of the doctor are sufficient for me, and it gives me enough time to adjust my blood sugar if there was a problem with it, and each appointment they give us new information and until the next appointment we get sufficient time to process the information and get used to it." K1.b.*

> *"Yes, I need more appointments and more fixed appointments with the dietitian and the psychologist. These really supports us." C7.*

One participant also added that the waiting list for the insulin pump is long and that they have to wait for a long time before they have it applied. Additionally, alternatives for the insulin pump devices are not available in Qatar so they have to order them and their accessories online but they again face a problem that there is no agent available who can provide any maintenance for the devices when needed.

> "*Honestly, they are available, but we have been on the waiting list for the pump for a long time and we still didn't get our turn. I don't know, I even forgot to follow-up if our name is still on the waiting list or not." C7.*

> *"I would have liked it if we had things [alternative insulin pumps] available in Qatar to help us with … Unfortunately, one of the things that we face is that I have to order these things online and bring them so that I could make available for her." C3.*

> *"I have another problem now which is that I buy devices online, but I don't have an agent. When something needs to be repaired, I have to pay from my pocket. I don't have an agent who can repair/fix it for me, so I have to throw this device and buy another one." C3.*

Moreover, patients addressed the issue of the healthcare system dealing with diabetes emergencies inefficiently, and not recognizing the risk of the delay of care.

> *"No no, you just came to a painful point. During the last period, let me give you 2 scenarios. One of them is that I went to the hospital with [daughter] on her legs having ketones, but not yet DKA. It is not acceptable that I have to wait for 10-15 patients to finish before my turn because this might cause her to go into DKA. I had to make a trouble and to talk to nurses. Sometimes the nurses don't realize how dangerous the situation would be if we waited for longer time. When I took it easy and I waited for my turn, the girl went into DKA and she stayed at hospital for 3 days, instead the ketones could have been fixed in 5 hours with 2 normal saline bags and that's it." C2.*

Cost associated with care:

Participants indicated that the cost of insulin is affordable and subsidized by the country. For other medical supplies such as the sensors for FGM or CGM, the cost is high, so its affordability is subject to the financial capability of the family. For the nationals, they receive all the medications and supplies at no cost.

> *"It depends on the financial capability of each individual. For me, Alhamdulillah, I am working, and my husband is working. So, it is*

> *reasonable. But I guess for someone else with different conditions, it would be expensive for him. These things are expensive, the sensor and the injections and so on." C10.*

> *"No Alhamdulillah, I am a national, so I take all medications and supplies for free and the items are always available." C13.*

Other costs that are indirectly associated with diabetes management include cost of regular exercise, cost of maintaining healthy diet, and cost of other illnesses linked to diabetes. These costs are not subsidized and they are costly.

> *"Another important point is that there are no discounts for patients with diabetes in gyms and sport clubs, and this is a very important point that we all want. One of the things that optimize diabetes control is exercise, but it is very costly. It is not logical that you pay thousands for medications and supplies and again pay thousands for gym. Not everyone can afford that." C1.*

> *"The [dietary] alternatives for patients with diabetes are limited and at the same time they could be costly. It is significantly more expensive than normal food, if you were able to find it." C3.*

> *"There are other diseases linked to diabetes, and for some of them, you cannot follow up except in private clinics such as dental*

> *issues because it is very difficult to take an appointment at the health center. This is also included in diabetes costs which are not subsided except for insulin, and diabetes is not insulin." C1.*

However, one participant suggested that they need insurance coverage to cover their expenses for supplies, and this would give them the freedom to choose whatever suits them, and would also allow them to get other options and alternatives that are available abroad.

> *"At least we want to have insurance companies to cover us. It could be through companies which would cover our expenses, such that I bring them the receipt for example, whether from here or online. This will give me more flexibility and I will not be forced to deal with Medtronic company because it is the only one available in Qatar and the Middle East. But I want to bring technology from abroad, provide me with an insurance company which I could deal with and which would pay for me because I am already, for example, an employee in the government, so some type of coverage, but this is not available of course." C3.*

Sources of information:

Participants indicated that access to information is now much easier as compared to before. However, this easy access to information is a double-edged sword. Not everyone can appraise the quality of published information and apply it properly, especially when it comes to adolescents that are usually more curios and reckless.

> *"Alhamdulillah, nowadays, it is easy to get any information. Even if the person is illiterate, by searching Google and YouTube they will find a lot of information." C2.*

> *"At the same time, another point is that there are lots of rumors. They always say, for example, that there is a new device, or there is a new discovery or a cure for diabetes, …etc. We, as mothers who do not know about this news, we do not know if it is correct or not, if it is suitable or not. What about this treatment or this device? Is it suitable for patients with diabetes type 1 or 2?" C12.*

> *"Some adolescents now search the Internet for example and read about Low-Carb diet and apply it. Or an adolescent girl who is upset can read about Ketogenic diet or Karatay diet and start applying it. It happened one time a girl had a ketone of 7, she was doing a diet without her mom knowing. I talked to her, she told me that she was doing a Low-Carb diet that she has read about, and her ketones were 7!" C1.*

A suggested solution to overcome that issue was to provide a trusted source of information through Sidra Medicine. This way, they would be sure that they will have access to an accurate, valid, and reliable information source.

> *"They should have a known source of information through Sidra, to explain that non-adherence is what causes the complications*

> *that they read about. Doctor visits and follow ups should not only focus on getting refills and adjusting the doses and that's it. I am speaking honestly with you. There should be diabetes education courses, so they won't need to look for other sources of information. That's it." C1.*

> *"I wish if Sidra could publish educational videos prepared by the diabetes educators working in Sidra to provide awareness about detailed issues and not just headlines. Most of the education provided is in the form of headnotes only, general information." C3.*

4.2.2.5. Theme 5: Lifestyle, school, and environment-related factors

Educational institution-related factors:

Many adolescents were bothered by the fact that they have to waste their break time with the nurse in order to adjust their glucose levels, take their insulin, and eat. They also stated that they sometimes need to take from the class time in case their sugar levels were not corrected during the break.

> *"They aren't considered as barriers, but they are kind of distractions. For example, before Corona [COVID-19 pandemic], during the break time in the school, I usually have a walk with my friends, and we start talking about our day and so on. So I forget that I'm diabetic and I forget to go to the nurse and measure my*

> *blood glucose level and sometimes also the break time is wasted by going to the nurse." K1.a.*

> *"No, but during the break time, I go to the nurse to check my glucose level and take my insulin dose, and this takes up too much time from the break. So I do not have enough time to enjoy my break, and if my glucose level is low, I stay with the nurse to eat or drink juice and then take my insulin and check my glucose level again, and this takes up the break time and part of the class after the break." K16.*

The role of the school nurse was perceived as positive, cooperative, and supportive in some cases. Some of them had even more proactive roles in trying to fit the adolescent within the school environment such as meeting with the physical education (PE) teachers and have a plan for the adolescent.

> *"Look for the nurse at school, honestly, sometimes I used to explain to her things but she was always, even if I give her signed papers from the hospital with the doses, she was not strict with [what is in] the paper like what happens with others. She calls me and tells me what they will eat exactly and how much insulin they should take. I talk to my son or daughter and we agree on the dose and the nurse injects." C1.*

> *“I have a doctor at school, l but I forgot his name, he is doing his best. There are 2 doctors one I forgot his name and the other one is [name]. Dr [name] helps me a lot and supports me. The other one is doctor [name] I think, those doctors are the strongest support for me at school.” K13.*

> *“He is in a private school, and they are very concerned to the extent that if they found unhealthy food in the lunch box, they would send an email and call for a meeting. They make us very worried. I said once, ‘O God, what happened? Is there anyone who died or something bad happened to anyone?’ Then I realized that this was because of the unhealthy food and there were no fruits in his lunch box. This is what I like about them. They also make meetings with the nurse and the teacher, for example, before the sports classes, they discuss what they will do. They do not prohibit him from swimming like other schools. They are organized.” C12.*

However, many caregivers emphasized that they cannot rely on the nurse for doing the calculations, and that the nurse might sometimes be afraid of hypoglycemia, so she prefers the glucose level to be a bit high before going back home and this was considered a problem because when they go home they will want to have lunch but they will have to wait for it to be adjusted first. One adolescent also stated the nurse is not always available when she needs her.

> *“Ok, there are several factors honestly in this issue. As for the nurse she is not responsible for calculating the carbohydrates. She asks her ‘your mother told you to take how much, check your glucose, take the insulin’ and that’s it. She prefers to let her go home with high glucose level rather than 150 or 180 and so on, as she is afraid that she gets hypoglycemia on the way back home in the bus and they will return her back to school which is really bad.” C16.*

> *“Sometimes she is busy, or she has a meeting, so I do not find her when I need her sometimes, so I act on my own.” K14.*

Some caregivers and adolescents indicated that they face difficulties at school as a result of lack of knowledge about diabetes and diabetes stigma.

> *“… but the only problem is when she has a supervisor at class, and she keeps telling her ‘you don’t go to the physical education (PE) class because you have diabetes’. She tells the girls at the school not to give her anything because she has diabetes. She goes to her class and tells her to sit and not to participate in the activity because she has diabetes. My daughter tells them that she is a normal human being, and that all what she needs to do is to check [glucose], see how much exercises she will do, and she will take a snack in the middle and will continue her day normally.” C16.*

> *"… but when I applied the pump I had a problem that some people are too curious and they used to think that the pump is a bomb or something, and when I was doing an exam in the school, they used to think that it is something I use to cheat or a calculator. They even prevented me from entering the bathroom alone until I brought them a document that made them understand what the pump is." K1.b.*

Environmental and lifestyle-related factors:

Some barriers to dietary adherence related to environment or lifestyle have emerged and those included healthy dietary alternatives that are not readily available in stores, unhealthy food advertisements that are available everywhere, and options that are available on food applications are not healthy. Moreover, the dietary habits of the country here are usually based on rice and wheat and this makes it more challenging for patients with diabetes to adhere.

> *"To have readily available sweets in the stores, ready-made, so that when she goes for shopping, she can eat from these things and feel safe. Of course, this is, I think, a marketing problem more than being... a problem [related to adherence], but still it is a problem, which is present, and we suffer from." C3.*

> *"In this age, they [adolescents] start to order food from outside, they see what their brothers are doing, see advertisements that*

> *do not allow anyone to adhere to a healthy lifestyle and they [food advertisements] are everywhere." C12.*

> *"Before, you know how our homes are … pastries are always in our homes at 'Ala'sr time' [mid-day], sweets are always there…etc. Of course, all are unhealthy. It is also fine that we have rice at lunch and at dinner. All of these things have changed completely after [daughter] was diagnosed with diabetes." C15.*

Other barriers to adherence to exercise related to environment or lifestyle were expressed by the participants. Those barriers were related to lack of medical support in gyms or sport clubs in cases of diabetes-related medical emergencies. Moreover, scheduling adolescents with men was perceived as a barrier as it prevented mothers from taking that role of medical support due to cultural issues.

> *"He likes exercising. However, for any club that I would like him to go to at this age, they should have a background about the condition. My son has diabetes, there should be someone to take care of him if for example, he had hypoglycemia. No one is responsible for that, and I cannot because he is older now and wants places and clubs for adolescents. So, I wish if I find a solution for this problem." C12.*

“For example, when I went with him to Aspire, the issue is that they will schedule him in men’s days, not women. You know how men dress there [not fully dressed]. That causes a lot of embarrassment for me, honestly (laughter).” C12.

“Note that the weather here is very hot, so we either go to malls, houses, or restaurants most of the year. Walking is very important but how can you go to the corniche in this hot weather and humidity, you will get allergy. So, most of the time you are forced to go to closed places.” C1.

CHAPTER 5: DISCUSSION

This chapter provides the interpretation of the key findings presented in the previous chapter and compares those findings to the existing literature. Additionally, it presents the strengths and limitations of the current work and recommendations for future research projects. The first part discusses the findings from the quantitative analysis and the second part discusses the qualitative results.

5.1.Phase I: Assessment of adherence and its association with glycemic control

This phase of the study of the study assessed the level of adherence among adolescents with T1DM in Qatar and investigated its relationship to glycemic control. Up to our knowledge, this is the first study in Qatar to assess the level of adherence among adolescent population with T1DM.

The findings of this study have shown that the level of adherence of adolescents with T1DM in Qatar is only around 40%. This level of adherence is comparable to a previous study that reported adherence rates to blood glucose monitoring recommendations of 48% (97). Moreover, a previous study has found that the percentage of days that adolescents had a BGMF of ≥4 ranged from 46%-48% (98). In contrast, another study have reported a higher level of adherence to blood glucose monitoring recommendations of 76.5% (99). However, it is important to note that this study included both children population and adolescents and this might be a justification for the higher adherence rate. Additionally, the level of adherence obtained in our study is in consensus with a study that reported that overall adherence for children with chronic illnesses does not exceed 50% especially with diseases requiring more complex behaviors such as blood glucose monitoring (100).

Furthermore, the median average BGMF was found to be 3 checks/day. This median was significantly higher among younger adolescents aged between 12-15 years compared to older adolescents (16-18). Previous studies that assessed the average BGMF of adolescents found comparable means of 2.75-3.5 checks/day (54, 59, 98). The effect of age on adherence and on glycemic control was assessed in many studies, and most studies concluded that younger adolescents had better adherence and lower HbA1c levels relative to older adolescents (53, 80, 97). This may be attributed to the fact that parents are usually more involved in monitoring and supervision at younger ages in comparison to older adolescents where parental involvement diminishes.

Moreover, more than 90% of adolescents had uncontrolled diabetes with an HbA1c of ≥7% which is alarming. The median HbA1c among adolescents was 9.3% which is relatively very high. Previous studies have found that the mean/median HbA1c levels among the adolescent and children population ranged from 8% to as high as 11% (21, 54, 59, 97, 99, 101). Additionally, a previous study conducted in 2018 in Qatar among adolescents and children with T1DM using CSII showed a baseline HbA1c of 9.7% which is comparable to our study findings (12).

Qatari nationals had a higher median HbA1c of 9.7% compared to non-nationals (8.9%) with a difference of around 1%. Moreover, adolescents using insulin pump had significantly lower HbA1c of 8.9% compared to patients using multiple daily injections (9.6%). This finding is in line with other studies that confirmed the effectiveness of CSII in reducing HbA1c levels (12, 102). However, it is important to note that only around 25% of adolescents in our study used CSII as the insulin delivery method which explains the high average HbA1c level.

Furthermore, this study did not find a significant effect for the duration of diabetes on adherence or glycemic control. In contrast, a previous study found that the shorter the duration of diabetes is, the better is the glycemic control with a difference of up to 2% in HbA1c (97). However, the later study compared patients with a duration of diabetes of less than 1 year to patients with a duration of diabetes of more than 1 year. Conversely, our study only included adolescents with a duration of diabetes of more than 1 year.

Around 5% of the adolescents who participated in the study had long-term diabetes complications specifically nephropathy (n=8) and retinopathy (n=2). This rate is lower than the rates presented in previous studies which were around 17%-38% (103, 104). However, a notable difference in these studies is that the mean duration of diabetes was higher ranging from 6.3 to 8.1 years, whereas in our study, the median duration of diabetes was 5 years.

Adherence -that was assessed by a BGMF of ≥4 checks/day- had a significant effect on glycemic control. For instance, adherent adolescents had significantly more controlled diabetes compared to non-adherent adolescents. This effect was also concluded by a previous study that found a significantly lower mean HbA1c among adherent adolescents (97). Additionally, a statistically significant weak negative correlation was found between the average BGMF per day and HbA1c level. Similarly, evidence from the published literature suggests that there is an association between improved adherence (measured as higher BGMF) and reduced HbA1c (8, 30, 31, 53-57). Moreover, a meta-analysis of 2492 youths with T1DM, reported that there was an adherence-glycemic control link with a mean effect size of -0.28 (95% confidence interval: -0.32 to -0.24) across 21 studies (22).

Consistent with prior findings, adherence to BGMF recommendations significantly predicted glycemic control (69, 97, 98, 105, 106). Yet the combined model was only able to explain 9% of the variance in glycemic control with all other co-factors such as duration of diabetes and BMI not significantly contributing to the final model. Similarly, previous evidence supported the lack of covariate's (age, insulin delivery method, and ethnicity) effect on HbA1c (106). In contrast, previous studies revealed that some other covariates contributed significantly to the model such as age (54, 97, 105), diabetes duration (54, 97, 105), depressive symptoms (54), primary caregiver (97), and daily insulin dose (105). Nevertheless, these studies included children in addition to adolescent populations and this might justify the fact that in this study, age and duration of diabetes were not significant contributors to glycemic control.

5.2.Phase II: Barriers and strengths to adherence from the perspectives of adolescents and their caregivers

This phase of the study aimed at identifying barriers and strengths to diabetes adherence from the perspectives of adolescents and their caregivers. Adolescents and caregivers described factors that are associated with adherence pertaining to five major themes, 1) Patient-related factors/influencers, 2) Societal influence, 3) Medication and device-related factors, 4) Healthcare system-related factors, and 5) Lifestyle, school, and environment- related factors.

A highly emergent theme was regarding patient-related factors. Studies investigating factors associated with adherence usually address some patients' characteristics as non-modifiable risk factors associated with adherence. Despite the fact that phase I of our study did not find any significant difference in adherence level among patients with different personal characteristics (age, gender, disease duration, … etc.), most participants interviewed perceived patients' characteristics as factors associated with adherence. Nonetheless, participants had conflicting conclusions on the direction of the effect. Previous studies have established the impact of adolescents' characteristics on poor diabetes control and those included age, gender, and duration of diabetes. Older adolescents and those who had longer disease durations were more likely to have poor adherence (5, 59, 75, 80-82). With regards to gender, some studies suggested that adherence with boys comes with greater difficulties (107), whereas other studies have shown poorer adherence among girls (75, 82, 83).

Adolescents had various perceptions particularly in relation to “feeling different”. Adolescents argued that they felt different than everyone whether at home, at school, or even among other family members. They also perceived diabetes as being restrictive to many daily activities and they felt left out from many activities. As suggested by previous studies, those feelings of confused identity can result in more frustrations towards the disease and eventually result in worse diabetes management (84). It could additionally lead to adolescents ignoring essential self-care tasks in the presence of others to avoid the unwanted attention that would further highlight their insecurity of feeling different (108, 109).

Psychological status was also expressed as a potential contributor to adherence to medications or other self-care tasks. Participants agreed that when they feel upset or depressed, they tend to have lower adherence levels as opposed to when they are feeling well. It is noteworthy to mention that the prevalence of mood and anxiety disorders is relatively high among adolescent population especially among those with T1DM (17, 110, 111). Interestingly, it was also found that among adolescents with T1DM, those who had poorer control had higher rates of depression compared to those with optimal glycemic control (111). Additionally, previous studies found that feeling depressed or anxious (without meeting the disease diagnosis criteria) was linked to poorer adherence (112, 113).

Participants agreed about the significance of knowledge on improving adherence, taking into consideration the ability to apply that knowledge. The knowledge was gained mainly through experience with diabetes or ‘trial and error’. Previous research has failed to demonstrate a positive association between knowledge and glycemic control among adolescents with T1DM (114). However, a recent study has found that the causal knowledge of biochemical processes related to glucose regulations was able to explain 17% of the variance in glucose control (115). Such knowledge made it easier for adolescents to store information and retrieve them when needed and improved their problem solving skills, hence, it can foster adherence (115). Nonetheless, when the knowledge was in relation to diabetes complications, participants had mixed viewpoints on the direction of that effect on adherence. The personalities of adolescents could determine how they react to their knowledge of diabetes complications and whether or not they will be adherent to their diabetes regimen. A previous study that assessed the knowledge of children and adolescents with T1DM, reported that participants knew and were willing to know more about all short- and long-term consequences. However, this study did not discuss the burden of these perceptions on adolescent’s behavior or psychology (116).

Parents play a crucial role in diabetes management and control as they usually share that responsibility with adolescents. Therefore, parent-adolescent relationship should be balanced. Too strict follow up and control was perceived to have a negative impact on adherence, whereas letting go sometimes and the trust relationship were associated with better outcomes. This is in line with the findings that Authoritative parenting style, which is characterized by warmth and behavioral control, was associated with better adherence (63, 65-67). Parents identified some beneficial aspects of support to improve adherence and those included; reminding them to perform self-care tasks, allowing some freedom, and recognizing adolescent’s efforts towards achieving better control (117). Moreover, previous studies have indicated that when adolescents proved to have a responsible behavior towards self-care and management, this yielded an overall more positive relationship (118-120). Parental motivation and support were considered a cornerstone towards optimal adherence among adolescents with T1DM. There was a consensus that motivation by reward is the strongest facilitator to enhanced adherence. Teaching parents to use incentives to improve adherence among adolescents with T1DM is a common practice and it was found to have a positive impact on adherence and glycemic control (121-124). Arguments about the economic impact of financial incentives were raised however, as long as the potential savings associated with optimal glycemic control overcome the cost of the incentives, this method can be used to facilitate health improvement (121).

Adolescents usually spend a considerable amount of time with their friends therefore, the impact of peers on adherence and peer support were widely expressed. Participants had conflicting opinions with that regard. Some adolescents felt that their peers had a role in enhancing their adherence through providing support during hypoglycemic episodes, reminding them of some self-care tasks, or even providing psychological support when needed. However other adolescents perceived that support to be bothering because they felt that their peers are acting like their guardians or are treating them in a special way. This is in line with previous research that identified peer support as instrumental to optimal diabetes management away from home (118). Whereas other adolescents avoided performing self-care tasks in front of peers to avoid the unnecessary attention and special treatment (74, 108). Additionally, adolescents with good glycemic control were found to be more comfortable including their peers in disease management (125). Overall available evidence suggests that adolescents perceive peers to be positively impacting adherence, however inconclusive conclusions were drawn from quantitative research on the nature of that influence (5, 17, 74, 75, 126).

Support from other patients with diabetes or their caregivers was perceived to have a positive impact on knowledge and psychology, eventually leading to improved adherence. A major form of support that was discussed is regarding diabetes camps. Diabetes camp experience was perceived to be of great benefit in terms or education and psychological support. Adolescents expressed that attending the diabetes camp was a motivational positive experience especially that they were able to see others with diabetes and to learn with and from them. Bawasil Camp is organized annually by Qatar Diabetes Association and it targets newly diagnosed children with diabetes (127). Tahadi Camp is also held annually, and it targets adolescents with T1DM to encourage them through self-care education, empowerment, and problem-solving sessions (128). Diabetes camps have become increasingly held worldwide as they were found to have positive impacts on knowledge (129-132), adherence (129, 130, 133), psychology (129, 130), and metabolic control (132, 133).

Another form of support that was commonly discussed by caregivers of adolescents was the support through social media or forums such as a WhatsApp group that involves caregivers of children with diabetes. Caregivers found it helpful in terms of immediate response to emergency situations or to any queries that require spontaneous actions, sharing experiences or coping strategies and making them feel that they are not alone, and providing psychological support to each other when needed. Previous research has explored the effect of photo sharing through online platforms in providing support for caregivers of children with T1DM. It was concluded that photo sharing helped in expressing feelings, creating a storyline for experience, sharing coping strategies, building awareness, and providing a source of support (134). Another study have also assessed the impact of patient education through WhatsApp groups on knowledge of the disease and glycemic control and it proved that education through WhatsApp can help improve knowledge and reduce complications without a direct effect on glycemic control (135). Additionally, a recent study conducted in Saudi Arabia have presented screens for a future gamified mobile application that can improve adherence which was designed based on suggestions of caregivers. The application addressed all aspects of adherence including eating habits, physical exercise, blood glucose monitoring, and medication adherence (136). However, the implementation and effectiveness of such applications are yet to be determined. Some insulin-related factors were perceived as potential barriers to adherence. Insulin pens or injections were commonly noted to leave marks at injection sites, and they are sometimes painful, time consuming, and associated with weight gain. Unlike previous studies, none of the adolescents indicated having phobia or fear of injections (76, 77), however, some parents stated that they had injection phobias and this made the acceptance of disease and its management more challenging. Intentional over and underdosing and insulin omission are frequently reported acts among adolescents with T1DM (137). These acts are irrespective of insulin delivery method. Omitting insulin dose was sometimes caused by the pain associated with injections or ignoring/forgetting the dose whereas overdosing was usually mediated by an intention to eat more carbohydrates or as an act of suicidal ideations (137). Additionally, females were more likely to manipulate insulin doses for weight reduction (108, 137-139).

Moreover, participants had mixed thoughts about diabetes devices. Adolescents and caregivers perceived the devices to be of extreme benefit, however, they also reported some barriers that are associated with the device use. Those barriers include not preferring to be attached to wires or to have cannula inserted, feeling restricted to perform some activities or to wear whatever they like, in addition to burden of maintaining adhesion of the device, and coping with the device alarming. Evidence from available literature suggests similar hassles of device wearing and other device related hassles such as responding to alarms and calibrating devices (140). Those barriers were similar to the barriers perceived by adults with T1DM and clinicians (141, 142). Trying to optimize device wearing and to cope with the devices were sometimes perceived as helpful. Until fully automated insulin delivery systems are implemented, clinicians and educators should be able to fully introduce the devices to patients with all the positive and negative expectations of device use prior to implementation (140).

Attending the clinic was an experience that was commonly discussed, and through that experience, many factors emerged in relation to the providers, healthcare system and the provided counseling. Healthcare providers are main contributors to diabetes management; therefore, their relationship, communication, and support are factors contributing to adherence. Participants had conflicting opinions on the amount of support provided by providers. Most of them felt that they are supportive, however, others felt that due to their delayed appointments and some communication barriers, the relationship is not that strong. Adolescents also explicitly stated that they felt a deficit of emotional support. This is in line with previous research that identified that good communication skills and relationship by healthcare providers are considered as facilitators of adherence and can result in an overall positive clinic experience. Whereas poor communication results in confusions with regards to treatment regimens and makes diabetes control more challenging (84, 87, 143-145). Inclusion in the decision-making and considering patient’s autonomy is also critical in adherence improvement, especially among this population of newly autonomous adolescents (85-87). An important point that raised was regarding healthcare providers being from a different culture, and in case of T1DM, this elicited an additional challenge because it highly relies on identifying food ingredients for carb calculations which is not easy to achieve due to cultural differences. Providing healthcare providers with resources that comprehensively address common food ingredients can be useful in easing the communication between patients and healthcare providers.

The healthcare system in Qatar is easily accessible and is provided at a subsidized rate. Medications are also highly subsidized for all residents. However, many participants emphasized the fact that diabetes is not insulin, it is way more than that. Although insulin is subsidized, however, other essential medical supplies and devices are costly. Additionally, obtaining healthy dietary alternatives and joining sports clubs are costly. This makes adherence influenced by the financial ability of the family. Previous studies have identified that cost-related concerns including device and supplies costs are the most common endorsed barriers to device use (140). Overall, the general cost of care was also identified as one of the most common barriers to care (87).

School plays an important role when it comes to diabetes management since adolescents spend a considerable amount of time at school. Previous research has identified some challenges that adolescents face at school such as availability of unhealthy food options, lack of adequate knowledge about diabetes among school personnel, and strict rules that hinder participation of adolescents with diabetes in any activity (108, 146-148). Similarly, adolescents in our study indicated that they were annoyed by the fact that they had to waste the break time with the nurse to perform self-care tasks. Additionally, most participants addressed issues related to school nurses. Although some participants indicated that school nurses had positive effects on adolescent's psychology and glucose control during school times, several participants expressed that their assistance is limited and that they expect a more involved and significant role. A previous study that assessed school nurses' experiences with regards to dealing with adolescents with T1DM addressed several challenges that they face as they care for students with T1DM (149). School nurses admitted that they are not diabetes experts and that their knowledge is sometimes outdated, so, they need self-development and continued education. They also stated that they prefer to have direct communications with student's physicians instead of having to rely on parents to provide the care plan. Moreover, they also expressed that they need collaborations from class teachers since they spend the majority of their time with students and they have the closest interactions with them (149).

Finally, some culture and environment related barriers were also identified that affected dietary adherence such as the widespread of unhealthy food advertisements and the difficulty in obtaining healthy alternatives. Other exercise related barriers identified include the lack of medical support in gyms or sports clubs. Those barriers are modifiable; however, they warrant state initiatives and population awareness to support healthier lifestyles for all.

5.3.Strengths and limitations

Up to our knowledge, this study is the first in Qatar assessing adherence among adolescents with T1DM. It also added to the available body of evidence regarding the relationship between adherence and glycemic control. This study also used objective data (meter downloads) to assess adherence and did not rely on any subjective data. This helped in getting more robust data that presents actual patient behaviors.

However, this comes with strengths and limitations. Relying on BGMF as a proxy for adherence is generally a well-established method, nevertheless, it only reflects adherence related to blood glucose monitoring without taking into consideration other essential aspects of diabetes adherence. Additionally, relying on meter downloads only makes the data subjected to some technological errors in addition to intentional or unintentional manipulations of meter readings reported earlier (150). Moreover, due to the retrospective study design utilized, some data was missing in addition to the difficulty to confirm whether patients used more than one device for blood glucose monitoring. Finally, convenient sampling technique was used due to the absence of a sampling frame.

Similarly, this study was the first in Qatar and the MENA region to qualitatively establish barriers and strengths to adherence among adolescents with T1DM from the perspectives of patients and their caregivers. This study is qualitative in nature which allowed the in depth understanding of the factors impacting adherence. Moreover, since this study interviewed adolescents and their caregivers, the integration of their perspectives and data triangulation allowed the in depth understanding and the trustworthy conclusion. Additionally, we followed best practices for conducting this study and ensuring quality outcomes such as interviewing patients and caregivers with diverse characteristics to ensure maximum variability and credible conclusions. However, this study has some limitations, some of which are inherent to its qualitative nature. Purposive sampling technique used might be associated with some biases that are not accounted for. Furthermore, since adolescents were interviewed, a possibility for a power relationship could have impacted the findings. Additionally, online interviews, especially those without video communication made the interpretation of facial expressions and hand gestures challenging. The interviewer perspective could have also impacted the transparency and data interpretation, however, all researchers had access to all documents and were involved in analysis and reporting. Finally, although all adolescents with T1DM in Qatar are treated at Sidra Medicine, some might be following up in other private clinics. and were missed in our study. This can affect the generalizability of the study the findings to other settings.

5.4.Recommendations for future research

This study provides the basis for many future studies. This study has found a very low level of adherence among adolescents with T1DM. This result warrants the need to facilitate more frequent blood glucose monitoring through directed interventions making use of technological advancements. Furthermore, since this study utilized only BGMF to determine adherence, future studies could be done to assess the level of adherence more comprehensively. Moreover, conducting a systematic review to bring together all the available evidence on methods used to assess adherence among adolescents with T1DM in a systematic way, would be of an additional benefit. Additionally, this study confirmed that more than 90% of adolescents had uncontrolled diabetes, this alarming percentage warrants further explorations of other reasons and contributors to this very poor glycemic control given that adherence only contributed to 9% of the variance.

Moreover, the qualitative phase of this study sets the base for other researches in different areas. This study assessed the perspectives of adolescents and caregivers; however, it would be also important to know the perspectives of healthcare providers including physicians and nurses who provide care for those adolescents. Additionally, our study included only mothers as they were always stated as the primary caregiver, however it might be of additional benefit to get the viewpoints of fathers. All interviewees were Arabic-speaking and were from closely related cultures, however, Qatar is a country that includes a diverse population, hence extending the research to other cultures might lead to different conclusions. Finally, since this study was able to identify barriers and strengths to adherence, future research should utilize those factors identified in order to design interventions that aim at improving the overall adherence and metabolic control among this vulnerable population.

5.5.Conclusion

In conclusion, this study was the first in Qatar to explore the levels of adherence among adolescents with T1DM in Qatar and it found that adolescents with T1DM in Qatar have a very poor adherence rates of around 40 % with more than 90% having uncontrolled diabetes mellitus. Moreover, adherence was a significant predictor for glycemic control, however, it only explained 9% of the variability. This warrants further detailed exploration of other possible predictors of poor glycemic control that is highly prevalent among adolescent population in Qatar.

This study also contributed to the existing body of knowledge through comprehensively identifying all barriers and strengths to adherence from perspectives of adolescents and their caregivers in Qatar. Factors affecting adherence are multifactorial in nature and our study yielded five general themes that impact adherence. The generated themes summarized factors related to patient, society, medications and devices, healthcare system, school and environment. Patient-related factors included some patient characteristics, perceptions, attitudes, knowledge, and other coping strategies that were linked directly or indirectly to adherence. Community influence was a major theme that included factors related to parental and peer influence and support. It also included factors related to support from other patients with diabetes. Insulin and devices related barriers were also identified and they were associated with adherence. Additionally, healthcare system-related barriers summarized factors in relation to healthcare providers, counselling and education, system and administration, cost, and information sources. Finally, the last theme addressed factors influencing adherence that are related to lifestyle, school and environment. Collectively, this work yielded a comprehensive understanding of factors associated with adherence and they require a lot of attention to be able to optimize adherence among adolescents with T1DM, hence, achieve glycemic control and prevent short- and long-term complications.

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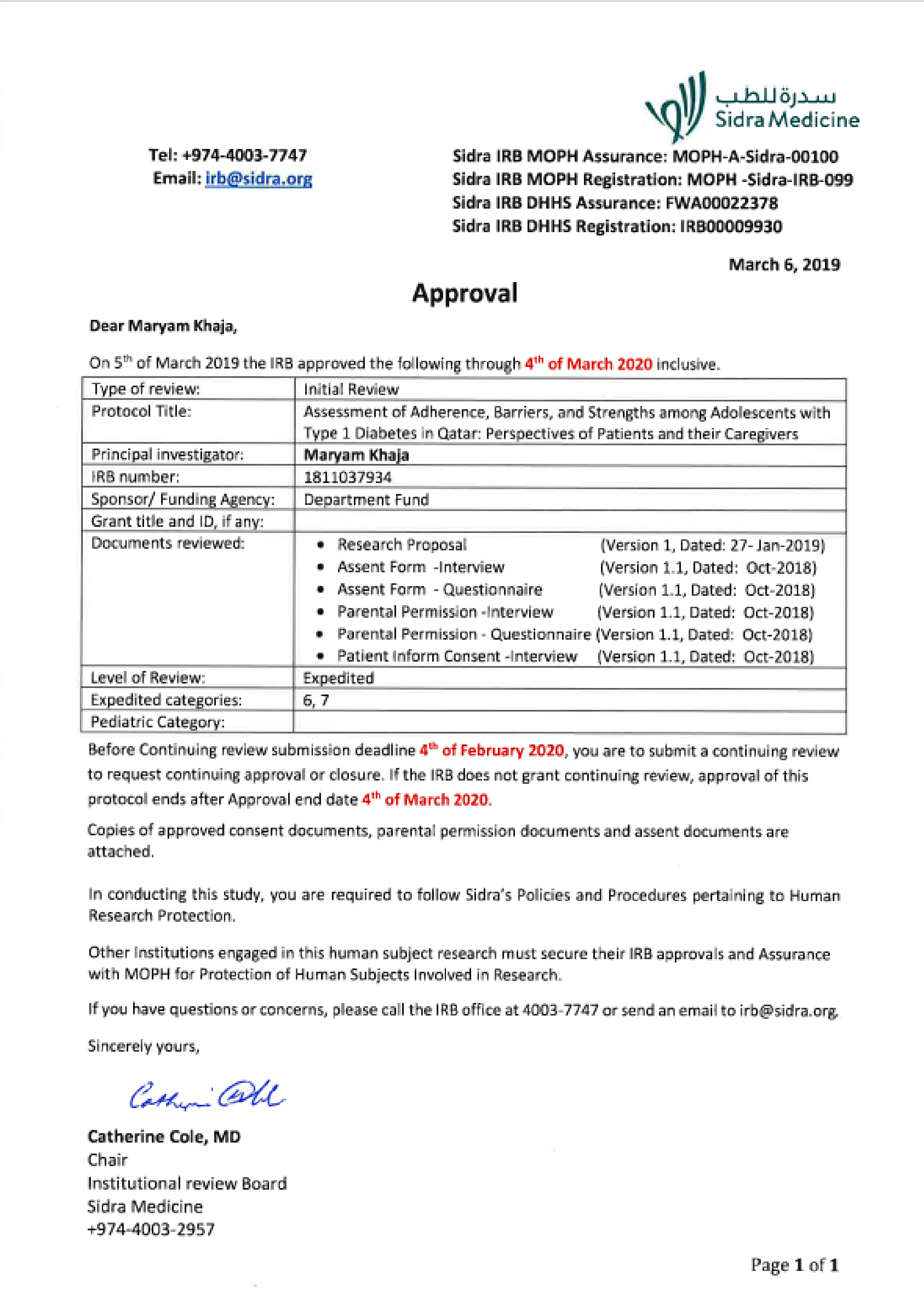
APPENDEX A: ETHICAL APPROVAL LETTERS



سدرة للطب
Sidra Medicine

Tel: +974-4003-7747
Email: irb@sidra.org

Sidra IRB MOPH Assurance: MOPH-A-Sidra-00100
Sidra IRB MOPH Registration: MOPH -Sidra-IRB-099
Sidra IRB DHHS Assurance: FWA00022378
Sidra IRB DHHS Registration: IRB00009930

March 6, 2019

Approval

Dear Maryam Khaja,

On 5th of March 2019 the IRB approved the following through **4th of March 2020** inclusive.

Type of review:	Initial Review
Protocol Title:	Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers
Principal investigator:	**Maryam Khaja**
IRB number:	1811037934
Sponsor/ Funding Agency:	Department Fund
Grant title and ID, if any:	
Documents reviewed:	• Research Proposal (Version 1, Dated: 27- Jan-2019) • Assent Form -Interview (Version 1.1, Dated: Oct-2018) • Assent Form - Questionnaire (Version 1.1, Dated: Oct-2018) • Parental Permission -Interview (Version 1.1, Dated: Oct-2018) • Parental Permission - Questionnaire (Version 1.1, Dated: Oct-2018) • Patient Inform Consent -Interview (Version 1.1, Dated: Oct-2018)
Level of Review:	Expedited
Expedited categories:	6, 7
Pediatric Category:	

Before Continuing review submission deadline **4th of February 2020**, you are to submit a continuing review to request continuing approval or closure. If the IRB does not grant continuing review, approval of this protocol ends after Approval end date **4th of March 2020**.

Copies of approved consent documents, parental permission documents and assent documents are attached.

In conducting this study, you are required to follow Sidra's Policies and Procedures pertaining to Human Research Protection.

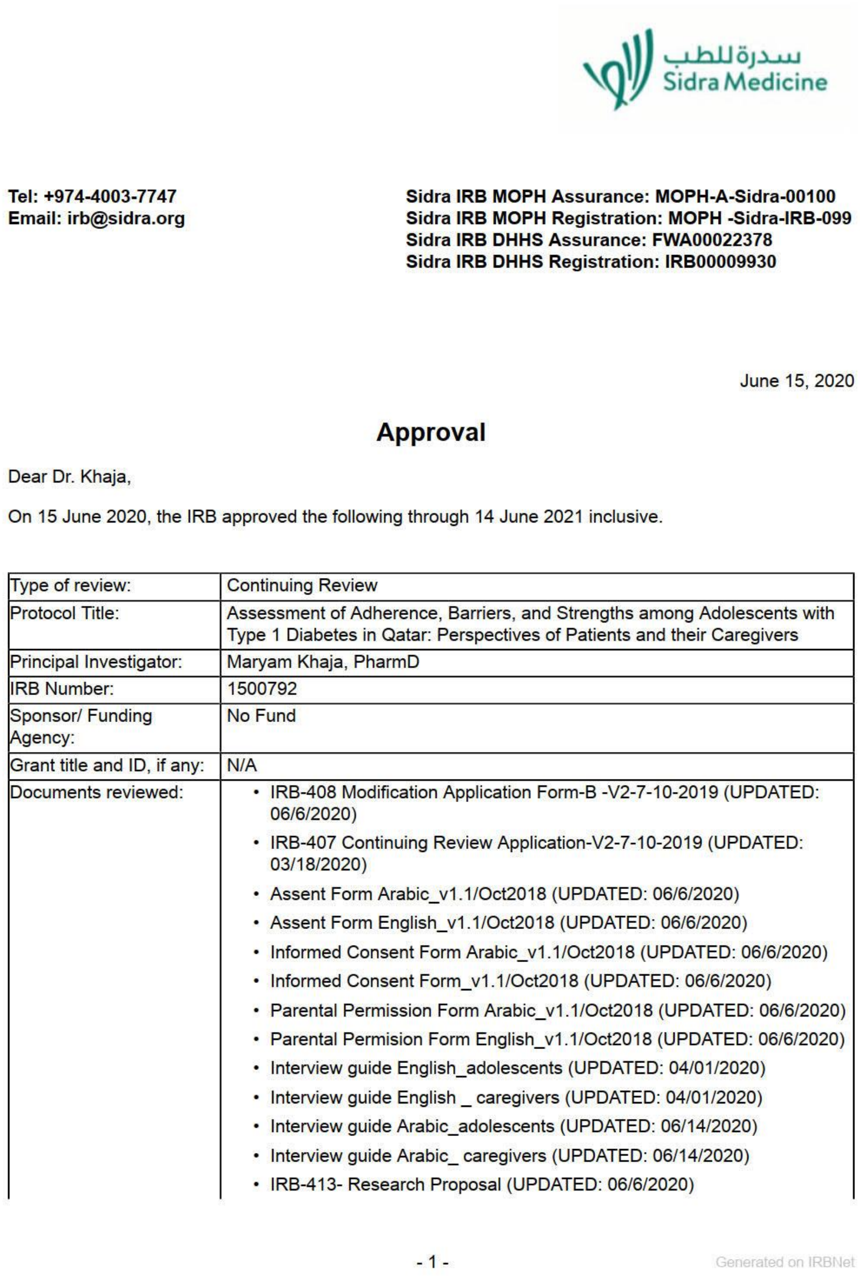
Other Institutions engaged in this human subject research must secure their IRB approvals and Assurance with MOPH for Protection of Human Subjects Involved in Research.

If you have questions or concerns, please call the IRB office at 4003-7747 or send an email to irb@sidra.org.

Sincerely yours,

Catherine Cole, MD
Chair
Institutional review Board
Sidra Medicine
+974-4003-2957

Page **1** of **1**



Tel: +974-4003-7747
Email: irb@sidra.org

Sidra IRB MOPH Assurance: MOPH-A-Sidra-00100
Sidra IRB MOPH Registration: MOPH -Sidra-IRB-099
Sidra IRB DHHS Assurance: FWA00022378
Sidra IRB DHHS Registration: IRB00009930

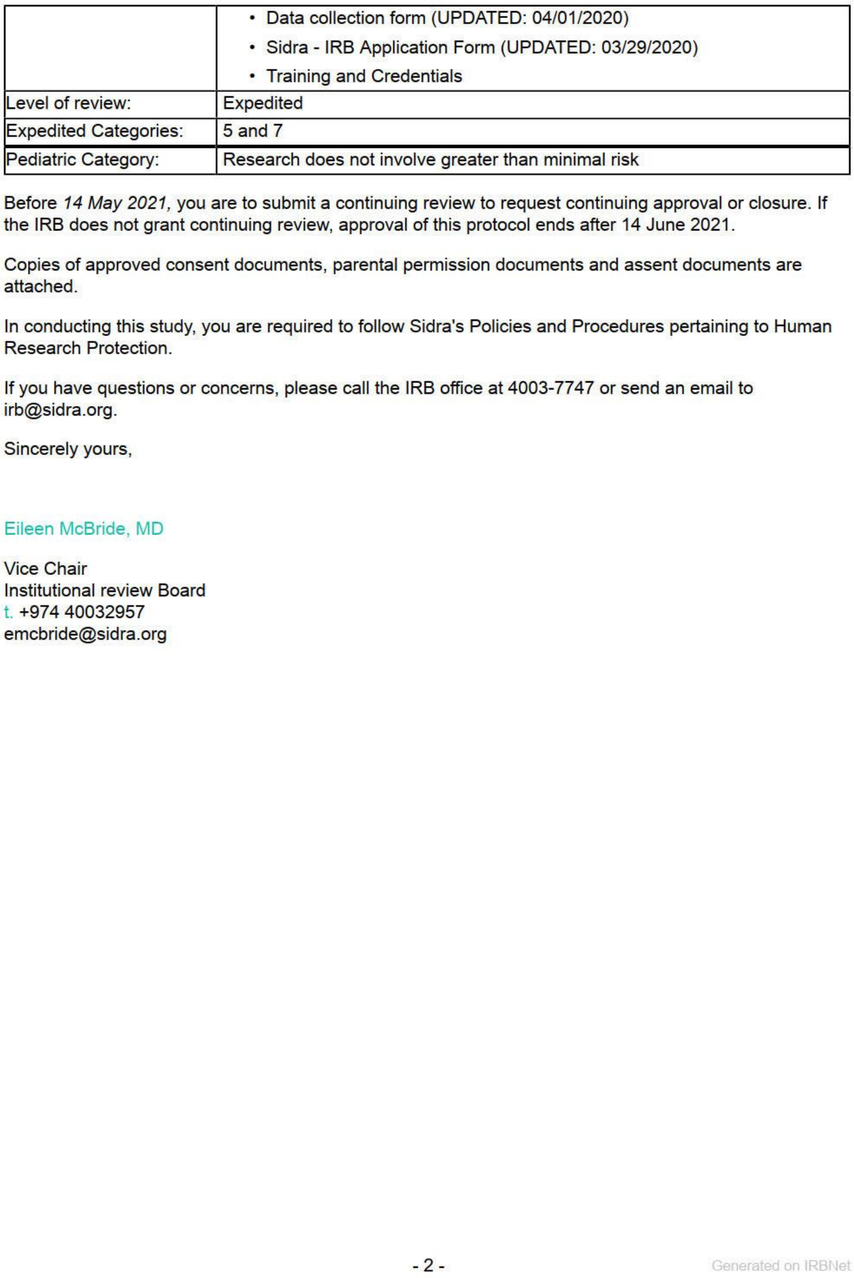
June 15, 2020

Approval

Dear Dr. Khaja,

On 15 June 2020, the IRB approved the following through 14 June 2021 inclusive.

Type of review:	Continuing Review
Protocol Title:	Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers
Principal Investigator:	Maryam Khaja, PharmD
IRB Number:	1500792
Sponsor/ Funding Agency:	No Fund
Grant title and ID, if any:	N/A
Documents reviewed:	• IRB-408 Modification Application Form-B -V2-7-10-2019 (UPDATED: 06/6/2020) • IRB-407 Continuing Review Application-V2-7-10-2019 (UPDATED: 03/18/2020) • Assent Form Arabic_v1.1/Oct2018 (UPDATED: 06/6/2020) • Assent Form English_v1.1/Oct2018 (UPDATED: 06/6/2020) • Informed Consent Form Arabic_v1.1/Oct2018 (UPDATED: 06/6/2020) • Informed Consent Form_v1.1/Oct2018 (UPDATED: 06/6/2020) • Parental Permission Form Arabic_v1.1/Oct2018 (UPDATED: 06/6/2020) • Parental Permision Form English_v1.1/Oct2018 (UPDATED: 06/6/2020) • Interview guide English_adolescents (UPDATED: 04/01/2020) • Interview guide English _ caregivers (UPDATED: 04/01/2020) • Interview guide Arabic_adolescents (UPDATED: 06/14/2020) • Interview guide Arabic_ caregivers (UPDATED: 06/14/2020) • IRB-413- Research Proposal (UPDATED: 06/6/2020)



	- Data collection form (UPDATED: 04/01/2020) - Sidra - IRB Application Form (UPDATED: 03/29/2020) - Training and Credentials
Level of review:	Expedited
Expedited Categories:	5 and 7
Pediatric Category:	Research does not involve greater than minimal risk

Before *14 May 2021,* you are to submit a continuing review to request continuing approval or closure. If the IRB does not grant continuing review, approval of this protocol ends after 14 June 2021.

Copies of approved consent documents, parental permission documents and assent documents are attached.

In conducting this study, you are required to follow Sidra's Policies and Procedures pertaining to Human Research Protection.

If you have questions or concerns, please call the IRB office at 4003-7747 or send an email to irb@sidra.org.

Sincerely yours,

Eileen McBride, MD

Vice Chair
Institutional review Board
t. +974 40032957
emcbride@sidra.org

- 2 -

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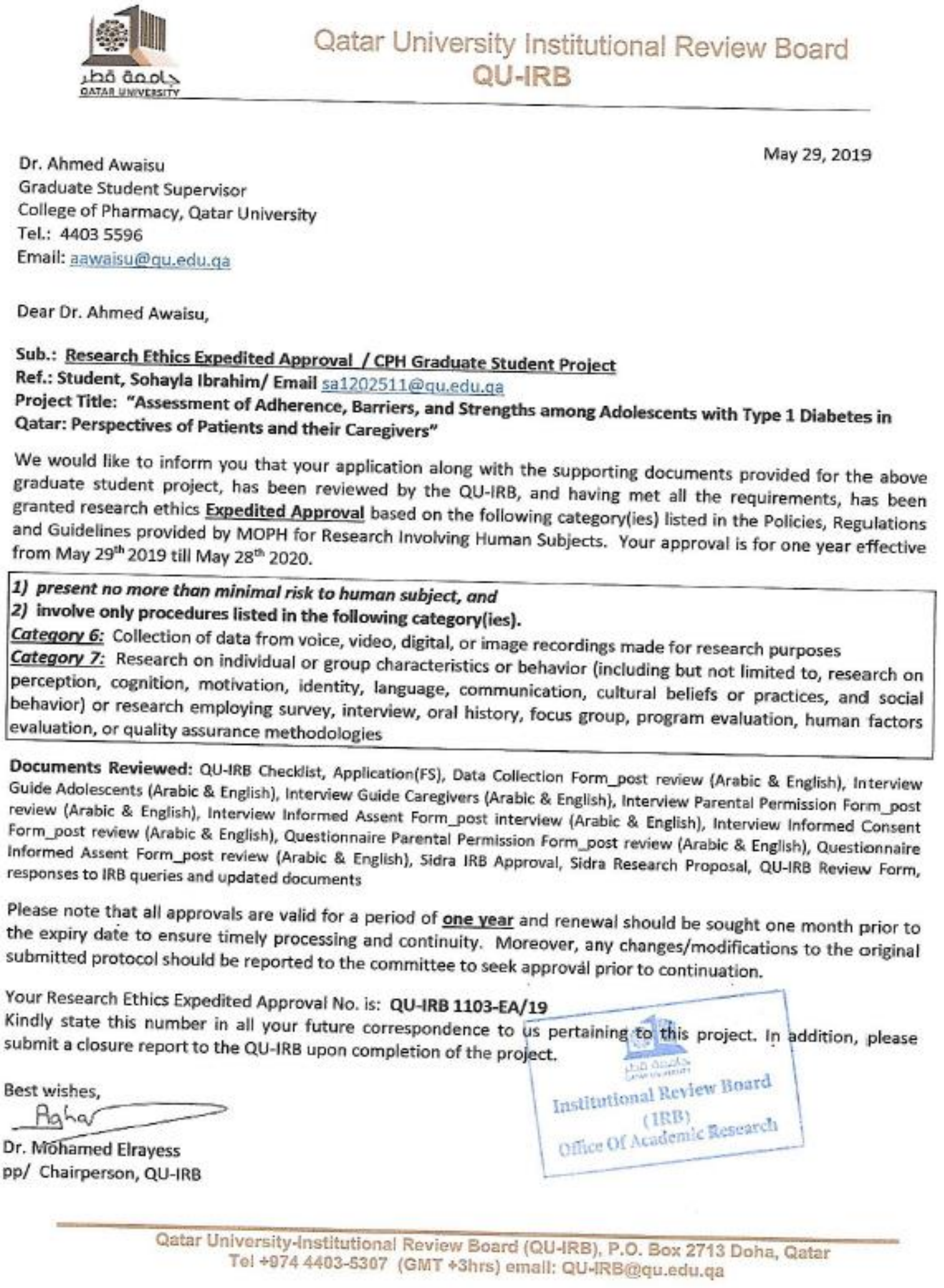


Qatar University Institutional Review Board
QU-IRB

May 29, 2019

Dr. Ahmed Awaisu
Graduate Student Supervisor
College of Pharmacy, Qatar University
Tel.: 4403 5596
Email: aawaisu@qu.edu.qa

Dear Dr. Ahmed Awaisu,

Sub.: Research Ethics Expedited Approval / CPH Graduate Student Project
Ref.: Student, Sohayla Ibrahim/ Email sa1202511@qu.edu.qa
Project Title: "Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers"

We would like to inform you that your application along with the supporting documents provided for the above graduate student project, has been reviewed by the QU-IRB, and having met all the requirements, has been granted research ethics **Expedited Approval** based on the following category(ies) listed in the Policies, Regulations and Guidelines provided by MOPH for Research Involving Human Subjects. Your approval is for one year effective from May 29th 2019 till May 28th 2020.

1) present no more than minimal risk to human subject, and
2) involve only procedures listed in the following category(ies).
Category 6: Collection of data from voice, video, digital, or image recordings made for research purposes
Category 7: Research on individual or group characteristics or behavior (including but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

Documents Reviewed: QU-IRB Checklist, Application(FS), Data Collection Form_post review (Arabic & English), Interview Guide Adolescents (Arabic & English), Interview Guide Caregivers (Arabic & English), Interview Parental Permission Form_post review (Arabic & English), Interview Informed Assent Form_post interview (Arabic & English), Interview Informed Consent Form_post review (Arabic & English), Questionnaire Parental Permission Form_post review (Arabic & English), Questionnaire Informed Assent Form_post review (Arabic & English), Sidra IRB Approval, Sidra Research Proposal, QU-IRB Review Form, responses to IRB queries and updated documents

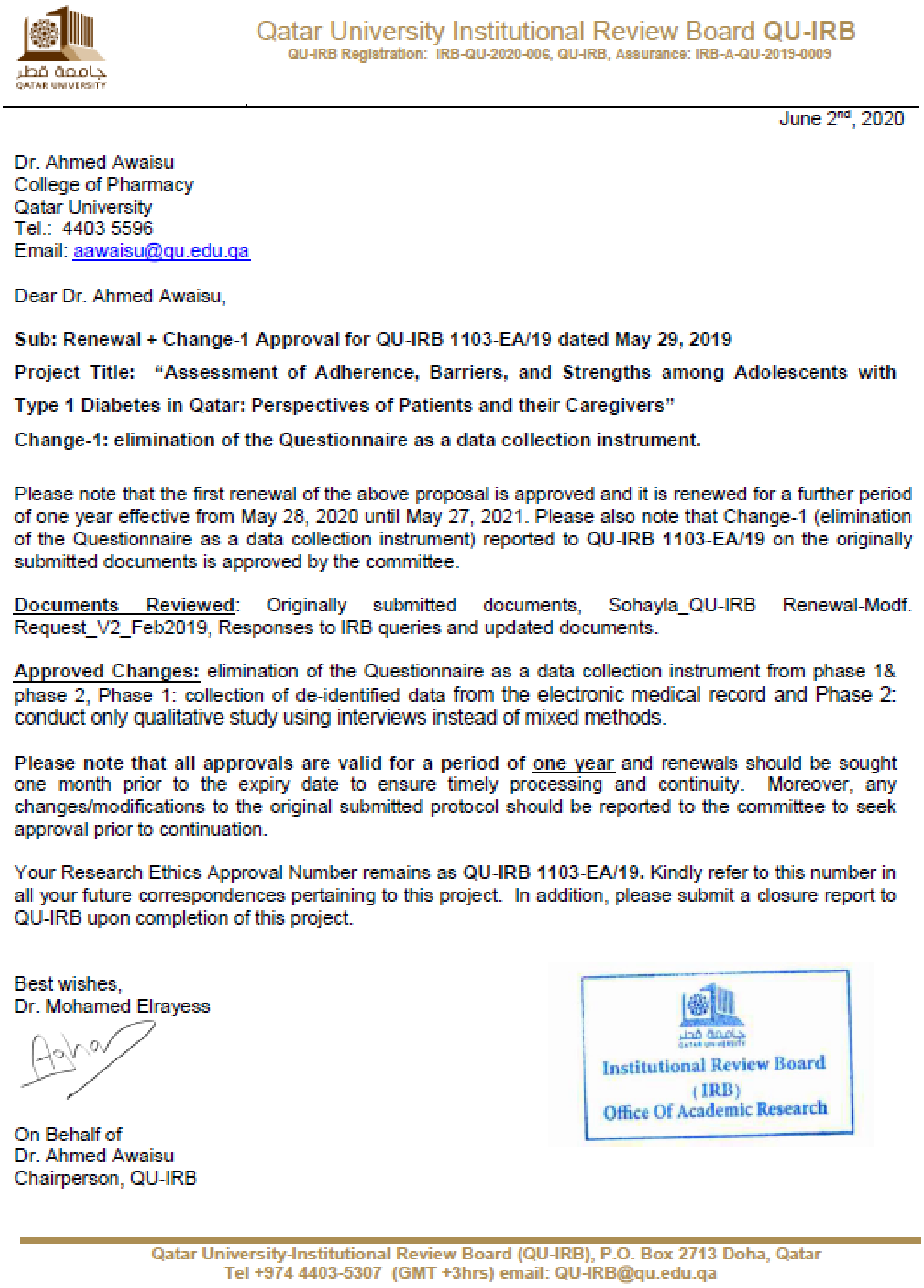
Please note that all approvals are valid for a period of **one year** and renewal should be sought one month prior to the expiry date to ensure timely processing and continuity. Moreover, any changes/modifications to the original submitted protocol should be reported to the committee to seek approval prior to continuation.

Your Research Ethics Expedited Approval No. is: **QU-IRB 1103-EA/19**
Kindly state this number in all your future correspondence to us pertaining to this project. In addition, please submit a closure report to the QU-IRB upon completion of the project.

Institutional Review Board
(IRB)
Office Of Academic Research

Best wishes,
Aghar

Dr. Mohamed Elrayess
pp/ Chairperson, QU-IRB



Qatar University Institutional Review Board **QU-IRB**
QU-IRB Registration: IRB-QU-2020-006, QU-IRB, Assurance: IRB-A-QU-2019-0009

June 2nd, 2020

Dr. Ahmed Awaisu
College of Pharmacy
Qatar University
Tel.: 4403 5596
Email: aawaisu@qu.edu.qa

Dear Dr. Ahmed Awaisu,

Sub: Renewal + Change-1 Approval for QU-IRB 1103-EA/19 dated May 29, 2019

Project Title: "Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers"

Change-1: elimination of the Questionnaire as a data collection instrument.

Please note that the first renewal of the above proposal is approved and it is renewed for a further period of one year effective from May 28, 2020 until May 27, 2021. Please also note that Change-1 (elimination of the Questionnaire as a data collection instrument) reported to **QU-IRB 1103-EA/19** on the originally submitted documents is approved by the committee.

Documents Reviewed: Originally submitted documents, Sohayla_QU-IRB Renewal-Modf. Request_V2_Feb2019, Responses to IRB queries and updated documents.

Approved Changes: elimination of the Questionnaire as a data collection instrument from phase 1& phase 2, Phase 1: collection of de-identified data from the electronic medical record and Phase 2: conduct only qualitative study using interviews instead of mixed methods.

Please note that all approvals are valid for a period of one year and renewals should be sought one month prior to the expiry date to ensure timely processing and continuity. Moreover, any changes/modifications to the original submitted protocol should be reported to the committee to seek approval prior to continuation.

Your Research Ethics Approval Number remains as QU-IRB **1103-EA/19.** Kindly refer to this number in all your future correspondences pertaining to this project. In addition, please submit a closure report to QU-IRB upon completion of this project.

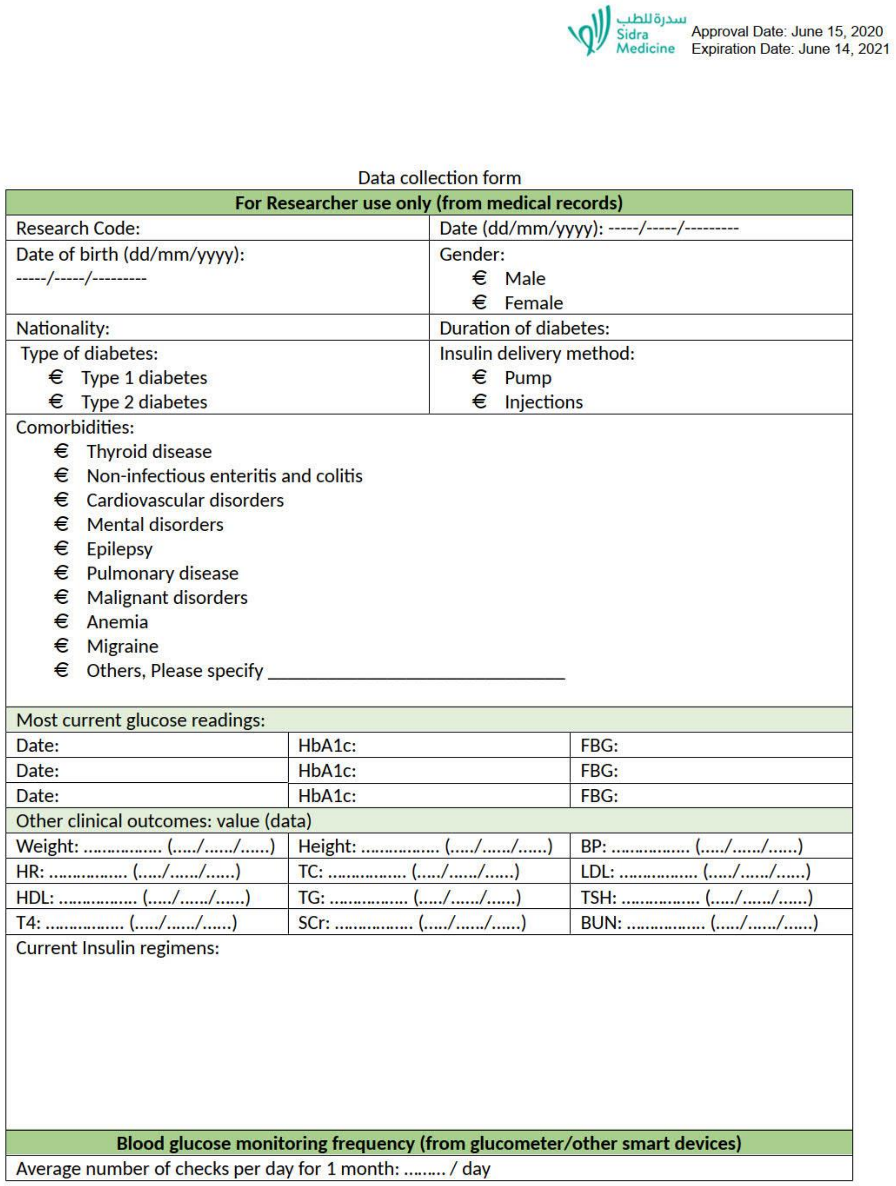
Best wishes,
Dr. Mohamed Elrayess

On Behalf of
Dr. Ahmed Awaisu
Chairperson, QU-IRB

Institutional Review Board
(IRB)
Office Of Academic Research

Qatar University-Institutional Review Board (QU-IRB), P.O. Box 2713 Doha, Qatar
Tel +974 4403-5307 (GMT +3hrs) email: QU-IRB@qu.edu.qa

APPENDEX B: DATA COLLECTION FORM



سدرة للطب
Sidra
Medicine

Approval Date: June 15, 2020
Expiration Date: June 14, 2021

Data collection form

For Researcher use only (from medical records)

Research Code:	Date (dd/mm/yyyy): -----/-----/---------
Date of birth (dd/mm/yyyy): -----/-----/---------	Gender: € Male € Female
Nationality:	Duration of diabetes:
Type of diabetes: € Type 1 diabetes € Type 2 diabetes	Insulin delivery method: € Pump € Injections

Comorbidities:

- € Thyroid disease
- € Non-infectious enteritis and colitis
- € Cardiovascular disorders
- € Mental disorders
- € Epilepsy
- € Pulmonary disease
- € Malignant disorders
- € Anemia
- € Migraine
- € Others, Please specify ______________________________

Most current glucose readings:

Date:	HbA1c:	FBG:
Date:	HbA1c:	FBG:
Date:	HbA1c:	FBG:

Other clinical outcomes: value (data)

Weight: .... (...../....../......)	Height: .... (...../....../......)	BP: .... (...../....../......)
HR: .... (...../....../......)	TC: .... (...../....../......)	LDL: .... (...../....../......)
HDL: .... (...../....../......)	TG: .... (...../....../......)	TSH: .... (...../....../......)
T4: .... (...../....../......)	SCr: .... (...../....../......)	BUN: .... (...../....../......)

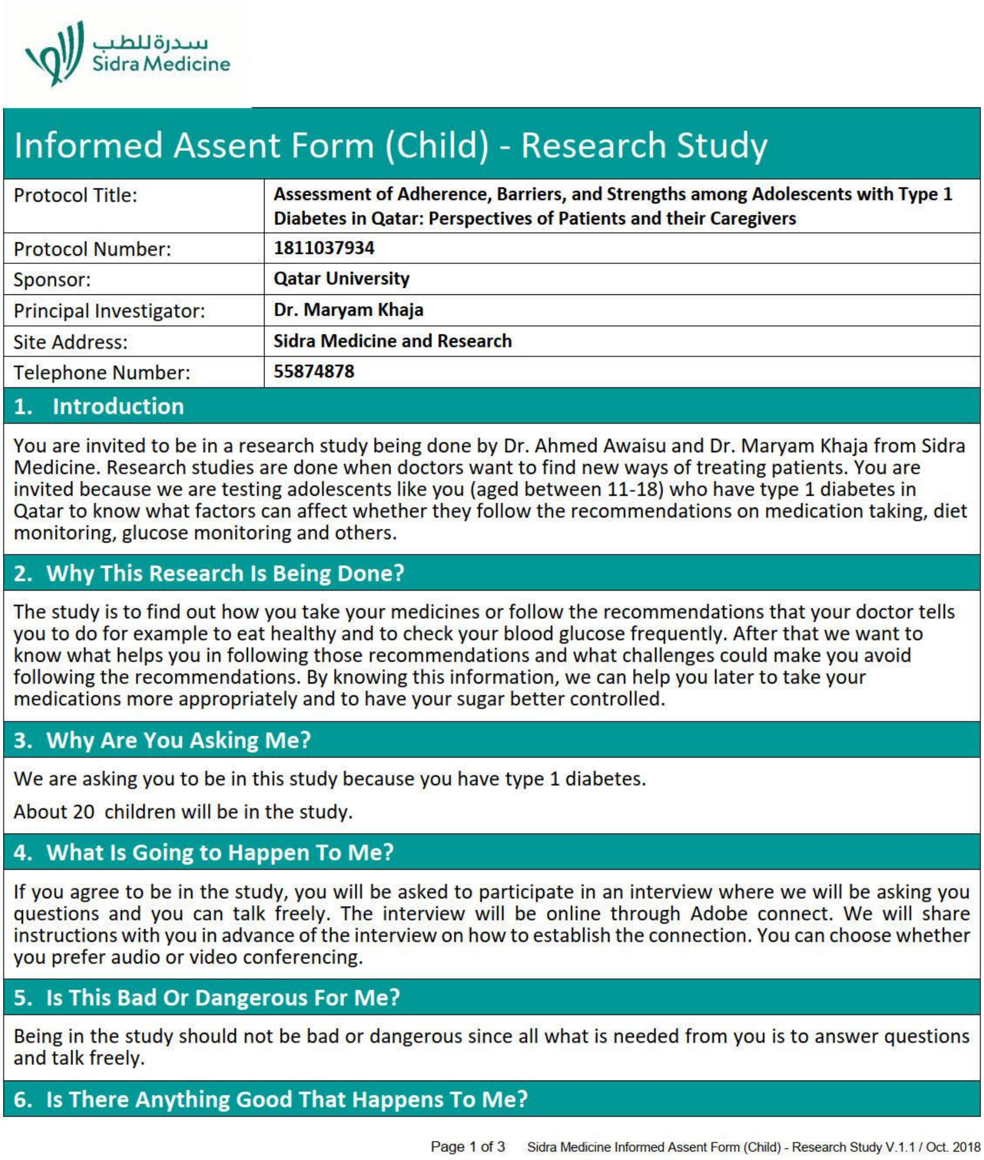
Current Insulin regimens:

Blood glucose monitoring frequency (from glucometer/other smart devices)

Average number of checks per day for 1 month: .... / day

APPENDEX C: INFORMED ASSENT, PARENTAL PERMISSION AND CONSENT FORMS

Sidra Medicine
Approval Date: June 15, 2020
Expiration Date: June 14, 2021



Sidra Medicine

Informed Assent Form (Child) - Research Study

Protocol Title:	**Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers**
Protocol Number:	**1811037934**
Sponsor:	**Qatar University**
Principal Investigator:	**Dr. Maryam Khaja**
Site Address:	**Sidra Medicine and Research**
Telephone Number:	**55874878**

1. Introduction

You are invited to be in a research study being done by Dr. Ahmed Awaisu and Dr. Maryam Khaja from Sidra Medicine. Research studies are done when doctors want to find new ways of treating patients. You are invited because we are testing adolescents like you (aged between 11-18) who have type 1 diabetes in Qatar to know what factors can affect whether they follow the recommendations on medication taking, diet monitoring, glucose monitoring and others.

2. Why This Research Is Being Done?

The study is to find out how you take your medicines or follow the recommendations that your doctor tells you to do for example to eat healthy and to check your blood glucose frequently. After that we want to know what helps you in following those recommendations and what challenges could make you avoid following the recommendations. By knowing this information, we can help you later to take your medications more appropriately and to have your sugar better controlled.

3. Why Are You Asking Me?

We are asking you to be in this study because you have type 1 diabetes.

About 20 children will be in the study.

4. What Is Going to Happen To Me?

If you agree to be in the study, you will be asked to participate in an interview where we will be asking you questions and you can talk freely. The interview will be online through Adobe connect. We will share instructions with you in advance of the interview on how to establish the connection. You can choose whether you prefer audio or video conferencing.

5. Is This Bad Or Dangerous For Me?

Being in the study should not be bad or dangerous since all what is needed from you is to answer questions and talk freely.

6. Is There Anything Good That Happens To Me?

Page 1 of 3 Sidra Medicine Informed Assent Form (Child) - Research Study V.1.1 / Oct. 2018

Being in the study may or may not help you. Nothing really good might happen to you now but your participation will help us to know how we can help you later with your diabetes.

7. Who Is Going To Know About This?

The study is private. However, your parents/guardians, your doctor and nurses will know that you are in the study. If anyone else is given information about you, they will not know your name. A number or initials will be used instead of your name.

8. What Else Should I Know?

No payment will be provided upon your participation in this research.

9. What Happens If I Get Hurt?

You are not expected to get hurt during the study but if for any reason this happens, we will look after you. Please tell Dr. Maryam Khaja, Clinical pharmacist, Sidra Medical and Research Centre, 55874878. or your parent. We have given your parents/guardians information about what to do if you are hurt during the study.

10. Who Can I Talk To Or Ask Questions To?

You can ask me questions now or later. You can also ask Dr. Maryam Khaja, Clinical pharmacist, Sidra Medical and Research Centre, 55874878. questions any time about anything in this study. You can also ask your parents/guardians any questions you might have about this study.

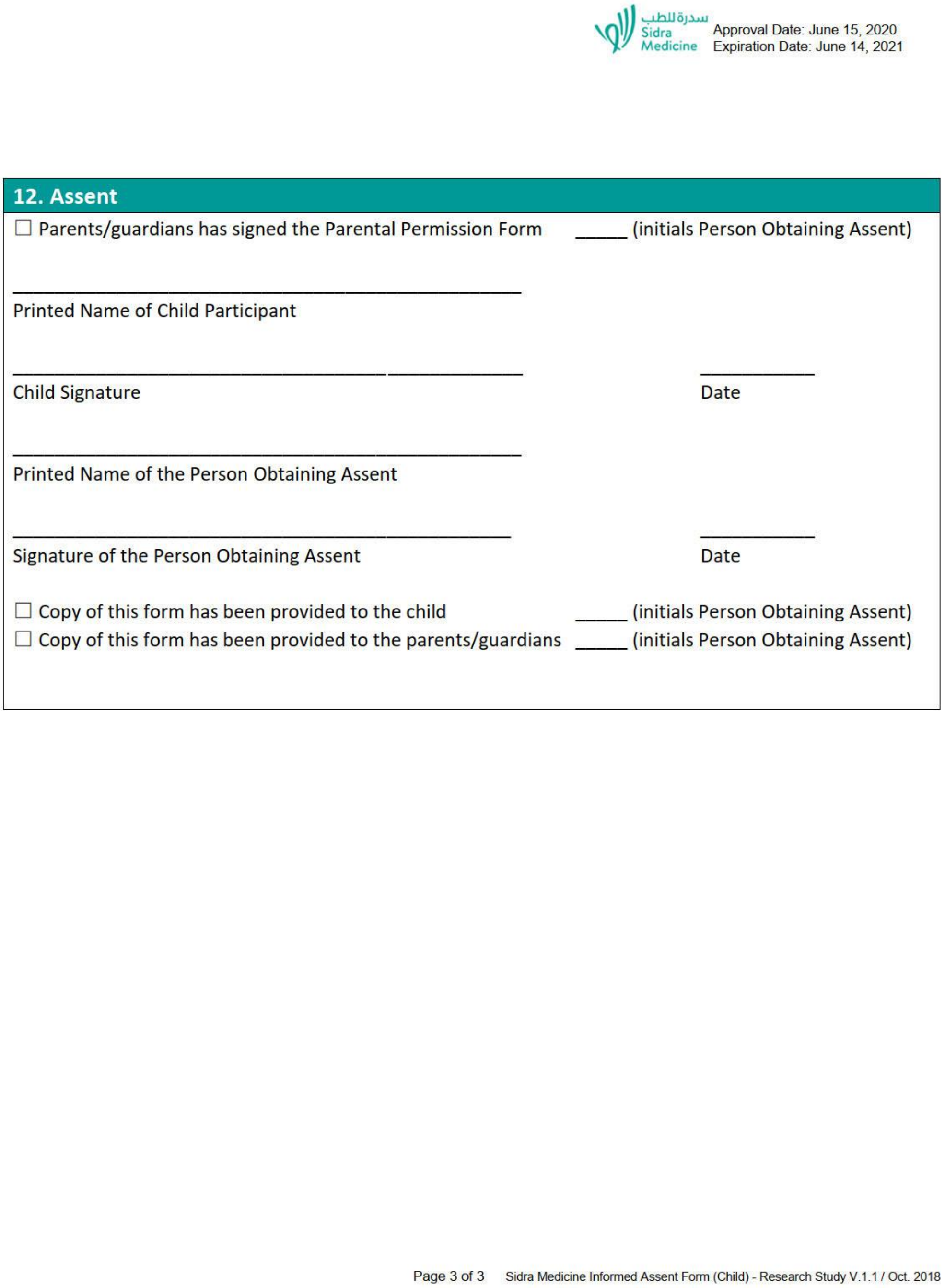
11. Do I Have To Be In The Study?

You don't have to be in this study if you don't want to be. It’s up to you. If you decide not to be in the study, it is ok. No one will be mad at you and nothing changes. Everything stays the same as before. This is still your clinic. Your regular doctor will still take care of you. Even if you say "yes" now, you can change your mind later and stop at any time and no one will be mad at you.

We have discussed this study with your parents/guardians. You can still say “no” to participate, even if your parents/ guardians say “yes”.

Signing this paper means that you have read this or had it read to you and that you want to be in the study. If you do not want to be in the study, do not sign the paper.

If you choose to be part of this study I will also give you a copy of this form to keep for yourself. Your parents /guardians will also have a copy.



12. Assent

☐ Parents/guardians has signed the Parental Permission Form _____ (initials Person Obtaining Assent)

____
Printed Name of Child Participant

____ __________
Child Signature Date

____
Printed Name of the Person Obtaining Assent

____ __________
Signature of the Person Obtaining Assent Date

☐ Copy of this form has been provided to the child _____ (initials Person Obtaining Assent)
☐ Copy of this form has been provided to the parents/guardians _____ (initials Person Obtaining Assent)

Approval Date: June 15, 2020
Expiration Date: June 14, 2021

نموذج موافقة مستنيرة (طفل) - دراسة بحثية

عنوان البروتوكول:	**تقييم مدى الإلتزام بالعلاج والحواجز ونقاط القوة لدى المراهقيين المصابين بالسكري من النوع الأول في قطر: وجهات نظر المرضى ومقدمي الرعاية لهم**
رقم البروتوكول:	**1811037934**
الجهة الراعية:	**جامعة قطر**
الباحث الرئيسي:	**د/مريم خاجه**
عنوان الموقع:	**سدرة للطب**
رقم الهاتف:	**55874878**

1. مقدمة

أنت مدعو للمشاركة في دراسة بحثية تُجرى بواسطة د/ أحمد عويسو ود/ مريم خاجة من سدرة للطب. يتم إجراء الدراسات البحثية عندما يرغب الأطباء في إيجاد طرق جديدة لعلاج المرضى. وأنت مدعو لأننا نختبر المراهقين مثلك (الذين تتراوح أعمارهم بين (11 و 18) الذين يعانون من مرض السكري من النوع الأول في قطر لمعرفة العوامل التي يمكن أن تؤثر على الطريقة التي يتبعون بها التوصيات الخاصة بتناول الأدوية ومراقبة الحمية ومراقبة الجلوكوز وغيرها..

2. ما الغرض من إجراء هذا البحث؟

الغرض من الدراسة هو معرفة كيفية تناولك لأدوية السكري أو اتباع النصائح التي يقدمها لك الطبيب أو غيره من مقدمي الرعاية الصحية، على سبيل المثال، نصائح تناول الطعام الصحي وفحص مستوى الجلوكوز في الدم بشكل متكرر. بالإضافة إلى ذلك، نريد أن نعرف ما الذي يساعدك في اتباع هذه التوصيات وما هي التحديات التي قد تجعلك تتجنب اتباع تلك التوصيات. من خلال معرفة هذه المعلومات، يمكننا مساعدتك لاحقا في أخذ أدويتك بشكل أكثر انتظام والسيطرة على نسبة السكر بشكل أفضل.

3. لماذا تطلب مني المشاركة؟

نطلب منك المشاركة في هذه الدراسة نظرًا لأنك تعاني من السكري من النوع الأول.

سيشارك حوالي 20 طفل في الدراسة.

4. ما الذي سيحدث لي؟

إذا وافقت على المشاركة في الدراسة، فستقوم بالمشاركة في مقابلة شخصية حيث سنقوم بسؤالك بعض الأسئلة ويمكنك التحث بحرية. ستجرى المقابلة عن بعد عن طريق برنامج Adobe Connect. قبل المقابلة, سنقوم بارسال لك تعليمات حول كيفية بدء التواصل. ويمكنك الاختيار ما بين الاتصال الصوتي او الفيديو حسب تفضيلك.

5. هل هذا أمر سيء أو خطر بالنسبة لي؟

إن المشاركة في هذه الدراسة لن تتسب لك في أي خطر حيث أن المطلوب منك فقك هو الإجابة عن بعض الأسئلة والتحدث بحرية.

6. هل سيكون هناك أي أمر جيد يحدث لي؟

إن المشاركة في الدراسة قد تساعدك أو لا تساعدك. قد لا يكون هناك فائدة فورية للمشاركة في الدراسة. ومع ذلك، فإن مشاركتك ستساعدنا على معرفة كيف يمكننا مساعدتك في وقت لاحق مع مرض السكري الخاص بك.

7. من سيعلم بهذا الأمر؟

الدراسة سرية. ولكن سيعرف والداك/الأوصياء عليك وطبيبك وممرضاتك أنك مشارك في الدراسة. وإذا تم إعطاء معلومات بشأنك لأي شخص آخر، فلن يعرف اسمك. إذ سيتم استخدام رقم أو الأحرف الأولى بدلًا من اسمك.

8. ما الذي ينبغي علي أيضًا معرفته؟

لن يتم تقديم أي مدفوعات على مشاركتك في هذا البحث.

9. ماذا سيحدث إذا تعرّضتُ لأذى؟

لا يفترض أن تتعرض للأذى أثناء الدراسة ولكن إدا حدث فسوف نتولى رعايتك. يُرجى إخبار الدكتورة مريم خاجة، الصيدلة الإكلينيكية، مركز السدرة للطب والبحوث، 55874878, أو أحد والديك. قمنا بإعطاء معلومات لوالديك/الأوصياء عليك بخصوص ما ينبغي فعله في حالة تعرضك لأذى أثناء الدراسة.

10. إلى من يمكننى التحدث أو طرح أسئلة؟

يمكنك سؤالي الآن أو فيما بعد. ويمكنك أيضًا طرح أسئلة على الدكتورة مريم خاجة، الصيدلة الإكلينيكية، مركز السدرة للطب والبحوث، 55874878, في أي وقت بشأن أي شيء في هذه الدراسة. كما يمكنك أيضًا أن تطرح أي أسئلة قد تراودك بشأن هذه الدراسة على والديك/الأوصياء عليك.

11. هل أنت ملزم بالمشاركة في الدراسة؟

لا يتعين عليك المشاركة في هذه الدراسة إذا كنت لا ترغب في ذلك. فالأمر متروك لك. إذا قررت عدم المشاركة في الدراسة، فلا بأس في ذلك. ولن يغضب أي شخص منك ولن يتغير أي شيء. بل سيبقى كل شيء كما كان عليه من قبل. ستظل هذه هي عيادتك. وسيستمر طبيبك المعتاد في تقديم الرعاية لك. وحتى إذا "وافقت" الآن، يمكنك تغيير رأيك لاحقًا والتوقف في أي وقت ولن يغضب أي شخص منك.

لقد ناقشنا هذه الدراسة مع والديك/الأوصياء عليك. وسيظل بإمكانك أن "ترفض" المشاركة، حتى إذا "وافق" والداك/الأوصياء عليك.

يعني التوقيع على هذه الورقة أنك قد قرأت هذه الورقة أو تم قراءتها لك وأنك ترغب في المشاركة في الدراسة. وإذا لم ترغب في المشاركة في الدراسة، فلا توقّع على الورقة.

إذا اخترت المشاركة في هذه الدراسة، فسوف أعطيك أيضًا نسخة من هذا النموذج لتحتفظ بها لنفسك. وستتوفر نسخة أيضًا لوالديك/الأوصياء عليك.

12. الموافقة

☐لقد قام والداك/الأوصياء بالتوقيع على نموذج إذن ولي الأمر ______ (الأحرف الأولى من اسم الشخص الذي يحصل على الموافقة)

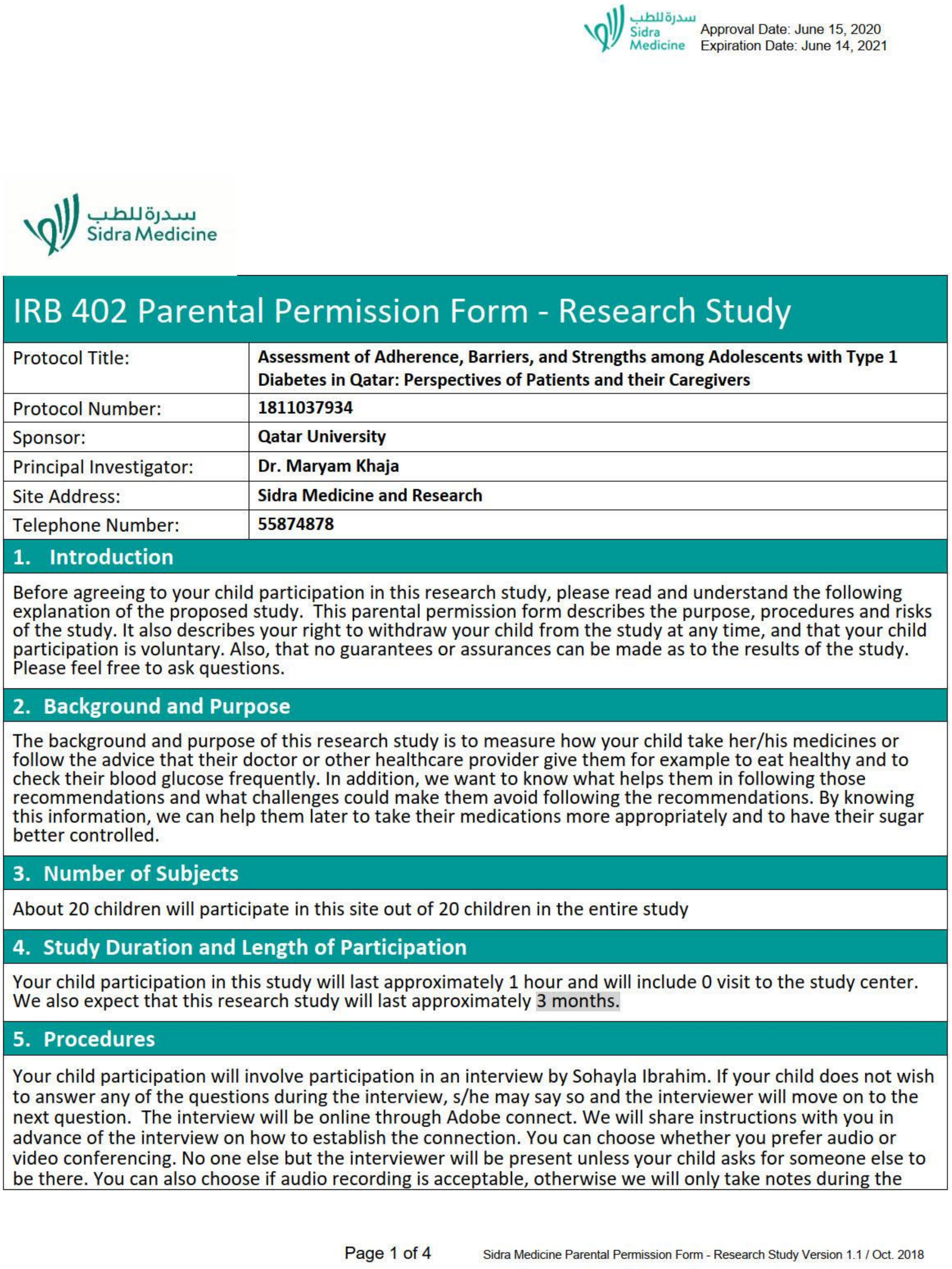
____
اسم الطفل المشارك بأحرف واضحة

______________________________ ______________
توقيع الطفل التاريخ

____
اسم الشخص الذي يحصل على الموافقة بأحرف واضحة

______________________________ ______________
توقيع الشخص الذي يحصل على الموافقة التاريخ

☐ تم تقديم نسخة من هذا النموذج إلى الطفل ______ (الأحرف الأولى من اسم الشخص الذي يحصل على الموافقة)
☐ تم تقديم نسخة من هذا النموذج إلى الوالدين/الأوصياء ______ (الأحرف الأولى من اسم الشخص الذي يحصل على الموافقة)



سدرة للطب Sidra Medicine Approval Date: June 15, 2020
Expiration Date: June 14, 2021

سدرة للطب Sidra Medicine

IRB 402 Parental Permission Form - Research Study

Protocol Title:	**Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers**
Protocol Number:	**1811037934**
Sponsor:	**Qatar University**
Principal Investigator:	**Dr. Maryam Khaja**
Site Address:	**Sidra Medicine and Research**
Telephone Number:	**55874878**

1. Introduction

Before agreeing to your child participation in this research study, please read and understand the following explanation of the proposed study. This parental permission form describes the purpose, procedures and risks of the study. It also describes your right to withdraw your child from the study at any time, and that your child participation is voluntary. Also, that no guarantees or assurances can be made as to the results of the study. Please feel free to ask questions.

2. Background and Purpose

The background and purpose of this research study is to measure how your child take her/his medicines or follow the advice that their doctor or other healthcare provider give them for example to eat healthy and to check their blood glucose frequently. In addition, we want to know what helps them in following those recommendations and what challenges could make them avoid following the recommendations. By knowing this information, we can help them later to take their medications more appropriately and to have their sugar better controlled.

3. Number of Subjects

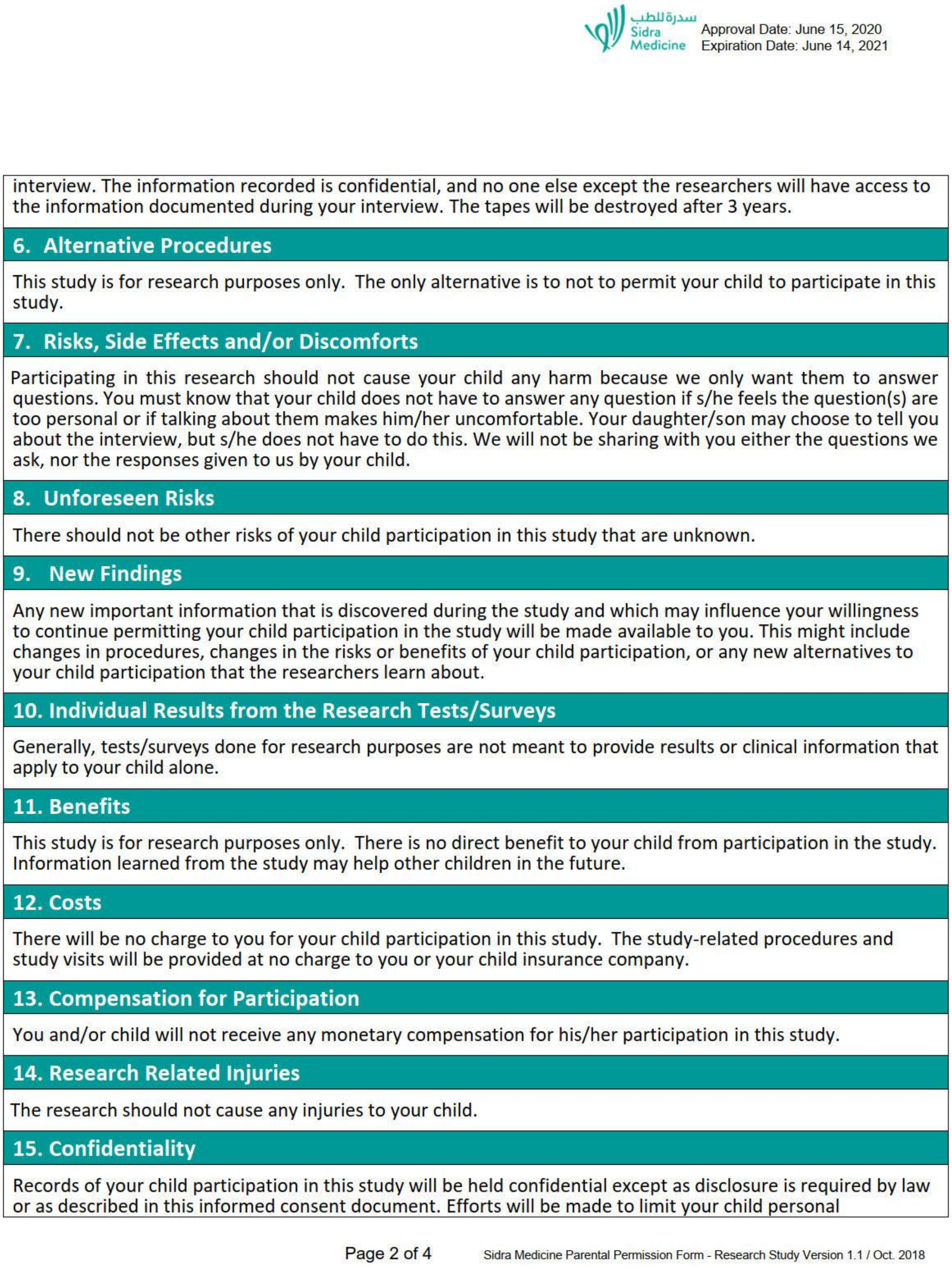
About 20 children will participate in this site out of 20 children in the entire study

4. Study Duration and Length of Participation

Your child participation in this study will last approximately 1 hour and will include 0 visit to the study center. We also expect that this research study will last approximately 3 months.

5. Procedures

Your child participation will involve participation in an interview by Sohayla Ibrahim. If your child does not wish to answer any of the questions during the interview, s/he may say so and the interviewer will move on to the next question. The interview will be online through Adobe connect. We will share instructions with you in advance of the interview on how to establish the connection. You can choose whether you prefer audio or video conferencing. No one else but the interviewer will be present unless your child asks for someone else to be there. You can also choose if audio recording is acceptable, otherwise we will only take notes during the



interview. The information recorded is confidential, and no one else except the researchers will have access to the information documented during your interview. The tapes will be destroyed after 3 years.

6. Alternative Procedures

This study is for research purposes only. The only alternative is to not to permit your child to participate in this study.

7. Risks, Side Effects and/or Discomforts

Participating in this research should not cause your child any harm because we only want them to answer questions. You must know that your child does not have to answer any question if s/he feels the question(s) are too personal or if talking about them makes him/her uncomfortable. Your daughter/son may choose to tell you about the interview, but s/he does not have to do this. We will not be sharing with you either the questions we ask, nor the responses given to us by your child.

8. Unforeseen Risks

There should not be other risks of your child participation in this study that are unknown.

9. New Findings

Any new important information that is discovered during the study and which may influence your willingness to continue permitting your child participation in the study will be made available to you. This might include changes in procedures, changes in the risks or benefits of your child participation, or any new alternatives to your child participation that the researchers learn about.

10. Individual Results from the Research Tests/Surveys

Generally, tests/surveys done for research purposes are not meant to provide results or clinical information that apply to your child alone.

11. Benefits

This study is for research purposes only. There is no direct benefit to your child from participation in the study. Information learned from the study may help other children in the future.

12. Costs

There will be no charge to you for your child participation in this study. The study-related procedures and study visits will be provided at no charge to you or your child insurance company.

13. Compensation for Participation

You and/or child will not receive any monetary compensation for his/her participation in this study.

14. Research Related Injuries

The research should not cause any injuries to your child.

15. Confidentiality

Records of your child participation in this study will be held confidential except as disclosure is required by law or as described in this informed consent document. Efforts will be made to limit your child personal information, including research study and medical records, to people who have a need to review this information.

The investigator, authorized research personnel, the sponsor or persons working on behalf of the sponsor, monitors, auditors, MOPH, other regulatory agencies (when applicable) and the Institutional Review Board (IRB) will be able to inspect and copy confidential study-related records which identify your child by name. They will be granted direct access to your child medical records for verification of the research procedures and date. Therefore, absolute confidentiality cannot be guaranteed. By signing this document, you are authorizing this access to your child medical records.

We may publish the results of this research. However, we will keep your child name and other identifying information confidential.

16. Research Team Contact

During the study, if your child experiences any medical problems, suffers a research-related injury, or you or your child have questions, concerns or complaints about the study, contact the investigator, Dr. Maryam Khaja, Clinical pharmacist, Sidra Medical and Research Centre, 55874878.

17. IRB Contact

An Institutional Review Board (IRB) is an independent committee established to help protect the rights of research subjects. IRB at Sidra has reviewed and approved this study. If you have any questions about your rights or the rights of your child as a research subject, and/or concerns or complaints regarding this research study, Email: irb@sidra.org, or T. +974-4003-7558 during business hours Sunday- Thursday 7:30 a.m. to 4:00 p.m.

18. Voluntary Participation/Withdrawal

Your decision to permit your child to participate in this study is voluntary. You may choose not to permit your child to participate or you may withdraw your child from the study for any reason without penalty or loss of benefits to which you and your child are otherwise entitled and without any effect on your child future medical care.

The investigator or the sponsor can stop your child participation at any time without your consent for the following reasons:

- If you and your child fail to follow directions for participating in the study;
- If it is discovered that your child does not meet the study requirements;
- If the study is cancelled.

19. Place and Duration of Storage of Your child Information or Samples

The information will be stored at Qatar University for 3 years.

Only the research team will have access to the information stored

20. Parental Permission/ Consent

I have read and understand the information in this informed consent document. I have had an opportunity to ask questions. All my questions have been answered to my satisfaction. I voluntarily agree to permit my child to participate in this study until I decide otherwise. I do not give up any of my legal rights or that of my child by signing this consent document. I will receive a copy of this signed consent document.

____
Printed Name of Child

____________________________________ Printed Name of Parent or Guardian	____________________________________ Signature of Parent or Guardian
____________________________________ Printed Name of the Second Parent *(if the IRB requested both parents' permissions)*	____________________________________ Signature of the Second Parent
____________________________________ Printed Name of the Person Conducting the Consent Discussion	____________________________________ Signature of the Person Conducting the Consent Discussion

____
Date

Tick one:

☐ Assent of the child was not required by the IRB.

☐ Assent of the child was obtained.

☐ Assent of the child was not obtained because the capability of the child is so limited that the child cannot reasonably be consulted.

Approval Date: June 15, 2020
Expiration Date: June 14, 2021

IRB-403 نموذج موافقة مستنيرة للوالدين أو الوصي على القاصر - دراسة بحثية

عنوان البروتوكول:	**تقييم مدى الإلتزام بالعلاج والحواجز ونقاط القوة لدى المراهقيين المصابين بالسكري من النوع الأول في قطر: وجهات نظر المرضى ومقدمي الرعاية لهم**
رقم البروتوكول:	**1811037934**
الجهة الراعية:	**جامعة قطر**
الباحث الرئيسي:	**د/مريم خاجه**
عنوان الموقع:	**سدرة للطب**
رقم الهاتف:	**55874878**

1. مقدمة

قبل الموافقة على مشاركة ابنك/ ابنتك في هذه الدراسة البحثية، يُرجى قراءة وفهم الشرح التالي للدراسة المقترحة. يوضح هذا النموذج للموافقة المستنيرة للوالدين غرض الدراسة وإجراءاتها ومخاطرها. ويوضح أيضًا حقك في إنسحاب ابنك/ ابنتك من الدراسة في أي وقت، ويوضح أنك ابنك/ ابنتك متطوع. كما يوضح أيضًا أنه لا يمكن تقديم أي ضمانات أو تأكيدات بشأن نتائج الدراسة. يُرجى ألا تتردد في طرح أي أسئلة لديك.

2. خلفية الدراسة والغرض منها

خلفية هذه الدراسة البحثية والغرض منها هواننا في هذا البحث، نرغب في قياس كيفية تناول طفلك لأدويته أو اتباع النصيحة التي يقدمها له الطبيب أو غيره من مقدمي الرعاية الصحية، على سبيل المثال، لتناول الطعام الصحي وفحص مستوى الجلوكوز في الدم بشكل متكرر. بالإضافة إلى ذلك، نريد أن نعرف ما الذي يساعدهم في اتباع هذه التوصيات وما هي التحديات التي قد تجعلهم يتجنبون اتباع التوصيات. من خلال معرفة هذه المعلومات، يمكننا مساعدتهم في وقت لاحق لأخذ أدويتهم بشكل أكثر ملاءمة والسيطرة على السكر بشكل أفضل.

3. عدد الأشخاص الخاضعين للدراسة

حوالي 20 ولداً خاضعًا للدراسة سوف يشارك في هذا الموقع من إجمالي 20 الأولاد في الدراسة بأكملها على المستوى الوطني.

4. مدة الدراسة وطول فترة المشاركة

ستستمر مشاركة ابنك/ابنتك في هذه الدراسة حوالي ساعة واحده وسوف تتضمن 1 زيارة إلى مركز الدراسة. ونتوقع أيضًا أن هذه الدراسة البحثية ستستمر حوالي 3 اشهر.

5. الإجراءات

ستشارك ابنك / ابنتك في مقابلة مع سهيلة إبراهيم. إذا كانت ابنتك / ابنك لا يرغبوا في الإجابة على أي من الأسئلة خلال المقابلة، فيمكنه يقول ذلك، وسوف ينتقل الشخص الذي يجري المقابلة إلى السؤال التالي. ستجرى المقابلة عن بعد عن طريق برنامج Adobe Connect. قبل المقابلة, سنقوم بارسال لك تعليمات حول كيفية بدء التواصل. ويمكنك الاختيار ما بين الاتصال الصوتي او الفيديو حسب تفضيلك. لن يكون هناك شخص آخر غير الشخص الذي سيجري المقابلة ما لم يطلب طفلك من شخص آخر أن يكون هناك. يمكنك ايضا الاختيار اذا كنت توافق على التسجيل الصوتي وفي حال عدم الموافقة سنقوم باخذ ملحظات اثناء المقابلة. تتسم المعلومات المسجلة بالسرية،

ولن يتمكن أي شخص آخر باستثناء الباحثين من الوصول إلى المعلومات الموثقة أثناء المقابلة. سيتم التخلص من هذه السجلات بعد 3 سنوات.

6. الإجراءات البديلة

تُجرى هذه الدراسة لأغراض بحثية فقط. والبديل الوحيد هو عدم مشاركة إبنك/ابنتك في هذه الدراسة.

7. المخاطر و/أو الآثار الجانبية و/أو الانزعاجات

لا تسبب المشاركة في هذا البحث أي ضرر لطفلك لأننا نريده فقط أن يجيب على الأسئلة. عليك أن تعرف أن طفلك لا يجب عليه أن يجيب على أي سؤال إذا كان يشعر أن السؤال (أو الأسئلة) شخصية للغاية أو إذا كان الحديث عنها غير مريح. قد يختار ابنك / ابنتك أن يخبروك عن الأسئلة، ولكن لا يتعين عليه / عليها القيام بذلك. لن نشارك معك الأسئلة التي نطرحها أو الإجابات التي قدمها لنا طفلك.

8. المخاطر غير المتوقعة

لا يفترض أن تكون هناك مخاطر أخرى غير معروفة للمشاركة في الدراسة.

9. النتائج الجديدة

أي معلومات جديدة يتم اكتشافها أثناء الدراسة ويُحتمل أن تؤثر على رغبتك أو رغبة إبنك/ابنتك في استمرار المشاركة في الدراسة ستتم مشاركتها معكم. وقد يتضمن هذا تغييرات في الإجراءات أو تغييرات في مخاطر وفوائد المشاركة أو أي بدائل جديدة للمشاركة يتوصل إليها الباحثون.

10. النتائج الفردية التي سنتوصل لها من الاختبارات/الاستبيانات الخاصة بالبحث

بشكل عام، فإن الاختبارات/الاستبيانات التي ستجري لأغراض البحث لا تهدف إلى تقديم نتائج أو معلومات سريرية تنطبق على إبنك/ابنتك فقط.

11. الفوائد

تُجرى هذه الدراسة لأغراض بحثية فقط. لن تعود على إبنك/ابنتك بأي فائدة مباشرة لقاء مشاركته (ها) في الدراسة. قد تساعد المعلومات التي يتم الحصول عليها من الدراسة أشخاصًا آخرين في المستقبل.

12. التكاليف

لن تُفرض عليك أي تكاليف لقاء مشاركة إبنك/ابنتك في هذه الدراسة. وسيتم توفير الإجراءات ذات الصلة بالدراسة وزيارات الدراسة دون فرض أي تكاليف عليك أو على شركة التأمين الخاصة بك.

13. التعويض مقابل المشاركة

لن تتلقى أي تعويض مالي مقابل مشاركة إبنك/ابنتك في هذه الدراسة.

14. الإصابات المتعلقة بالبحزث

لا ينبغي أن يتسبب البحث في أي اصابة لابنك/ ابنتك.

15. السرية

سيتم الاحتفاظ بسرية السجلات الخاصة بمشاركة إبنك/ابنتك في هذه الدراسة إلا إذا كان الكشف عنها مطلوبًا بموجب القانون أو على النحو الموضح في وثيقة الموافقة المستنيرة هذه. وسنبذل ما في وسعنا للحدّ من الوصول إلى معلومات إبنك/ابنتك الشخصية، بما في ذلك الدراسة البحثية والسجلات الطبية، على الأفراد الذين يلزم اطّلاعهم على هذه المعلومات.

سيتمكن الباحث وموظفو البحث المصرح لهم والجهة الراعية أو الأشخاص الذين يعملون بالنيابة عن الجهة الراعية والمراقبون والمدققون ووزارة الصحة العامة والهيئات التنظيمية الأخرى (عندما ينطبق الأمر) و لجنة مراجعة البحوث المعتمدة (IRB) من فحص ونسخ السجلات السرية ذات الصلة بالدراسة التي تعرّف هوية إبنك/ابنتك عن طريق الاسم. وسيتم منحهم إمكانية الوصول المباشر إلى سجلات

إبنك/ابنتك الطبية للتحقق من إجراءات البحث وتاريخه. بالتالي، لا يمكن ضمان السرية التامة. وبتوقيعك كوصي على هذه الوثيقة، فإنك تصرح بهذا الوصول.

قد نقوم بنشر نتائج هذا البحث. ومع ذلك، فإننا سنحافظ على سرية اسم إبنك/ابنتك وغيره من المعلومات المُعرّفة بهويته (ها).

16. جهة الاتصال بفريق المشروع

أثناء الدراسة، إذا أصيب(ت) إبنك/ابنتك بأي مشكلات طبية أو تعرض(ت) لإصابة ذات صلة بالبحث أو كانت لديكم أسئلة أو مخاوف أو شكاوى حول الدراسة، فتواصل مع الباحث، الدكتورة مريم خاجة، الصيدلة الإكلينيكية، مركز السدرة للطب والبحوث، 55874878

17. جهة الاتصال بلجنة مراجعة البحوث المعتمدة (IRB)

لجنة مراجعة البحوث المعتمدة هي لجنة مستقلة أسست للمساعدة في حماية حقوق الأفراد الخاضعين للبحث. قامت لجنة مراجعة البحوث المعتمدة في سدرة بمراجعة هذه الدراسة والموافقة عليها. فإذا كانت لديك أي أسئلة بشأن حقوقك أو حقوق إبنك/ابنتك كشخص خاضع للبحث و/أو مخاوف أو شكاوى فيما يتعلق بهذه الدراسة البحثية، فأرسل رسالة عبر البريد الإلكتروني: irb@sidra.org، أو اتصل على الرقم 7558-4003-974+ خلال ساعات العمل من الأحد إلى الخميس من الساعة 7:30 صباحًا حتى الساعة 4:00 مساءً.

18. المشاركة/الانسحاب بشكل طوعي

إن قرار موافقتك على مشاركة إبنك/ابنتك في هذه الدراسة هو قرار طوعي. يمكنك اختيار عدم مشاركته (ها) أو يمكنك اختيار إنسحابه(ها) من الدراسة لأي سبب ودون أي عقوبة أو فقدان لفوائد يحق لك أو لإبنك/ابنتك الحصول عليها في حالة أخرى ودون أي تأثير على رعايته(ها)الطبية المستقبلية.

يمكن للباحث أو الجهة الراعية أن يوقفا مشاركة إبنك/ابنتك في أي وقت دون موافقتك للأسباب التالية:

- إذا لم تقم أو لم يقم إبنك/ابنتك باتباع توجيهات المشاركة في الدراسة؛
- إذا وُجد أن إبنك/ابنتك لا يستوفي متطلبات الدراسة؛
- إذا تم إلغاء الدراسة.

19. مكان ومدة تخزين المعلومات أو العينات

سيتم تخزين المعلومات في جامعة قطر لمدة 3 سنوات.

فقط الفريق البحثي هو من سيتمكن من الوصول لهذه المعلومات المخزنة.

20.الموافقة

لقد قرأت المعلومات الواردة في وثيقة الموافقة المستنيرة هذه وفهمتها. وقد أتيحت لي فرصة لطرح الأسئلة. وتمت الإجابة على جميع أسئلتي بشكل كاف ومرضِي. أنا أوافق طوعًا على مشاركة إبني/ابنتي في هذه الدراسة إلى أن أقرر غير ذلك. ولا أتنازل عن أي من حقوقي القانونية أو حقوق إبني/ابنتي القانونية بالتوقيع على وثيقة الموافقة هذه. وسوف أحصل على نسخة من وثيقة الموافقة الموقعة هذه.

____
اسم القاصر (الولد أو الفتاة) الخاضع للدراسة

____
اسم الوالد/ الوالدة / الوصي بأحرف واضحة

________________________________ ________________
توقيع الوالد/ الوالدة / الوصي التاريخ

____
اسم الوالد/ الوالدة / الوصي بأحرف واضحة *(في حال توقيع كلا الوالدين مطلوب من قبل لجنة مراجعة البحوث المعتمدة)*

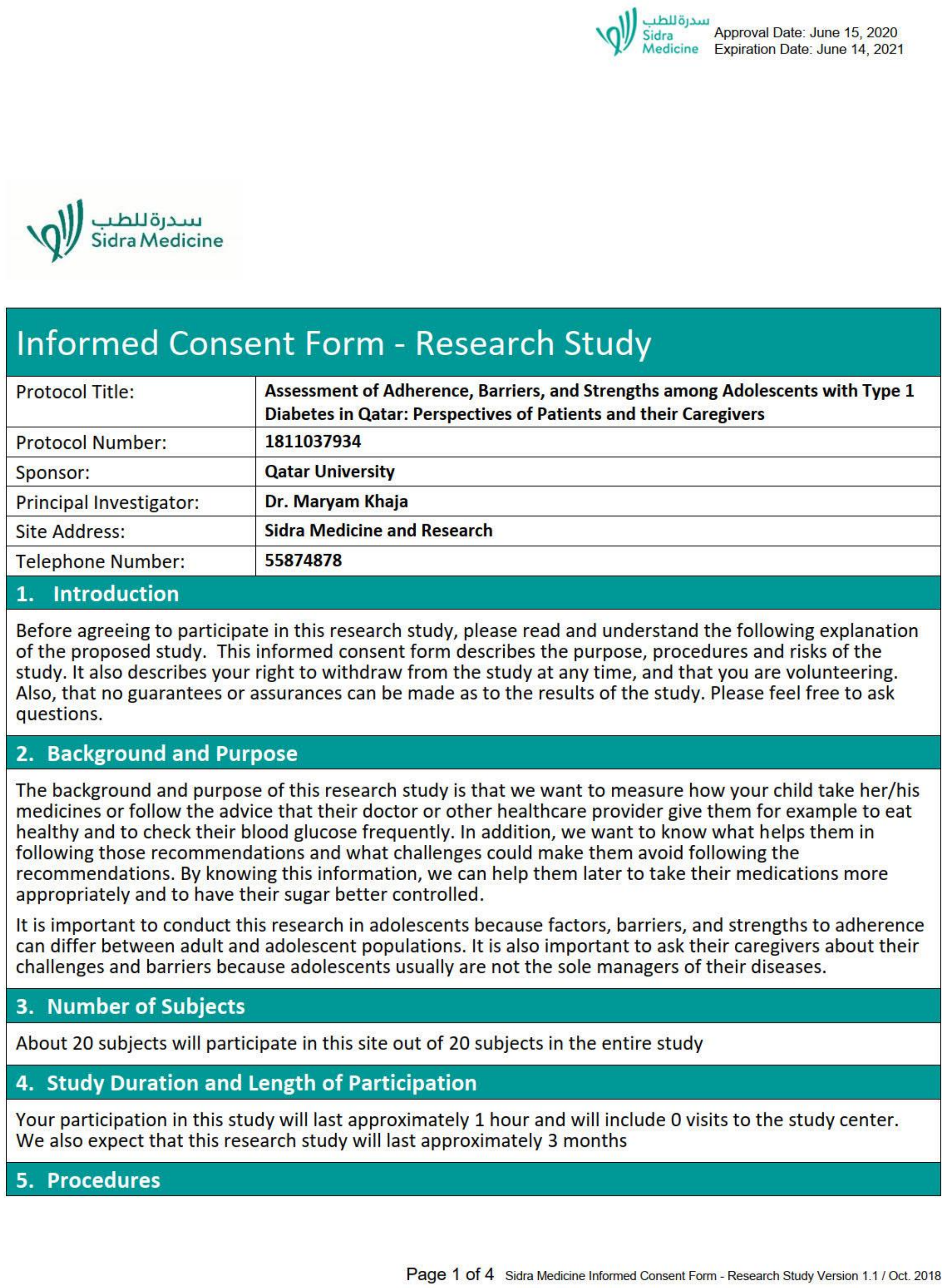
________________________________ ________________
توقيع الوالد/ الوالدة / الوصي *(في حال توقيع كلا الوالدين مطلوب من قبل لجنة مراجعة البحوث المعتمدة)* التاريخ

________________________________ ________________________________
اسم الشخص الذي يجري مناقشة الموافقة بأحرف واضحة توقيع الشخص الذي يجري مناقشة الموافقة

____
التاريخ

إختر واحد من الاختيارات التالية:

☐ موافقة الولد/الفتاة لم تطلب من لجنة مراجعة البحوث المعتمدة
☐ موافقة الولد/الفتاة تم الحصول عليها
☐ موافقة الولد/الفتاة لم يتم الحصول عليها لأن قدراته (ها) محدودة بحيث أن الباحث لا يستطيع استشارته والوقوف عند رأيه بما يمكن



Informed Consent Form - Research Study

Protocol Title:	**Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers**
Protocol Number:	**1811037934**
Sponsor:	**Qatar University**
Principal Investigator:	**Dr. Maryam Khaja**
Site Address:	**Sidra Medicine and Research**
Telephone Number:	**55874878**

1. Introduction

Before agreeing to participate in this research study, please read and understand the following explanation of the proposed study. This informed consent form describes the purpose, procedures and risks of the study. It also describes your right to withdraw from the study at any time, and that you are volunteering. Also, that no guarantees or assurances can be made as to the results of the study. Please feel free to ask questions.

2. Background and Purpose

The background and purpose of this research study is that we want to measure how your child take her/his medicines or follow the advice that their doctor or other healthcare provider give them for example to eat healthy and to check their blood glucose frequently. In addition, we want to know what helps them in following those recommendations and what challenges could make them avoid following the recommendations. By knowing this information, we can help them later to take their medications more appropriately and to have their sugar better controlled.

It is important to conduct this research in adolescents because factors, barriers, and strengths to adherence can differ between adult and adolescent populations. It is also important to ask their caregivers about their challenges and barriers because adolescents usually are not the sole managers of their diseases.

3. Number of Subjects

About 20 subjects will participate in this site out of 20 subjects in the entire study

4. Study Duration and Length of Participation

Your participation in this study will last approximately 1 hour and will include 0 visits to the study center. We also expect that this research study will last approximately 3 months

5. Procedures

Your participation will involve taking part in an interview. We are asking you to help us learn more about barriers and strengths to adherence among adolescents with type 1 diabetes in Qatar. We are inviting you to take part in this research project. If you accept, you will be asked to participate in an interview by Sohayla Ibrahim.

The interview will be conducted online through Adobe connect. We will share instructions with you in advance of the interview on how to establish the connection. You can choose whether you prefer audio or video conferencing. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except the researchers will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. If you do not prefer audio recording, we will only take notes throughout the interview. The tape will be locked in a locker and no one will have access to it. The tapes will be destroyed after 3 years.

6. Alternative Procedures

This study is for research purposes only. The only alternative is to not participate in this study.

7. Risks, Side Effects and/or Discomforts

Participating in this research should not cause you any harm because we only want you to answer questions. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question or for refusing to take part in the interview.

8. Unforeseen Risks

There should not be other risks of study participation that are unknown.

9. New Findings

Any new important information that is discovered during the study and which may influence your willingness to continue participation in the study will be made available to you. This might include changes in procedures, changes in the risks or benefits of participation, or any new alternatives to participation that the researchers learn about.

10. Individual Results from the Research Tests/Surveys

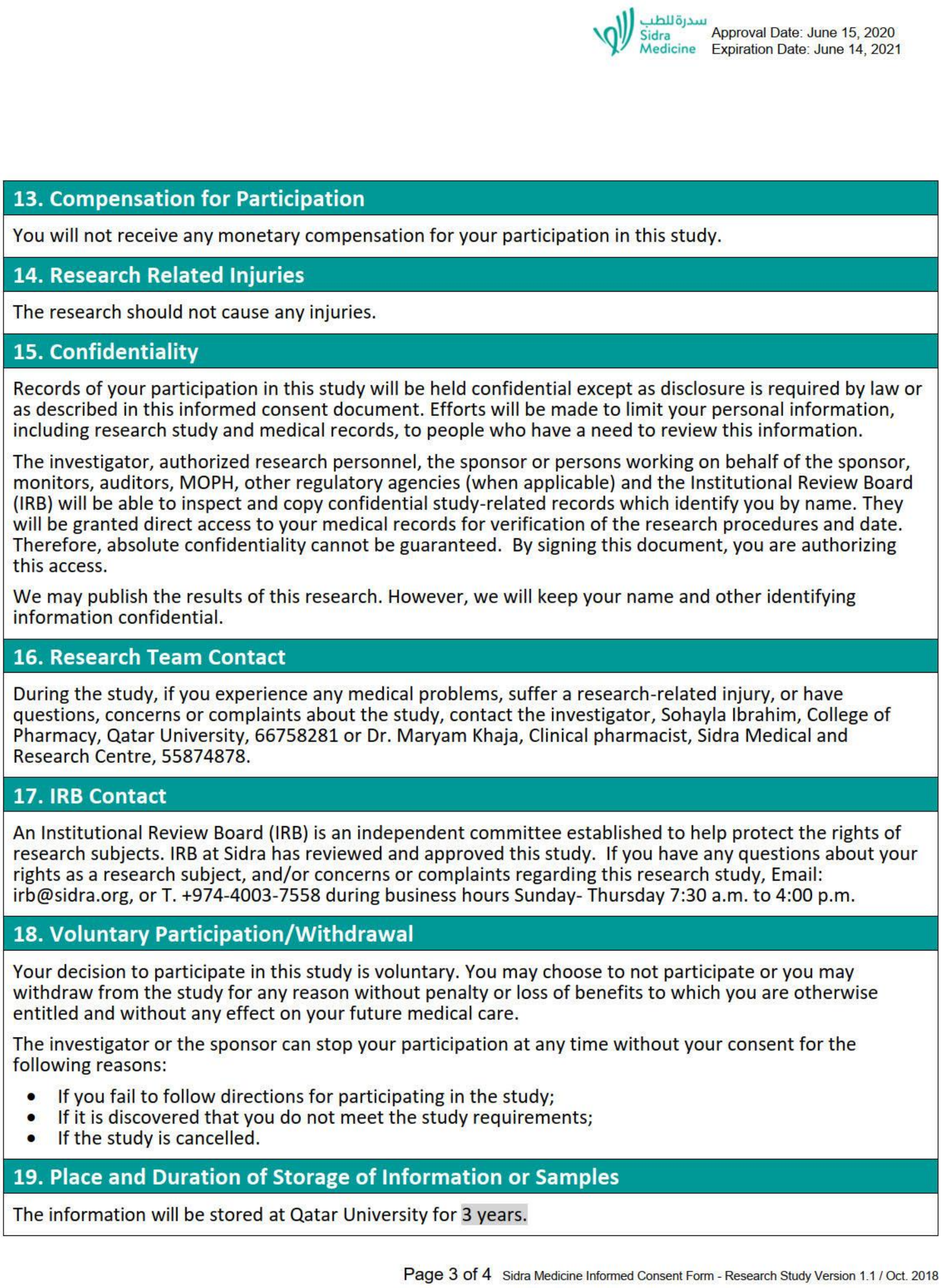
Generally, tests/surveys done for research purposes are not meant to provide results or clinical information that apply to you alone.

11. Benefits

This study is for research purposes only. There is no direct benefit to you from your participation in the study. Information learned from the study may help other people in the future.

12. Costs

There will be no charge to you for your participation in this study. The study-related procedures and study visits will be provided at no charge to you or your insurance company.



13. Compensation for Participation

You will not receive any monetary compensation for your participation in this study.

14. Research Related Injuries

The research should not cause any injuries.

15. Confidentiality

Records of your participation in this study will be held confidential except as disclosure is required by law or as described in this informed consent document. Efforts will be made to limit your personal information, including research study and medical records, to people who have a need to review this information.

The investigator, authorized research personnel, the sponsor or persons working on behalf of the sponsor, monitors, auditors, MOPH, other regulatory agencies (when applicable) and the Institutional Review Board (IRB) will be able to inspect and copy confidential study-related records which identify you by name. They will be granted direct access to your medical records for verification of the research procedures and date. Therefore, absolute confidentiality cannot be guaranteed. By signing this document, you are authorizing this access.

We may publish the results of this research. However, we will keep your name and other identifying information confidential.

16. Research Team Contact

During the study, if you experience any medical problems, suffer a research-related injury, or have questions, concerns or complaints about the study, contact the investigator, Sohayla Ibrahim, College of Pharmacy, Qatar University, 66758281 or Dr. Maryam Khaja, Clinical pharmacist, Sidra Medical and Research Centre, 55874878.

17. IRB Contact

An Institutional Review Board (IRB) is an independent committee established to help protect the rights of research subjects. IRB at Sidra has reviewed and approved this study. If you have any questions about your rights as a research subject, and/or concerns or complaints regarding this research study, Email: irb@sidra.org, or T. +974-4003-7558 during business hours Sunday- Thursday 7:30 a.m. to 4:00 p.m.

18. Voluntary Participation/Withdrawal

Your decision to participate in this study is voluntary. You may choose to not participate or you may withdraw from the study for any reason without penalty or loss of benefits to which you are otherwise entitled and without any effect on your future medical care.

The investigator or the sponsor can stop your participation at any time without your consent for the following reasons:

- If you fail to follow directions for participating in the study;
- If it is discovered that you do not meet the study requirements;
- If the study is cancelled.

19. Place and Duration of Storage of Information or Samples

The information will be stored at Qatar University for 3 years.

Only the research team will have access to the information stored

20. Consent

I have read and understand the information in this informed consent document. I have had an opportunity to ask questions. All my questions have been answered to my satisfaction. I voluntarily agree to participate in this study until I decide otherwise. I do not give up any of my legal rights by signing this consent document. I will receive a copy of this signed consent document.

______________________________	______________________________
Printed Name of Subject	Signature of Subject
______________________________	______________________________
Printed Name of the Person Conducting the Consent Discussion	Signature of the Person Conducting the Consent Discussion
	____________ Date

Sidra Medicine
Approval Date: June 15, 2020
Expiration Date: June 14, 2021

Sidra Medicine

نموذج موافقة مستنيرة - دراسة بحثية

عنوان البروتوكول:	**تقييم مدى الإلتزام بالعلاج والحواجز ونقاط القوة لدى المراهقيين المصابين بالسكري من النوع الأول في قطر: وجهات نظر المرضى ومقدمي الرعاية لهم**
رقم البروتوكول:	**1811037934**
الجهة الراعية:	**جامعة قطر**
الباحث الرئيسي:	**د/مريم خاجه**
عنوان الموقع:	**سدرة للطب**
رقم الهاتف:	**55874878**

1. مقدمة

قبل الموافقة على المشاركة في هذه الدراسة البحثية، يُرجى قراءة وفهم الشرح التالي للدراسة المقترحة. يوضح نموذج الموافقة المستنيرة هذا غرض الدراسة وإجراءاتها ومخاطرها. ويوضح أيضًا حقك في الانسحاب من الدراسة في أي وقت، ويوضح أنك متطوع. كما يوضح أيضًا أنه لا يمكن تقديم أي ضمانات أو تأكيدات بشأن نتائج الدراسة. يُرجى ألا تتردد في طرح أي أسئلة لديك.

2. خلفية الدراسة والغرض منها

خلفية هذه الدراسة البحثية والغرض منها هو أننا نرغب في قياس كيفية تناول طفلك لأدويته أو اتباع النصيحة التي يقدمها له الطبيب أو غيره من مقدمي الرعاية الصحية، على سبيل المثال، لتناول الطعام الصحي وفحص مستوى الجلوكوز في الدم بشكل متكرر. بالإضافة إلى ذلك، نريد أن نعرف ما الذي يساعدهم في اتباع هذه التوصيات وما هي التحديات التي قد تجعلهم يتجنبون اتباع التوصيات. من خلال معرفة هذه المعلومات، يمكننا مساعدتهم في وقت لاحق لأخذ أدويتهم بشكل أكثر ملاءمة والسيطرة على السكر بشكل أفضل. من المهم إجراء هذا البحث للمراهقين لأن العوامل، والحواجز، ونقاط القوة للالتزام بالعلاج يمكن أن تختلف بين البالغين والمراهقين. من المهم أيضا ان بسال مقدمي الرعايه لهم عن المشاكل والتحديات التي تواجههم لان المراهقين عاده ليسوا المسؤولين الوحيدين في ادارة مرض السكري.

3. عدد الأشخاص الخاضعين للدراسة

حوالي 20 شخصًا خاضعًا للدراسة سوف يشارك في هذا الموقع من إجمالي 20 شخصًا في الدراسة بأكملها

4. مدة الدراسة وطول فترة المشاركة

ستستمر مشاركتك في هذه الدراسة حوالي ساعة واحدة وسوف تتضمن زيارة واحدة إلى مركز الدراسة. ونتوقع أيضًا أن هذه الدراسة البحثية ستستمر حوالي ثلاث أشهر.

5. الإجراءات

ستتضمن مشاركتك مقابلة شخصية. نطلب منك مساعدتنا لدراسة التحديات ومصادر القوة للإلتزام بالعلاج لدى المراهقين المصابين بمرض السكري من النوع الأول في قطر. لذا، ندعوك للمشاركة في هذا البحث. إذا وافقت على المشاركة، ستقوم سهيلة إبراهيم بإجراء مقابلة معك.

ستجرى المقابلة عن بعد عن طريق برنامج Adobe Connect. قبل المقابلة, سنقوم بارسال لك تعليمات حول كيفية بدء التواصل. ويمكنك الاختيار ما بين الاتصال الصوتي او الفيديو حسب تفضيلك. إذا كنت لا تريد الإجابة عن أي سؤال خلال المقابلة يمكنك إخبار الشخص الذي يجري المقابلة وسوف ينتقل للسؤال التالي. لن يتواجد أي شخص اخر أثناء المقابلة ألا إذا كنت تفضل وجود شخص ما هناك. المعلومات المسجله سرية ولن يتمكن أي شخص عدا الباحثين من الوصول لتلك المعلومات. سنقوم بتسجيل هذه المقابلة ولكن لن يكون الشريط معرفا

باسمك. أذا كنت لا تفضل التسجيل الصوتي, سنقوم باخد ملاحظات كتابية اثناء المقابلة. سيحفظ التسجيل في خزانة مغلقة ولن يتمكن احد من الوصول اليها. سنتخلص من التسجيلات بعد 3 سنوات.

6. الإجراءات البديلة

تُجرى هذه الدراسة لأغراض بحثية فقط. والبديل الوحيد هو عدم المشاركة في هذه الدراسة.

7. المخاطر و/أو الآثار الجانبية و/أو الانزعاجات

لا تسبب المشاركة في هذا البحث أي ضرر لك لأننا نريدك فقط أن تجيب على الأسئلة المطروحة. لا يجب عليك الإجابة على أي سؤال او المشاركة فالمقابلة إذا كنت لا تريد ذلك. وليس عليك ان تقدم اسباب حيال عدم اجابتك على أي سؤال أو حيال رفضك للمشاركة في المقابلة.

8. المخاطر غير المتوقعة

لا يفترض أن تكون هناك مخاطر أخرى غير معروفة للمشاركة في الدراسة.

9. النتائج الجديدة

أي معلومات جديدة يتم اكتشافها أثناء الدراسة ويُحتمل أن تؤثر على رغبتك في استمرار المشاركة في الدراسة ستتم مشاركتها معك. وقد يتضمن هذا تغييرات في الإجراءات أو تغييرات في مخاطر وفوائد المشاركة أو أي بدائل جديدة للمشاركة يتوصل إليها الباحثون.

10. النتائج الفردية المستقاة من الاختبارات/الاستبيانات الخاصة بالبحث

بشكل عام، فإن الاختبارات/الاستبيانات التي ستجري لأغراض البحث لا تهدف إلى تقديم نتائج أو معلومات سريرية تنطبق عليك فقط.

11. الفوائد

تُجرى هذه الدراسة لأغراض بحثية فقط. لن تعود عليك بأي فائدة مباشرة لقاء مشاركتك في الدراسة. قد تساعد المعلومات التي يتم الحصول عليها من الدراسة أشخاصًا آخرين في المستقبل.

12. التكاليف

لن تُفرض عليك أي تكاليف لقاء مشاركتك في هذه الدراسة. وسيتم توفير الإجراءات ذات الصلة بالدراسة وزيارات الدراسة دون فرض أي تكاليف عليك أو على شركة التأمين الخاصة بك.

13. التعويض مقابل المشاركة

لن تتلقى أي تعويض مالي مقابل مشاركتك في هذه الدراسة.

14. الإصابات المتعلقة بالبحث

لا ينبغي أن يتسبب البحث في أي اصابة لك

15. السرية

سيتم الاحتفاظ بسرية السجلات الخاصة بمشاركتك في هذه الدراسة إلا إذا كان الكشف عنها مطلوبًا بموجب القانون أو على النحو الموضح في وثيقة الموافقة المستنيرة هذه. وسنبذل ما في وسعنا للحدّ من الوصول إلى معلوماتك الشخصية، بما في ذلك الدراسة البحثية والسجلات الطبية، على الأفراد الذين يلزم اطّلاعهم على هذه المعلومات.

سيتمكن الباحث وموظفو البحث المصرح لهم والجهة الراعية أو الأشخاص الذين يعملون بالنيابة عن الجهة الراعية والمراقبون والمدققون ووزارة الصحة العامة والهيئات التنظيمية الأخرى (عندما ينطبق الأمر) و لجنة مراجعة البحوث المعتمدة (IRB) من فحص ونسخ السجلات السرية ذات الصلة بالدراسة التي تعرّف هويتك عن طريق الاسم. وسيتم منحهم إمكانية الوصول المباشر إلى سجلاتك الطبية للتحقق من إجراءات البحث وتاريخه. بالتالي، لا يمكن ضمان السرية التامة. وبتوقيعك على هذه الوثيقة، فإنك تصرح بهذا الوصول.

قد نقوم بنشر نتائج هذا البحث. ومع ذلك، فإننا سنحافظ على سرية اسمك وغيره من المعلومات المُعرّفة بهويتك.

16. جهة الاتصال بفريق المشروع

أثناء الدراسة، إذا أصبت بأي مشكلات طبية أو تعرضت لإصابة ذات صلة بالبحث أو كانت لديك أسئلة أو مخاوف أو شكاوى حول الدراسة، فتواصل مع الباحث، سهيلة إبراهيم، كلية الصيدلة، جامعة قطر، 66758281 او الدكتورة مريم خاجة، الصيدلة الإكلينيكية، مركز السدرة للطب والبحوث، 55874878.

17. جهة الاتصال بلجنة مراجعة البحوث المعتمدة (IRB)

لجنة مراجعة البحوث المعتمدة هي لجنة مستقلة أسست للمساعدة في حماية حقوق الأفراد الخاضعين للبحث. قامت لجنة مراجعة البحوث المعتمدة في سدرة بمراجعة هذه الدراسة والموافقة عليها. فإذا كانت لديك أي أسئلة بشأن حقوقك كشخص خاضع للبحث و/أو مخاوف أو شكاوى فيما يتعلق بهذه الدراسة البحثية، فأرسل رسالة عبر البريد الإلكتروني: irb@sidra.org، أو اتصل على الرقم +974-4003-7558 خلال ساعات العمل من الأحد إلى الخميس من الساعة 7:30 صباحًا حتى الساعة 4:00 مساءً.

18. المشاركة/الانسحاب بشكل طوعي

إن قرار مشاركتك في هذه الدراسة هو قرار طوعي. يمكنك اختيار عدم المشاركة أو يمكنك اختيار الانسحاب من الدراسة لأي سبب ودون أي عقوبة أو فقدان لفوائد يحق لك الحصول عليها في حالة أخرى ودون أي تأثير على رعايتك الطبية المستقبلية.

يمكن للباحث أو الجهة الراعية أن يوقفا مشاركتك في أي وقت دون موافقتك للأسباب التالية:

- إذا لم تقم باتباع توجيهات المشاركة في الدراسة؛
- إذا وُجد أنك لا تستوفي متطلبات الدراسة؛
- إذا تم إلغاء الدراسة.

19. مكان ومدة تخزين المعلومات أو العينات

سيتم تخزين المعلومات في جامعة قطر لمدة 3 سنوات

فقط الفريق البحثي هو من سيتمكن من الوصول للمعلومات المخزنة

20. الموافقة

لقد قرأت المعلومات الواردة في وثيقة الموافقة المستنيرة هذه وفهمتها. وقد أتيحت لي فرصة لطرح الأسئلة. وتمت الإجابة على جميع أسئلتي بشكل كاف ومرضيي. أنا أوافق طوعًا على المشاركة في هذه الدراسة إلى أن أقرر غير ذلك. ولا أتنازل عن أي من حقوقي القانونية بالتوقيع على وثيقة الموافقة هذه. وسوف أحصل على نسخة من وثيقة الموافقة الموقعة هذه.

اسم الشخص الخاضع للدراسة بأحرف واضحة

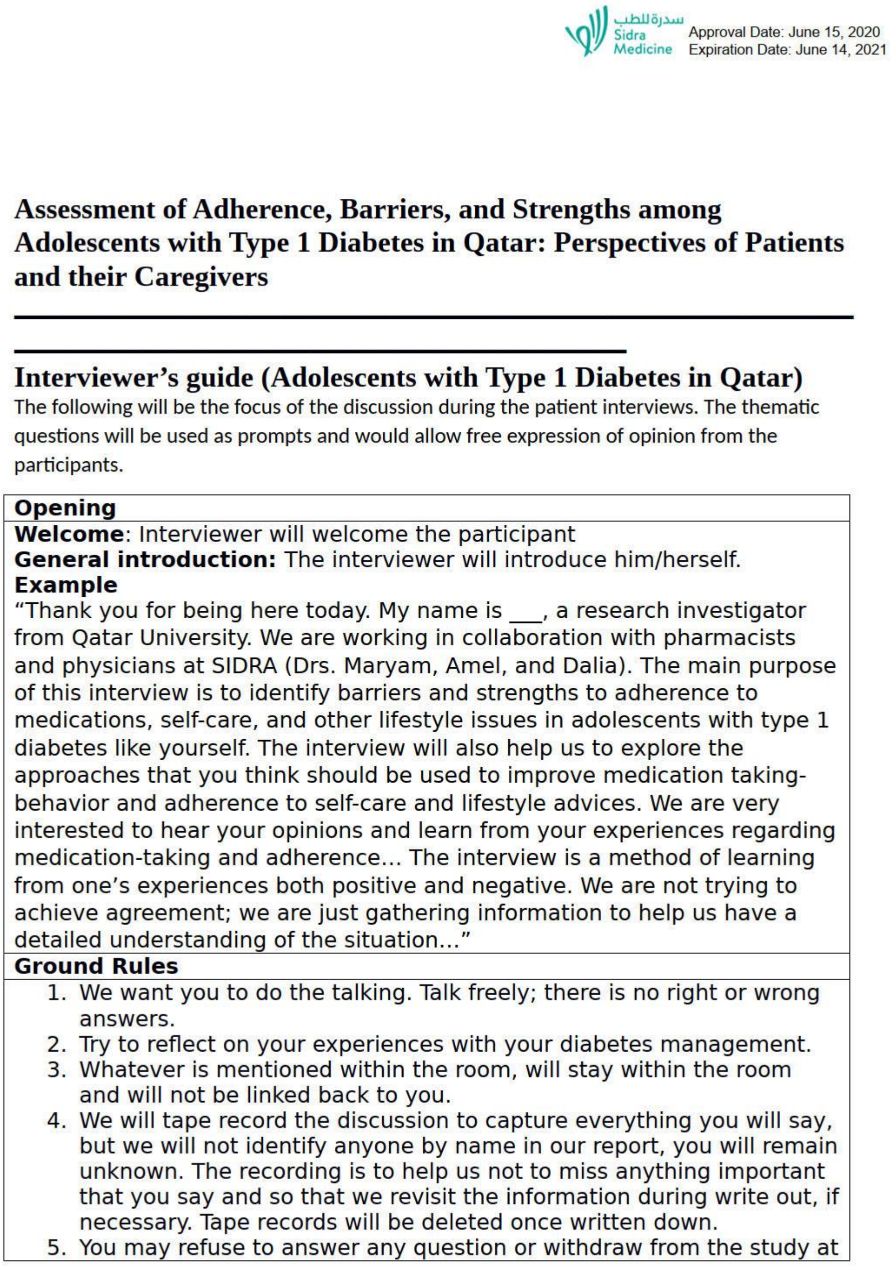
توقيع الشخص الخاضع للدراسة

اسم الشخص الذي يجري مناقشة الموافقة
بأحرف واضحة

توقيع الشخص الذي يجري مناقشة الموافقة

التاريخ

APPENDEX D: INTERVIEW GUIDES



سدرة للطب
Sidra
Medicine

Approval Date: June 15, 2020
Expiration Date: June 14, 2021

Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers

Interviewer's guide (Adolescents with Type 1 Diabetes in Qatar)

The following will be the focus of the discussion during the patient interviews. The thematic questions will be used as prompts and would allow free expression of opinion from the participants.

Opening

Welcome: Interviewer will welcome the participant
General introduction: The interviewer will introduce him/herself.
Example
"Thank you for being here today. My name is ___, a research investigator from Qatar University. We are working in collaboration with pharmacists and physicians at SIDRA (Drs. Maryam, Amel, and Dalia). The main purpose of this interview is to identify barriers and strengths to adherence to medications, self-care, and other lifestyle issues in adolescents with type 1 diabetes like yourself. The interview will also help us to explore the approaches that you think should be used to improve medication taking-behavior and adherence to self-care and lifestyle advices. We are very interested to hear your opinions and learn from your experiences regarding medication-taking and adherence… The interview is a method of learning from one's experiences both positive and negative. We are not trying to achieve agreement; we are just gathering information to help us have a detailed understanding of the situation…"

Ground Rules

1. We want you to do the talking. Talk freely; there is no right or wrong answers.
2. Try to reflect on your experiences with your diabetes management.
3. Whatever is mentioned within the room, will stay within the room and will not be linked back to you.
4. We will tape record the discussion to capture everything you will say, but we will not identify anyone by name in our report, you will remain unknown. The recording is to help us not to miss anything important that you say and so that we revisit the information during write out, if necessary. Tape records will be deleted once written down.
5. You may refuse to answer any question or withdraw from the study at

anytime.

6. We would appreciate if you could please turn off your mobile phone to avoid distractions during the interview session.
7. The duration of this interview is about 30-45 minutes.

Participant's introduction

Ask participant to introduce herself/himself (grade, age, school).

Introductory questions

1- Can you please tell me the story of your diabetes (since when, at what age)?
2- What medications do you currently take?
3- What other things do you do to help with your diabetes? (e.g. checking blood glucose, diet, exercise,..)
    a. Glucose testing
    b. Insulin (correct dose, correct time, adjusting insulin based on glucose readings)
    c. Diet (regular snacks, meals on time, sticking to meal plan)
    d. Exercise (type, frequency)
    e. Appointments
4- What other recommendations does your doctor provide for you other than your medications?
5- Who helps you in taking care of your diabetes?

Barriers to adherence

1- What problems do you face when trying to follow your doctor's recommendations related to medicines, diet, exercise, glucose monitoring?
2- What about those factors?

- **Patient – related factors:**
    - Demographics (Age, gender, family history)
    - Psychological status (Motivation, frustration, anxious, stress, energy and willpower, threat to social/emotional/physical/mental wellbeing)
    - Knowledge, attitude
    - Perceptions/Beliefs (health beliefs)
    - Comorbidities (depression, eating disorders)
    - Other (school, holidays, social gatherings, restaurants, travelling, too busy, forgetfulness -supplies/care)
- **Medication – related factors:**
    - frequency, duration of therapy, polypharmacy, timing, side effects, complexity of treatment

- **Disease – related factors:**
    - Diabetes duration, diabetes specific conflicts, experience of results
- **Provider – related factors:**
    - support from nurses and physicians, inclusion in decision making, relationship, language, assumptions
- **Societal – related factors:**
    - Peer influence/ support
    - Parental influence/ support/ monitoring/ autonomy support (inclusion in decision making) / family conflicts/ shared responsibility
    - Stigma
    - Acceptance (hard time telling people that you have diabetes)
    - Privacy (embarrassed)
- **Healthcare system – related factors:**
    - cost, continuity of care, convenience, appointments, availability

Strengths to adherence

1- What strengths do you think help you in following your doctor’s recommendations?
(strengths are defined as “adaptive processes, behaviors, and attitudes that facilitate achievement of resilient outcomes when faced with disease-related challenges”).
Example: Coping skills

2- What about those factors

- **Self-efficacy and diabetes-related confidence**
    - Taking care of diabetes, responding to high/low levels, asking questions, problem solving
- **Help with diabetes**
    - friends, family, nurse, doctor
- **Time management**
    - Figure out ways to manage even if busy, at school, outside home, travelling,…

- Some patients start by being adherent to therapy and then they become non-adherent or vice versa, what do you think are the reasons behind such changes in adherence?
- What do you think can help based on the barriers/strengths that you identified?

Concluding

- Ok X, Do you have any additional comments related to adherence in diabetes or in general that you would like to share with us?

- X, we have come to the end of the interview.
- Thank you very much for your time today and for your honest opinion and fruitful discussions. We greatly appreciate your support and contribution to this study.

Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers

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دليل مقابلات (المراهقين المصابين بداء السكري من النوع الأول في قطر)

ما يلي سيكون محور المناقشة خلال مقابلات المرضى وستستخدم أسئلة موضوعية لتحفيز المشاركة ويُسمح للمشاركين بالتعبير عن آرائهم بحرّية.

البدء

الترحيب: سيرحب الباحث بالشخص المشارك.

مقدمة عامة: يقوم الشخص المحاور بتقديم نفسه.

مثال

"شكراً لكم لحضوركم معنا اليوم. اسمي ___، باحثة في جامعة قطر ويشاركنا في هذا المشروع صيادلة واطباء من سدرة (د/مريم خاجه ود/امل خليفه ود/داليا)، والهدف من هذه المقابلة هو التعرف على المشاكل ونقاط القوة اثناء الالتزام بالأدوية والرعاية الذاتية والمشاكل الحياتية الأخرى التي تواجه المراهقين المصابين بالنوع الأول من السكري مثلك، وستساعدنا المقابلة أيضًا على ايجاد الأساليب التي قد تحسن الالتزام بالادوية وبنصائح الرعاية الذاتية واساليب الحياة من وجهة نظرك، ونحن مهتمون جدا لسماع آرائك والتعلم من خبراتك فيما يتعلق بتجربتك في الالتزام بـالعلاج وتعد المقابلة طريقة للتعلم من التجارب الشخصية الإيجابية منها والسلبية، ولا نسعي للتوفيق بين الآراء بل نجمع المعلومات التي تساعدنا على الفهم العميق لهذه الحالة..."

قواعد المقابلة

1. نريدك ان تتحدث بحرية فليس هناك إجابة صواب أو خطأ.
2. حاول ان تتذكر وتسترجع خبراتك في التحكم بمرض السكري.
3. يبقي الحديث بيننا خاصا ولن يفصح فيه عن اسمك.
4. سيتم تسجيل المقابلة لاستخلاص كل ما يقال لكننا لن نذكر في تقريرنا أي شخص باسمه، وستبقى غير معروف، وسيتم التسجيل حتى لا يفوتنا أي من النقاط الهامة التي تذكرها وحتى يمكننا إعادة النظر في هذه المعلومات أثناء الكتابة، إذا لزم الأمر، وسيحذف التسجيل بعد تفريغه كتابة.
5. لك الحق في رفض الإجابة عن أي سؤال أو الانسحاب من هذه الدراسة في أي وقت.
6. وسأكون ممتنا لو تفضلتم بغلق هاتفكم حتى لا يتم التشويش على المقابلة.
7. تترواح مدة المقابلة من 30-45 دقيقة.

تقديم المشارك

اطلب من المشاركين تقديم أنفسهم (الصف الدراسي، العمر، المدرسة).

الأسئلة تمهيدية

1-هل يمكن أن تخبرني عن قصة اصابتك بمرض السكري (منذ متى، في أي سن)؟
2-ما هي الأدوية التي تتناولها حاليًا؟
3-ما هي الأشياء الأخرى التي تساعدك في علاج مرض السكري؟ (مثل فحص نسبة الجلوكوز في الدم، والنظام الغذائي، وممارسة الرياضة، ..)
  a. فحص نسبة السكر فالدم
  b. الانسولين (الجرعه الصحيحه، الوقت الصحيح، ظبط الانسولين بناء على نسبة سكر الدم)
  c. النظام الغذائي (سناكس منتظمه، الوجبات في الوقت الصحيح، الالتزام بخطة تناول الوجبات)

d. الرياضة (النوع، الكميه)
e. المواعيد
4-ما هي التوصيات الأخرى لطبيبك بخلاف الأدوية الخاصة بك؟
5-من يساعدك في علاج مرض السكري؟

المشاكل التي تواجهها اثناء الالتزام بالعلاج

1. ما المشكلات التي تواجهها عند محاولة اتباع توصيات طبيبك المتعلقة بالأدوية والنظام الغذائي وممارسة الرياضة ومتابعة نسبة السكر؟
2. ماذا عن هذه العوامل؟

- **العوامل المتعلقة بالمريض:**
  - الدِّيموغْرافِيَّات (العمر، الجنس، تاريخ العائلة).
  - الحالة النفسية (الدافع، الإجهاد، التوتر، الضغط، العزيمة وقوة الارادة، التهديد الاجتماعي / العاطفي / الجسدي / الذهني).
  - المعرفة، الاسلوب.
  - التصورات / المعتقدات (المعتقدات الصحية).
  - لأمراض المصاحبة (الاكتئاب، واضطرابات الأكل).
  - أخرى (المدرسة، الإجازات، التجمعات العائلية، المطاعم، السفر، الانشغال، النسيان-الادوات/الرعاية).
- **العوامل المتعلقة بالأدوية:**
  - التكرار، ومدة العلاج، كمية الادوية، والتوقيت، والآثار الجانبية، وتعقيدات العلاج.
- **العوامل المرتبطة بالمرض:**
  - مدة الإصابة بالسكري، المشاكل المصاحبة للسكري، تجربة النتائج.
- **العوامل المرتبطة بمقدم الرِّعاية الصِّحية:**
  - دعم من الممرضات والأطباء، وإشراكك في صنع القرار ،العلاقة معهم، واللغة، والافتراضات.
- **العوامل المرتبطة بالمجتمع**:
  - تأثير / دعم الأقران.
  - تأثير الوالدين / الدعم / المراقبة / الدعم الذاتي (الاشراك في صنع القرار) / الخلافات العائلية / المسؤولية المشتركة.
  - الصورة النمطية.
  - القبول (اواجه صعوبة في اخبار الناس عن اصابتك بالسكري).
  - الخصوصية.
- **العوامل المرتبطة بنظام الرعاية الصحية:**
  - التكلفة ، واستمرارية الرعاية ، والملائمة، والمواعيد، والتوافر.

نقاط القوة التي تساعد على الالتزام بالعلاج

1. ما هي نقاط القوة التي تعتقد أنها تساعدك في اتباع توصيات طبيبك؟

(يتم تعريف نقاط القوة على أنها "عمليات التكيف والسلوكيات والمواقف التي تسهل تحقيق النتائج المرجوة عند مواجهة التحديات المرتبطة بالأمراض").
مثال: مهارات التكيّف

2. ماذا عن هذه العوامل؟

- **الكفائة الذاتية والثقة المتعلقة بادارة السكري.**
  - العناية بالسكري، الاستجابة للمستويات المرتفعه/المنخفضة، طرح الأسئلة، وحل

المشاكل.

- **المساعدة في علاج السكري**
  - أصدقاء، عائلة، ممرضة، طبيب
- **إدارة الوقت**
  - العناية بالسكري حتى اثناء الانشغال، في المدرسة، خارج المنزل, أثناء السفر...

- يبدأ بعض المرضى بالالتزام بالعلاج ثم يصبحون غير متحمسين أو العكس، ما هي الأسباب التي تقف وراء هذه التغييرات في الالتزام بالعلاج من رايك؟
- ما الذي يمكن أن يساعد في ذلك برأيك اعتمادا على نقاط الضعف والقوة التي حددتها؟

الخاتمة

- حسنا X، هل لديك أي تعليقات إضافية تخص الالتزام بعلاج السكري أو تعليقات عامة ترغب في مشاركتها معنا؟
- X، لقد وصلنا إلى نهاية المقابلة.
- شكراً جزيلاً على وقتك اليوم وعلى رأيك الصادق والمناقشة المثمرة معك. نحن نقدر دعمك ومساهمتك في هذه الدراسة.

Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers

Interviewer's guide (Caregivers of Adolescents with Type 1 Diabetes in Qatar)

The following will be the focus of the discussion during the caregiver interviews. The thematic questions will be used as prompts and would allow free expression of opinion from the participant.

Opening

Welcome: Interviewer will welcome the participant.
General introduction: The interviewer will introduce him/herself.
Example
"Thank you for being here today. My name is ___, a research investigator at Qatar University. We are working in collaboration with pharmacists and physicians at SIDRA (Drs. Maryam, Amel, and Dalia). The main purpose of this interview is to identify barriers and strengths/facilitators to adherence (to medications, self-care, and lifestyle) in adolescents with type 1 diabetes like your kids. This interview will also help us to explore the approaches that you think should be used to improve medication taking-behavior and adherence to self-care and lifestyle recommendations. We are very interested to hear your opinions and learn from your experiences regarding medication-taking and adherence… The interview is a method of learning from one's experiences, both positive and negative. We are not trying to achieve consensus; we are just gathering information to help us have an in-depth understanding of the situation…"

Ground Rules

1. We want you to do the talking. Talk freely; there is no right or wrong answers.
2. Try to reflect on your experiences supporting and managing your kid with diabetes.
3. Whatever is mentioned within the room, will stay within the room and will not be linked back to you.
4. We will tape record the discussion to capture everything you will say, but we will not identify anyone by name in our report, you will remain anonymous (i.e. unknown). The recording is to help us not to miss anything important that you say and so that we revisit the

information during write out, if necessary. Tape records will be deleted once written down.

5. You may refuse to answer any question or withdraw from the study at anytime
6. We would appreciate if you could please turn off your mobile phone to avoid distractions during the interview session.
7. The duration of this interview is about 30-45 minutes.

Participant's introduction

Ask participants to introduce themselves and a brief introduction about their kids.

Introductory questions

1- Can you please tell me the story of diabetes in your kid (since when, at what age, feelings, what changes happened)?
2- What medications does he currently take?
3- What other things do you do to help your kid with his diabetes? (e.g. glucose monitoring, reminding them on glucose monitoring, diet, exercise)
    a. Glucose testing
    b. Insulin (correct dose, correct time, adjusting insulin based on glucose readings)
    c. Diet (regular snacks, meals on time, sticking to meal plan)
    d. Exercise (type, frequency)
    e. Appointments
4- What other recommendations does your doctor provide for you and your kid other than their medications (e.g. related to diet, exercise, glucose monitoring)?
5- Who helps your kid in taking care of his/her diabetes?

Barriers to adherence

- What problems do you and your kid face when trying to follow their doctor's recommendations related to medicines, diet, exercise, glucose monitoring?
- What about those factors
- **Patient – related factors:**
    - Demographics (Age, gender, family history)
    - Psychological status (Motivation, frustration, anxious, stress, energy and willpower, threat to social/emotional/physical/mental wellbeing)
    - Knowledge, attitude
    - Perceptions/Beliefs (health beliefs)
    - Comorbidities (depression, eating disorders)
    - Other (school, holidays, social gatherings, restaurants,

travelling, too busy, forgetfulness -supplies/care)

- **Medication – related factors:**
    - frequency, duration of therapy, polypharmacy, timing, side effects, complexity of treatment
- **Disease – related factors:**
    - Diabetes duration, diabetes specific conflicts, experience of results
- **Provider – related factors:**
    - support from nurses and physicians, inclusion in decision making, relationship, language, assumptions
- **Societal – related factors:**
    - Peer influence/ support
    - Parental influence/ support/ monitoring/ autonomy support (inclusion in decision making) / family conflicts/ shared responsibility
    - Stigma
    - Acceptance (hard time telling people that you have diabetes)
    - Privacy (embarrassed)
- **Healthcare system – related factors:**
    - cost, continuity of care, convenience, appointments, availability

Strengths to adherence

1- What strengths do you think help your kid in following their doctor’s recommendations?
(strengths are defined as “adaptive processes, behaviors, and attitudes that facilitate achievement of resilient outcomes when faced with disease-related challenges”).
Example: Coping skills

2- What about those factors

- **Self efficacy and diabetes related confidence**
    - Taking care of diabetes, responding to high/low levels, asking questions, problem solving
- **Help with diabetes**
    - friends, family, nurse, doctor
- **Time management**
    - Figure out ways to manage even if busy, at school, outside home, travelling,…

- Some patients start by being adherent to therapy and then they become non-adherent or vice versa, what do you think are the reasons behind such changes in adherence?

- What do you think can help based on the barriers/strengths that you identified?
Concluding
- Ok Mr./Mrs. X, Do you have any additional comments related to adherence in diabetes or in general that you would like to share with us? - Mr./Mrs. X, we have come to the end of the interview. - Thank you very much for your time today and for your honest opinion and fruitful discussions. We greatly appreciate your support and contribution to this study.

Assessment of Adherence, Barriers, and Strengths among Adolescents with Type 1 Diabetes in Qatar: Perspectives of Patients and their Caregivers

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دليل مقابلات (اولياء امورالمراهقين المصابين بداء السكري من النوع الأول في قطر)

ما يلي سيكون محور المناقشة خلال مقابلات المرضى وتستخدم أسئلة موضوعية ويُسمح للمشاركين بالتعبير عن آرائهم بحرّية.

البدء
الترحيب: سيرحب الباحث بالشخص المشارك. **مقدمة عامة**: يقوم الشخص المحاور بتقديم نفسه. **مثال** "شكراَ لكم لحضوركم معنا اليوم. اسمي ____، باحثة في جامعة قطر ويشاركنا في هذا المشروع صيادلة واطباء من سدرة (د/مريم خاجه ود/امل خليفه ود/داليا)، والهدف من هذه المقابلة هو التعرف على المشاكل ونقاط القوة اثناء الالتزام بالأدوية والرعاية الذاتية والمشاكل الحياتية الأخرى التي تواجه المراهقين المصابين بالنوع الأول من السكري مثل طفلك، وستساعدنا المقابلة أيضًا على ايجاد الأساليب التي قد تحسن الالتزام بالادوية وبنصائح الرعاية الذاتية واساليب الحياة من وجهة نظرك، ونحن مهتمون جدا لسماع آرائك والتعلم من خبراتك فيما يتعلق بتجربتك في الالتزام بـالعلاج وتعد المقابلة طريقة للتعلم من التجارب الشخصية الإيجابية منها والسلبية، ولا نسعي للتوفيق بين الآراء بل نجمع المعلومات التي تساعدنا على الفهم العميق لهذه الحالة..."
قواعد المقابلة
1. . نريدك ان تتحدث بحرية فليس هناك إجابة صواب أو خطأ. 2. حاول ان تتذكر وتسترجع خبراتك في التحكم بمرض السكري. 3. يبقي الحديث بيننا خاصا ولن يفصح فيه عن اسمك. 4. سيتم تسجيل المقابلة لاستخلاص كل ما يقال لكننا لن نذكر في تقريرنا أي شخص باسمه، وستبقى غير معروف، وسيتم التسجيل حتى لا يفوتنا أي من النقاط الهامة التي تذكرها وحتى يمكننا إعادة النظر في هذه المعلومات أثناء الكتابة، إذا لزم الأمر، وسيحذف التسجيل بعد تفريغه كتابة. 5. لك الحق في رفض الإجابة عن أي سؤال أو الانسحاب من هذه الدراسة في أي وقت. 6. وسأكون ممتنا لو تفضلتم بغلق هاتفكم حتى لا يتم التشويش على المقابلة. 7.تتروح مدة المقابلة من 30-45 دقيقة.
تقديم المشارك
اطلب من المشاركين تقديم أنفسهم ونبذة عن أطفالهم.
الأسئلة تمهيدية
1. هل يمكن أن تخبرني عن إصابة طفلك بمرض السكري (منذ متى، في أي سن)، مشاعرك، ما هي التغييرات التي حدثت)؟ 2. ما هي الأدوية التي يتناولها طفلك حاليًا؟ 3. ما هي الأشياء الأخرى التي تفعلها لمساعدة ابنك في العلاج من مرض السكري؟ (مثل متابعة نسبة السكر، وتذكيرهم بمتابعة نسبة السكر ، والنظام الغذائي ، وممارسة الرياضة)؟ a. فحص نسبة السكر فالدم b. الانسولين (الجرعه الصحيحه، الوقت الصحيح، ظبط الانسولين بناء على نسبة سكر الدم) c. النظام الغذائي (سناكس منتظمه، الوجبات في الوقت الصحيح، الالتزام

بخطة تناول الوجبات)

d. الرياضة (النوع، الكميه)

e. المواعيد

4. ما هي توصيات الطبيب الأخرى لك ولطفلك بخلاف الأدوية (على سبيل المثال، الحمية الغذائية وممارسة الرياضة ومتابعة نسبة السكر)؟
5. من يساعد ابنك فالاهتمام بالسكري؟

معوقات الاتزام بالعلاج

1. ما المشكلات التي تواجهك أنت وطفلك عند محاولة اتباع توصيات الطبيب المتعلقة بالادوية، الغذاء, الرياضه، فحص سكر الدم؟
2. ماذا عن هذه العوامل؟

- **العوامل المتعلقة بالمريض:**
  - الدِّيموغْرافِيَّات (العمر، الجنس، تاريخ العائلة).
  - الحالة النفسية (الدافع، الإجهاد، التوتر، الضغط، العزيمة وقوة الارادة، التهديد الاجتماعي / العاطفي / الجسدي / الذهني).
  - المعرفة، الاسلوب.
  - التصورات / المعتقدات (المعتقدات الصحية).
  - لأمراض المصاحبة (الاكتئاب، واضطرابات الأكل).
  - أخرى (المدرسة، الإجازات، التجمعات العائلية، المطاعم، السفر، الانشغال، النسيان-الادوات/الرعاية).
- **العوامل المتعلقة بالأدوية:**
  - التكرار، ومدة العلاج، كمية الادوية، والتوقيت، والآثار الجانبية، وتعقيدات العلاج.
- **العوامل المرتبطة بالمرض:**
  - مدة الإصابة بالسكري، المشاكل المصاحبة للسكري، تجربة النتائج.
- **العوامل المرتبطة بمقدم الرِّعاية الصِّحية:**
  - دعم من الممرضات والأطباء، وإشراكك في صنع القرار ،العلاقة معهم، واللغة، والافتراضات.
- **العوامل المرتبطة بالمجتمع**:
  - تأثير / دعم الأقران.
  - تأثير الوالدين / الدعم / المراقبة / الدعم الذاتي (الاشراك في صنع القرار) / الخلافات العائلية / المسؤولية المشتركة.
  - الصورة النمطية.
  - القبول (اواجه صعوبة في اخبار الناس عن اصابتك بالسكري).
  - الخصوصية.
- **العوامل المرتبطة بنظام الرعاية الصحية:**

  التكلفة ، واستمرارية الرعاية ، والملائمة، والمواعيد، والتوافر.

نقاط القوة التي تساعد على الالتزام بالعلاج

1. ما هي نقاط القوة التي تعتقد أنها تساعد طفلك في اتباع توصيات طبيبك؟
(يتم تعريف نقاط القوة على أنها "عمليات التكيف والسلوكيات والمواقف التي تسهل تحقيق النتائج المرجوة عند مواجهة التحديات المرتبطة بالأمراض").
مثال: مهارات التكيّف

1. ماذا عن هذه العوامل؟

- **الكفائة الذاتية والثقة المتعلقة بادارة السكري.**
    - العناية بالسكري، الاستجابة للمستويات المرتفعه/المنخفضة، طرح الأسئلة، وحل المشاكل.
- **المساعدة في علاج السكري**
    - أصدقاء، عائلة، ممرضة، طبيب
- **إدارة الوقت**
    - العناية بالسكري حتى اثناء الانشغال، في المدرسة، خارج المنزل, أثناء السفر...

- يبدأ بعض المرضى بالالتزام بالعلاج ثم يصبحون غير متحمسين أ والعكس، ما هي الأسباب التي تقف وراء هذه التغييرات في الالتزام بالعلاج؟
- ما الذي يمكن أن يساعد في ذلك برأيك اعتمادا على نقاط الضعف والقوة التي حددتها؟

الخاتمة

- حسنا X، هل لديك أي تعليقات إضافية تخص بالالتزام بعلاج السكري أ وعامة ترغب في مشاركتها معنا؟
- السيد/ X، لقد وصلنا إلى نهاية المقابلة.
- شكراً جزيلاً على وقتك اليوم وعلى رأيك الصادق والمناقشة المثمرة معك. نحن نقدر دعمكم ومساهمتكم في هذه الدراسة.