Ehealth intervention to optimize adherence in late adolescents and young adults with type 1 diabetes

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CHAPTER

Chapter 1

General introduction and outline of the thesis

DIABETES BURDEN, COMPLICATIONS, AND GLYCEMIC GOALS

Type 1 diabetes (T1D) is a metabolic disease characterized by chronic hyperglycemia that occurs when the pancreas fails to produce insulin, the hormone that allows glucose to be absorbed into cells and converted into energy. T1D typically affects children and adolescents, but it can occur at any age and is managed with insulin and lifestyle modifications. T1D is the third most commonly diagnosed chronic disease in adolescents and young adults (AYAs) [1]. The prevalence and incidence of type 1 diabetes are increasing worldwide [2-4], with an estimated annual increase in incidence of around 2-5% [5]. In Qatar, as in the rest of the world, diabetes, including T1D, is a major health problem that poses a significant impact on patients, families, and healthcare systems [6-8]. The International Diabetes Federation ranks Qatar fourth globally in terms of the incidence rates (per 100,000 population per annum) of T1D in children (0–14 years), at a rate of 38.1 [3]. Qatar has been reported to have a higher incidence of T1D than other Middle Eastern countries [9,10]. According to Soliman and colleagues (2022) [11], the incidence of T1D in Qatar increased from 28.39/100 000 (95% CI: 31.82-40.03) in 2012–2016 to 38.05/100 000 (95% CI: 32.5-44.28) in 2020. However, the incidence rates of specifically T1D in AYAs are not available because of the overlapping reports with children and with type 2 diabetes (T2D). Given the high incidence rate among children, AYAs also may have a high incidence rate [4].

T1D is associated with significant acute complications, such as hypoglycemia and diabetic ketoacidosis (DKA), and debilitating chronic complications. The latter includes both microvascular complications (primarily retinopathy, nephropathy, and neuropathy) and macrovascular complications (particularly cardiovascular disease) [12,13]. In people with T1D hospitalized for DKA in Qatar, non-adherence to insulin therapy was identified as the most identifiable cause (40.5%). Additionally, they had higher rates of DKA recurrence (35.6%) compared to people with T2D (21.2%) ($p < 0.001$) [14]. Furthermore, the metabolic syndrome is becoming more prevalent in the T1D population [12,15]. However, diabetes complications are preventable through improved diabetes management.

The primary goal of diabetes management is control of glycemia to improve symptoms of diabetes and prevent or delay diabetic complications, thus improving the quality of life for people with diabetes [16]. The measurement of glycosylated hemoglobin (HbA1c) levels has become widely accepted as an indicator of long-term glucose control and the risk of microvascular complications in people with diabetes. It can be used to guide clinical management and adjust therapies [17]. In Qatar, routine determinations of HbA1c values have become an essential component of the standard of care for patients with diabetes and should be measured approximately every 3 months and at least biannually

if treatment goals are met [7,8]. The goals of glycemic control are set according to the American Diabetes Association (ADA) guidelines. A target HbA1c of <7% (53 mmol/mol) is appropriate for many adolescents (aged <18 years) [18] and nonpregnant adults [19] (without significant hypoglycemia. However, more or less stringent HbA1C targets may be appropriate based on a benefit-risk assessment [18,19]. Therefore, treatment goals and intensity of insulin therapy must be individualized since young patients may benefit the most from intensive therapy [7,8].

ADHERENCE TO DIABETES SELF-MANAGEMENT (DSM) IN ADOLESCENTS AND YOUNG ADULTS WITH T1D

Because diabetes is a self-managed disease, people with T1D need to possess technical and decision-making skills to perform the daily regimen tasks, manage daily barriers to regimen adherence, and make the necessary adjustments to the self-management regimen [20]. AYAs with T1D are of particular concern because they exhibit deterioration in adherence to diabetes management and glycemic control [21,22]. Pubertal physiology, psychosocial factors (such as loneliness, anger, and unhappiness brought on by having diabetes, stress, depression, etc.), a marked decline in self-care behaviors, shifting family dynamics, perceived social pressures, an early transfer of management responsibilities from parents to AYAs, diabetes burnout, and increased burden as a result of treatment intensifications are some of the factors that contribute to this deterioration [23,24].

The ongoing intensive self-management requirements, such as daily insulin administration, managing equipment and injection sites, blood glucose monitoring (BGM) and carbohydrates counting in meals to guide self-regulation for dose adjustment, coordinating dietary intake and physical activity (PA), managing complications like hypoglycemia, and accessing healthcare and education sessions, may interfere with their desired lifestyles and social relationships [25,26]. They also have to face the significant physiological and environmental changes [1] accompanied by the transition from pediatric to adult care. Therefore, recognizing the factors associated with adherence to the diabetes regimen in this age group constitutes an important part of managing diabetes, and since adherence to the various behaviors (e.g., healthy eating, PA, insulin administration, and BGM) of the DSM does not highly correlate, it is important to assess each behavior and the factors related to it separately.

HEALTHY EATING AND PHYSICAL ACTIVITY

Healthy eating (HE) and physical activity (PA) are important aspects of the diabetes management plan. Regarding HE, the Hamad General Hospital, the largest public hospital in Doha, Qatar, has introduced DAFNE (Dose Adjustment for Normal Eating), a program that advocates dietary freedom and appropriate flexibility of insulin doses, to help persons with T1D (over 17 years old) learn to match insulin doses to their food preferences and amount of consumed carbohydrates [7]. DAFNE is a UK-based adaptation of the German Diabetes Treatment and Teaching Programme. In the UK, it has been demonstrated to not only enhance glycemic control but also increase patient treatment satisfaction and lower the incidence of severe hypoglycemia. Thus, it is very likely to result in improved long-term metabolic control, better adherence to treatment goals, and improved quality of life while saving costs [15,27]. However, a typical healthy eating plan that emphasizes low-fat and high-fiber foods, avoiding concentrated carbohydrates, and consuming complex carbohydrates evenly throughout the day should be encouraged in people with diabetes [28], despite the eating freedom DAFNE affords them, in order to prevent weight gain. Additionally, patients with T1D must learn how to calculate carbohydrates in food portions, but this skill can be difficult at times [29], underscoring the importance of routinely testing this ability. When looking at PA, both moderate-intensity and vigorous PA can improve insulin sensitivity [30,31]. Because people with T1D present features of peripheral insulin resistance that can be improved by increasing PA, this can also improve glycemic control in T1D [32]. The recommendation is that people with diabetes should perform at least 150 minutes per week of moderate-intensity aerobic physical activity [31]. However, 64% of people with T1D do not achieve this recommended PA level [15] because of barriers such as fear of hypoglycemia [15,33] and a lack of knowledge about managing diabetes before, during, and after PA among both patients and healthcare professionals (HCPs) [33]. Therefore, identifying PA patterns, barriers, and facilitators to PA adherence is a critical first step in promoting and developing structured PA regimens tailored to individual needs.

INSULIN ADMINISTRATION AND BLOOD GLUCOSE MONITORING

People with T1D are recommended to adjust their insulin on the basis of their blood glucose levels, diet, PA, physical condition, and intercurrent illness [15]. The regulation of insulin intake is important as a way of feeling a sense of control, yet it can be a challenging task and should be considered an essential part of patient education to support informed decision-making for the maintenance of insulin therapy. Applying proper carbohydrate counting is a crucial part of managing T1D and, when done properly, can lower HbA1c. Yet, people with T1D find it to be one of the most difficult tasks, and they often do it

incorrectly and inconsistently [34]. This suggests that individuals with low motivation for and limited skill in carbohydrate counting need to receive more attention.

Blood glucose monitoring (BGM), either by self-monitoring of blood glucose (SMBG) or continuous glucose monitoring (CGM), is one of the key components of the diabetes self-care regimen. Data from BGM are used for immediate action, like in response to hyper- or hypoglycemia, and for retrospective review to permit identification of patterns and problems to make adjustments in insulin dosage and lifestyle, like control of timing or amount of food intake [35,36]. BGM requires a combination of both technical and cognitive skills, including the ability to interpret patterns of results and make appropriate treatment decisions [36]. For optimal use of BGM, it is important for people with diabetes to link between specific behaviors (diet, PA, insulin dosing) and blood glucose levels (e.g., which behaviors lower an above-target reading and which raise a below-target reading). However, results show that SMBG or CGM have not been used to their fullest advantage [37]. This is partly due to the extent of monitoring usage and the lack of proper interpretation of data by the patient to adjust his or her diet, PA, or insulin, in addition to the low accuracy of CGM [35,38]. Effective structured BGM education requires an informed patient-provider team and ongoing assessment of the patient's knowledge and skills [36].

DETERMINANTS OF ADHERENCE TO DIABETES SELF-MANAGEMENT AND THE THEORETICAL FRAMEWORK: THE I-CHANGE MODEL

The adherence of AYAs with T1D to their treatment regimen is influenced by a variety of patient-related factors. Some factors, such as socio-demographic and socio-economic factors as well as disease- or medication-related factors, such as the duration of diabetes, insulin devices, and regimen [39], are difficult to change. Other factors may be less difficult to change, such as socio-cognitive determinants (SCDs) such as patients' awareness, motivation, and action planning [40]. It is crucial to identify these modifiable factors that affect adherence behaviors in this population so that behavior-improving interventions can be tailored to them.

A theory-based approach to identifying SCDs of behavior offers explicit guidance for designing interventions [41]. When using theory, it is important to take a holistic approach that integrates and applies different theories to encourage health behavior modification [42,43]. One example of such an approach concerns the Integrated Change Model (ICM), a model for identifying and changing SCDs of a behavior [40], which was used in this dissertation as a guiding framework to help identify the key SCDs of adherence to PA, HE, BGM, and insulin in AYAs with T1D. The ICM integrates various well-known socio-cognitive

theories, such as Theory of Reasoned Action [44], the Trans Theoretical Model [45], the Health Belief Model [46], Theory of Planned Behavior [47], and the Social Cognitive Theory [48]. Therefore, it provides a comprehensive view of the SCDs associated with a behavior and has been successfully used to identify and modify various health behaviors such as smoking cessation, adherence to medication in type 2 diabetes, and other conditions [49,50]. The ICM consists of different phases: awareness, motivation, and action, which are influenced by distal information factors [40,51]. There are different behavioral determinants in each phase.

The awareness phase, which is a person's self-awareness about his or her current behavior and the need to engage in it, includes knowledge, cognizance, risk perceptions, and cues to action. Knowledge is the understanding of factual information regarding behavior. Cognizance concerns the level of a person's awareness about his or her own health behavior and whether he/she meets the agreed recommendations. Risk perceptions consist of two elements: the perceived susceptibility to health threats, which is an individual's perception of the chances of getting the disease or its complications, and the perceived severity of the threats, which is an individual's perception of the seriousness of the consequences of a disease or its complications. Cues to action refer to hints or signals a person notices in his/her surroundings (external) or within himself/herself (internal) that cause an action connected to the behavior. The awareness phase factors are assumed to have an indirect relationship to behavior through factors in the motivational phase [51,52]. The motivational phase includes factors such as attitude, social support, and self-efficacy, which are also addressed in traditional social cognitive models such as the Theory of Planned Action [53] and Social Cognitive Theory [48]. Attitude in the ICM is defined as the perceived cognitive and emotional advantages and disadvantages of a particular health behavior. Social influence involves the support a person encounters from others in carrying out a behavior and entails social norms, social modeling, and social support. Social norms are beliefs about the behaviors held by people; social modeling includes perceptions of others engaging in this behavior; and social support involves the support received from others to engage in a particular behavior [54]. Self-efficacy refers to the confidence in one's power to perform the required behavior in different situations; in other words, the perception of how easy or difficult it is to perform the behavior in different situations. Together, these three types of factors determine a person's motivation to intend to perform a specific behavior. However, high intentions do not always result in the intended change. People must have a clear action plan that outlines their behavior, including when, where, and how they will act. In addition, despite having the best of intentions, people frequently fail to behave as they would like to when faced with difficult situations [55]. Therefore, it's crucial to identify the supposedly difficult situations and put coping plans into place to get through them. Hence, the factors in the action phase are important to translating an intention into the desired health behavior and include preparatory planning (identifying

which actions can and need to be undertaken for translating the intention into the desired behavior), action planning (choosing the desired action or set of actions), and coping planning (planning how to cope with challenging situations that may hinder the execution of the actions chosen) [40,56,57].

The ICM postulates that these motivational processes are influenced by predisposing factors such as information factors (the quality of messages, channels, and sources used) [58]. WHO recommends following six principles of effective communication to make sure that information is accessible, credible, trusted, relevant, timely, understandable, and actionable [59]. An important step towards more effective health communication is to embed behavioral science into health messaging [60,61]. Additionally, to effectively tailor communication messages, it is necessary to identify the determinants that influence people's behavior the most [62].

The SCDs from the awareness, motivation, and action phases could be targeted in patients' consultations and future focused interventions to optimize adherence behavior. However, there is a dearth of empirical research regarding adherence to DSM behaviors and their SCDs in Qatar and GCC states in general. To the best of our knowledge, this is the first study to be conducted in Qatar that provides information on the comprehensive factors affecting adherence in AYAs with T1D. It aims to fill the research gap on the relevant adherence factors among young people in Qatar who have T1D. In the present dissertation, a mixed-methods approach is applied in formative research to identify the key SCDs associated with adherence to HE, PA, insulin administration, and BGM.

DIABETES SELF-MANAGEMENT EDUCATION AND SUPPORT (DSME/S) AND eHEALTH

The International Diabetes Federation standards advocate that implementation of diabetes education is learner-centered and supports cognitive learning, behavior modifications, and self-management [63]. Effective AYAs' education plays a crucial role in producing successful treatment outcomes and has been considered the cornerstone of the clinical management of diabetes. Various delivery approaches have been identified for DSME/S interventions for AYAs with T1D, including one-on-one or group face-to-face education, consultation, diabetes campaigns, etc. [64,65]. However, AYAs are less likely to attend diabetes clinics and education sessions [22,66], and the transition to adult care is inadequate [67]. Additionally, the complexity of T1D management, budget and workforce constraints, brief consultations, and the approximate three-month interval between clinic visits require the consideration of alternative strategies to reach patients and support and empower them in their everyday diabetes routine [68,69]. Therefore, ongoing support

that may be incorporated into routine care is required for achieving and maintaining DSM behaviors.

As health care resources become more limited and with the advancement of technology, which enables higher levels of individual engagement and more individualized self-management plans, a new era is emerging to transform healthcare delivery [64]. Health information and communication technologies (ICTs) in health, also known as eHealth, is one of the new approaches to reaching and engaging patients (CDC, 2022; World Health Organization [70]. It is a critical success factor for the future healthcare system, driving quality and efficiency if used effectively [71]. eHealth interventions have the potential to improve diabetes management and insulin adherence, reduce the challenges and burden of patient education, improve care processes, delay diabetes complications, reduce healthcare costs, and increase the quality of care [72,73]. Additionally, eHealth can assist with the provision of tailored and personalized education, feedback, and goal setting, thereby facilitating patient-centered care. eHealth has been proven to be effective in promoting adherence to different treatment regimens [74]. Thus, internet-based interactive behavioral intervention (IBIBI), which employs techniques to improve medication self-management behaviors [74] and determinants of adherence [75], should be considered for adoption in clinical practice. However, eHealth interventions are not always adopted automatically [76]. Therefore, it is crucial to investigate factors and strategies that facilitate the content development and adoption of an intervention in clinical practice before it is developed, using a co-creation perspective. This will facilitate sharing ideas about and objectives of the intervention and increase stakeholder buy-in [76,77]. It will also make it easier to take these factors and strategies into account at the very beginning of the development stage (the ideation stage). Considering the importance of interactive behavioral eHealth intervention in health education, its uniqueness compared to other software, and the crucial roles that HCPs and organizations play in the adoption of this type of intervention to ensure its success and usage [78], it is imperative to explore experts' views on the factors relating to the development of IBIBI and its adoption, as well as the strategies that facilitate optimal adoption by HCPs and organizations.

THE CONTEXT OF QATAR

The majority of the research conducted during this Ph.D. program focused on the Arab context in Qatar. Qatar, one of the Gulf Cooperation Council (GCC) countries, has witnessed rapid development in terms of human health [79]. The diabetes center at Hamad General Hospital in Qatar accommodates both adults and pediatrics with diabetes, of whom about 1200 are children (17 years of age or younger), 150 of whom are on insulin pumps [80]. The diabetes team consists of diabetes educators, dietitians, psychologists,

podiatry consultants, clinical pharmacists, and clinical nurse specialists to provide the best care possible [80,81]. Diabetes prevention and treatment are national priorities in Qatar [6,82,83] and one of the top National Priority Research Programme (NPRP) areas. Some of the strategic goals of the National Diabetes Strategy in Qatar are to improve patient empowerment, enhance treatment adherence, delay disease progression and complications, improve health and quality of life, and invest in research areas regarding diabetes [6].

Despite these national initiatives, adherence to treatment regimens remains a challenge for people with diabetes and has been a high-priority research area in Qatar [9,10]. According to a recent study [10], a sample of 216 adolescents with T1D in Qatar had a high prevalence of nonadherence to glucose monitoring, and more than 90% of them had suboptimal diabetes control with a HbA1c of ≥ 7% [10]. The median HbA1c was 9.3% in the later study, compared to 9.7% in an earlier one [82]. Given the high prevalence of nonadherence and suboptimal diabetes control in this population, it is imperative to look into the determinants of nonadherence and poor control. However, most research on understanding the factors that influence adherence to treatment regimens has focused mainly on adults with type 2 diabetes. These factors may not be applicable to AYAs because they display unique personal, environmental, and social characteristics as they start to take on more responsibilities toward their social life and health [22,84,85]. Besides, culture plays an important role in shaping the attitudes, perceptions, and behaviors of AYAs [86,87], particularly those with chronic conditions [9,10,88]. Therefore, understanding the key factors that influence the adherence of AYAs with T1D to the various DSM behaviors like HE, PA, insulin administration, and BGM in Qatar is crucial to filling this gap and identifying targets for focused interventions aimed at optimizing these behaviors.

AIM AND OUTLINE OF DISSERTATION

Aim of dissertation

The main aim of this dissertation was to provide insight into the content, information delivery, and clinical adoption of an internet-based interactive behavioral intervention (IBIBI), which aims to improve the adherence of AYAs with T1D to DSM behaviors while also adapting to Arabic cultural and contextual factors. This dissertation consists of two parts, each of which addresses a main research question that contributes to its overall aim. In the first part of this dissertation, we focused on what the core content of IBIBI would have to be. We used semi-structured interviews (chapter 2 and chapter 3) and a systematic review approach (chapter 4 and chapter 5) to identify the key SCDs influencing adherence to the DSM regime to be included in IBIBI. In the second part, we focused on

the content delivery and clinical adoption. We used a Delphi study approach to investigate experts' views on the content delivery and adoption of IBIBI, which aimed to optimize insulin adherence in AYAs with T1D.

OUTLINE OF DISSERTATION

Part I: content of IBIBI, the Key SCDs influencing adherence to DSM regimen

For designing the content and educational objectives of the IBIBI, it is needed to identify specific adherence determinants with respect to the performance of each self-management behavior. This information will indicate which specific factors and variables within those factors should be incorporated into the content of the intervention to ensure that the relevant determinants of the target population are addressed. Therefore, the first part of this thesis aims to answer research question 1 (RQ1): what are the key SCDs influencing adherence to the DSM regimen, specifically to HE, PA, insulin administration, and BGM in AYAs with T1D in the age range of 17–24 years?

Consequently, the first part of this thesis discusses the role of awareness-, motivational-, action-, and distal-information factors associated with adherence to the DSM regime in AYAs with T1D. The awareness factors included cognition of one's adherence behavior, knowledge, and risk perception factors. The motivational factors included attitude, social support, and self-efficacy factors, and finally, the action factors included action planning and coping planning factors. Firstly, we aimed to explore these factors in Arab AYAs with T1D living in Qatar by using semi-structured interviews. The choice of Arab nationality was made in order to create a sample that would be representative of the target population for future IBIBI. These findings are outlined in chapters 2 and 3. Chapter 2 provides an overall description of the main SCDs associated with adherence to HE and PA. Chapter 3 explores the main SCDs associated with adherence to insulin administration and BGM.

Given the large number of identified SCDs from chapter 2 and chapter 3, which relate to four distinct DSM behaviors, a decision was made to narrow the research question to insulin adherence due to the significant negative effects of insulin sub-optimal or non-adherence on the individual, family, and healthcare system. In Chapter 4, we describe the protocol to conduct a systematic review of the literature on the key socio-cognitive determinants of insulin adherence or non-adherence among AYAs with T1D, as this target group has received less attention. The published protocol helps ensure the rigorous execution of the systematic review. In Chapter 5, the review systematically describes the key SCDs related to factors that account for variations in adherence among AYAs with T1D.

Part II: key factors and strategies influencing content delivery and clinical adoption of IBIBI

The second part of this thesis aims to answer research question 2 (RQ2): what are the factors and strategies that facilitate content delivery and clinical adoption of IBIBI aimed at optimizing insulin adherence in AYAs with T1D?

Since the ultimate aim was to develop an IBIBI aimed at optimizing insulin adherence in AYAs with T1D, this part examines the factors associated with the optimal content delivery of IBIBI and the factors and strategies influencing its adoption in clinical practice by HCPs and organizations (hospitals or primary care centers) in the context of Qatar and other GCC countries. This is described in Chapter 6, in which we employed a Delphi study design to investigate experts' views on the topic at hand.

The studies outlined in this thesis will help our comprehensive understanding of SCDs, adoption factors, and strategies that are important for designing IBIBI for AYAs with T1D in Qatar and the GCC region in general. Finally, Chapter 7 provides a broad overview of the findings from all the various studies. It also discusses the methodological and practical recommendations for future research as well as the implications for both research and policy.

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CHAPTER

2

Chapter 2

Determinants of healthful eating and physical activity among adolescents and young adults with type 1 diabetes in Qatar: a qualitative study

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ABSTRACT

Background

In Qatar, as in the rest of the world, the sharp rise in the prevalence of type 1 diabetes (T1D) is a leading cause for concern, in terms associated with morbidity, mortality, and increasing health costs. Besides adhering to medication, the outcome of diabetes management is also dependent on patient adherence to the variable self-care behaviors including healthful eating (HE) and physical activity (PA). Yet, dietary intake and PA in adolescents and young adults (AYAs) with T1D are known to fall short of recommended guidelines. The aim of this study was to develop an in-depth understanding of the behavioral determinants of HE and PA adherence among Arab AYAs within the age range of 17–24 years with T1D attending Hamad General Hospital.

Methods

Semi-structured, face-to-face individual interviews were conducted with 20 participants. Interviews were based on an integrative health behavior change model, the I-Change model (ICM). All interviews were audio-recorded, transcribed verbatim, and analyzed using the framework method.

Results

More participants reported non-adherence than adherence. Several motivational determinants of adherence to HE and PA were identified. The majority of participants were cognizant of their own behaviors towards HE and PA. Yet, some did not link low adherence to HE and PA with increased risks of health problems resulting from T1D. Facilitators to adherence were identified as being convinced of the advantages of HE and PA, having support and high self-efficacy, a high level of intention, and a good health care system.

Conclusions

The suboptimal adherence in AYAs to HE and PA needs more attention. Supportive actions are needed to encourage adherence to a healthy lifestyle to achieve benefits in terms of glycemic control and overall health outcomes, with a special focus on adolescents. Interventions are needed to foster motivation by addressing the relevant determinants in order to promote adherence to these two behaviors in AYAs with T1D.

INTRODUCTION

Type 1 diabetes (T1D) is the major type of diabetes in adolescents and young adults (AYAs) [1,2] accounting for more than 85% of all diabetes cases in AYAs under the age of 20 worldwide [1]. Globally, the prevalence of T1D in children and young adults has doubled since the nineteen nineties and is expected to double again in the coming few years [3] at an annual increment rate of 2–5% in many countries [4,5]. The Arab world has one of the highest global incidence and prevalence rates of T1D [6–8]. In Qatar, as in the rest of the world, the sharp rise in the prevalence of T1D is a leading cause for concern, in terms associated with morbidity, mortality, and increasing health costs [9,10]. AYAs with T1D are at an increased risk of developing diabetes-related complications including retinopathy, nephropathy, neuropathy, and cardiovascular disease at an early age [11,12].

T1D is a chronic disease that needs to be largely self-managed. Hence, the outcome of diabetes management is highly dependent on patient adherence to personal self-care behaviors, including healthful eating (HE) and physical activity (PA) [13–15]. However, less attention has been given to adherence to lifestyle in T1D [16,17] than in type 2 diabetes (T2D) [17]. Non-adherence to HE and PA can contribute to poor glycemic control, increased risk of obesity, dyslipidemia, and cardiovascular disease (CVD) in T1D [18–21]. Additionally, a mismatch between carbohydrate intake and insulin can result in hypo- and hyperglycemia, leading to short- and long-term complications [18]. Previous research supports the significance of HE adherence to diabetes outcomes [22–24]. HE has been shown to improve blood glucose control [23] and contribute to weight management in people with T1D [24]. Regular PA, on the other hand, has been shown to reduce cardiovascular risk factors [25,26], decrease insulin resistance, have a beneficial effect on physical fitness [25] and long-term blood glucose control [27].

Given the importance of HE and PA for health outcomes for people living with diabetes, international guidelines promote its adherence in this population. The American Diabetes Association (ADA) guidelines recommend that “adolescents with T1D should be advised to perform at least 60 min per day of moderate- or vigorous-intensity aerobic activity, with strength training at least 3 days per week” [28,29]. Additionally, most young adults with T1D should be advised to perform at least 150 min/week of moderate-intensity aerobic PA (50– 70% of maximum heart rate). Patients should also be encouraged to perform resistance exercise “at least two times per week on non-consecutive days” [29,30]. AYAs with T1D should also be encouraged to make improved food choices, limit consumption of fat-containing foods, added sugar and sodium, and consume sufficient amounts of whole-grain foods, vegetables, and fruits [18,31]. They also need to match insulin dose to carbohydrate intake. National and international guidelines call for dietetic advice on HE and carbohydrates counting techniques to be part of the routine diabetes review [29,32,33].

Further, the ADA recommends that all AYAs with T1D should limit energy consumption from saturated fat to less than 7% [34]. Research has highlighted the importance of individual dietary advice for people with T1D [35]. A higher level of dietetic input is certainly appropriate for people with living T1D on intensive insulin therapy regimes [36].

Despite these recommendations and known benefits of adherence, HE and PA in AYAs with T1D are known to fall short of recommended guidelines [15,18,23,37,38]. The published estimates of non-adherence rates to HE behaviors have ranged from 21% to 95% across studies [18]. It was found that adolescents with T1D were less active compared to their peers [37]. According to some studies, people living with diabetes have more difficulties adhering to a suitable diet and PA than to insulin medication [39,40]. These findings affirm the need for further investigations into adherence to HE and PA and their corresponding determinants in AYAs with T1D to better understand non-adherence and to guide developing interventions to increase adherence.

Several behavioral determinants have been found to affect patient adherence and, hence, metabolic control. These are related to various individual, social, and environmental variables [18,41]. At the individual level, research has identified knowledge, outcome expectations, emotional factors, self-efficacy, motivation, physical skills, and goal setting as important factors in self-care behaviors, including HE and PA [42–45]. At the social and environmental levels, communication with health care providers, and cultural, social, and family support were identified as important factors [46,47]. Still, suboptimal adherence and gaps in the literature exist. Additionally, many studies do not include all relevant determinants, hindering a comprehensive overview of its importance and decisions concerning what to focus on in interventions. Very few studies are available in Qatar and the rest of the Arab world that can be used to guide intervention development for AYAs. Consequently, this study employed an integrative model, the I-Change model (ICM) [48–50] to facilitate a more comprehensive understanding of these two lifestyle behaviors and their corresponding determinants in people living with T1D. The ICM has been successfully used to predict and change lifestyle behaviors in people without diabetes [49–53] and in people living with type 2 diabetes [54,55]. An essential feature of the ICM is that it acknowledges three phases in the process of behavior change: awareness, motivation, and action. These phases are particularly relevant for diabetes control as several patients are not optimally aware of non-adherence to the recommendations and do not plan or execute relevant actions to realize the prescribed recommendations. The ICM suggests that motivation factors (attitude, social influence beliefs, and self-efficacy) are influenced by different pre-motivational factors such as awareness factors (cognizance, knowledge, risk perceptions, and cues to action) and predisposing factors such as information factors (the quality of messages, channels, and sources used) [48,50]. Within the post-motivational phase, factors that increase the likelihood of intention being translated into action are action and coping

planning [48]. Additionally, it is important to explore determinants within the dynamics of different family, social, and cultural environments. A greater understanding of health issues related to culture is critical because cultural beliefs and practices may facilitate or discourage diabetes management. In Qatar, factors related to HE and PA were reported in adults [56–58] and adolescents from the general population [59], women with coronary disease [60], and in children with T1D [61]. Results showed the specific socio-cultural context of this region influences the decisions and behaviors to participate in a healthy lifestyle. However, evidence from AYAs with T1D is lacking. In this context, understanding the behaviors, their social-ecological and motivational determinants of individuals with T1D is vital to meet the complex demands of managing diabetes [62,63]. To the best of our knowledge, no research has studied this in Qatar. In sum then, the objectives of this study were, first, to identify the behaviors of AYAs with T1D towards HE and PA and, second, to examine the facilitating and hindering factors associated with these behaviors.

METHODS

Research design

This study used a qualitative design by means of semi-structured, face-to-face individual interviews. Qualitative description design, frequently used in health behavior research, is recommended to describe as well as understand participants' perspectives on a phenomenon [64,65]. This is essential to facilitate engaging diverse participants' perspectives, integrating findings into the design and conduct of future research [66], and into more effective diabetes management programs and services aimed at minimizing barriers and maintaining/promoting facilitators towards HE and PA. Individual interviews were chosen to make allowances for cultural barriers on disclosing sensitive issues, but also to encourage open discussion in a free way without reservation or group factors, as research has shown that young people are often reserved about expressing themselves in front of other people [67]. The Institutional Review Board (IRB), Medical Research Centre Committee-Hamad Medical Corporation granted ethical approval. Research number 17017/17. Data was collected over a period of four months (October 2017 – January 2018).

Participants and recruitment

The target population of interest in this study consisted of AYAs living with T1D within the age range of 17–24 years, Qatari and non-Qatari (from countries in the Gulf Cooperation Council (GCC) and the Middle East and North Africa (MENA) region) living in Qatar, and who had been diagnosed with T1D for at least two months prior to the study. This was based on evidence from behavior psychology research which estimates the average time required for a new behavior to become automatic (assuming that the patients will

start the new healthy behaviors at the time of their diagnosis, although some may be already engaged in HE and PA before their diagnosis) to be around 66 days [68]. The selection of an all-Arab sample was aimed at providing a genetically and/or culturally near-homogenous sample population to help eliminate extraneous factors that could act as potential confounders, such as socio-cultural factors like food habits. Patients with secondary diabetes that is a consequence of another medical condition or consumption of certain medications such as corticosteroids, and people with cognitive impairments, drug or alcohol dependence, or gestational diabetes were excluded.

In order to recruit AYAs, a purposive sampling method was used [69,70], i.e., physicians attending patients intentionally selected participants who met the predefined eligible criteria and referred them to the principal investigator (PI) (first author) for confirmation of eligibility. This sampling method was used to recruit patients with a diverse range of metabolic control (optimal, suboptimal, and poor), aiming to broaden the perspective on the topic. In adolescents, optimal metabolic control was defined as having HbA1c value <7.5% (<58mmol/mol), a poor metabolic control denoted an HbA1c >9% (>75mmol/mol), and suboptimal metabolic control was when the HbA1c value lay between 7.5–9% (58-75mmol/mol) [71]. In young adults, HbA1c levels were categorized into <7% (<53mmol/mol), 7–7.9% (53-63mmol/mol), and 8% (64mmol/mol), reflecting optimal, suboptimal, and poor metabolic control, respectively. This was based on the international HbA1c consensus committee recommendations [72] and clinical practice guidelines' recommendations [73–75]. At the beginning of each interview, the PI obtained the informed written consent forms from young adults aged 18 years or older and the written assent forms from those under 18 years old with their carers' consents, using the procedure approved by the ethics committee. The forms included a sufficient explanation of the study.

Sample size

A total of 20 interviews was judged to be suitable for determining sample size adequacy to achieve data saturation based on similar previous research [76,77]. Additionally, we were guided by saturation parameters found in prior studies, i.e., focused research questions [78,79], mainly theory-driven themes [80], a relatively homogeneous sample, relatively long individual interviews, and the use of an intensive framework analysis strategy [81]. Further, we examined the depth and the richness of the collected information by using an analysis saturation grid during the analysis process [82].

Interview process and procedure

The first author (HB), trained in patients' consultation and qualitative research, interviewed the participants using an interview guide. HB did not have a previous relationship with the participants. The interviews were conducted in a quiet area at the diabetes clinics in Hamad General Hospital, which is the major public hospital in Doha, Qatar, and were

scheduled for approximately 60 minutes. Participants were assured that all data would be anonymized. At the beginning of each interview, the participants were familiarized with their diabetes care team and ADA recommendations for HE and PA [34,83] and were asked about demographics and clinical characteristics such as age, level of education, duration of diagnosis with diabetes, etc. All interviews were audio-recorded and transcribed verbatim.

Tool development

An open-ended interview guide was piloted and culturally adapted prior to its use. The guide was developed based on the socio-cognitive constructs in the ICM proposed by Vries [48] (Table 1). The guide was reviewed by an advisory group consisting of experts (e.g., those with knowledge and experience) in the areas of change theories, qualitative research, and T1D specialized health care providers (HCPs). Changes were made as appropriate, based on both a field test and expert opinion. The guide was aimed at enabling the interviewer to identify behavioral determinants while at the same time allowing some more exploration by using prompts and probes. The socio-demographic and medical background included information on gender, age, educational level, and diabetes and insulin history.

Table 1. Interview Guide

Topic	Discussion
Pre-motivational section	
Awareness factors	awareness of one's behavior (cognizance): asking young people about their adherence to healthful eating (HE) habits and performing physical activity (PA), based on the agreed recommendations from their diabetes care team.
	awareness of the level of diabetes control (cognizance): whether their treatment regimen is controlled and why.
	awareness of the need to change (cognizance).
Risk perceptions	perceived susceptibility and severity of diabetes complications.
Motivations or intentions section	
Individual's attitude	identification of advantages and disadvantages of behaviors related to being active and eating healthy food.
Social influences	participants' recognition of the support that they encounter from others in carrying out the behavior.
Self-efficacy	situations in which a person finds it easy/difficult to eat healthy food/perform physical activity.
Post-motivational section: action planning	
Preparatory planning	plans to help the participant to undertake attempts towards performing physical activity and eating healthy food.
Coping or maintenance planning	plans how to cope with difficult situations, barriers, and relapse.
Distal predisposing factors	
Information factors	related to the quality of messages, channels and sources used.

DATA ANALYSIS

Demographic and clinical characteristics

Results of demographic and clinical characteristics data were expressed as mean [standard deviation (SD)] or percentage of total responses. Adherence and non-adherence were self-reported and assessed in the interview. At the beginning of the interviews, the participants were familiarized with their diabetes care team and ADA recommendations for HE and PA. Then, based on their answers during the interview, they were considered adherents; those respondents who reported that they always or most of the time follow the agreed recommendations from their diabetes care team for HE and PA; otherwise, they were considered non-adherents. The percentages of patients with optimal, suboptimal, or poor metabolic control were determined as reflected by HbA1c, as an index of glycemic control over the previous 6–8 weeks. Data on HbA1c was collected from patients' records, the purpose was to compare HbA1c results with participants' perceptions of their level of control, and whether they perceive diabetes adherence to HE and PA would influence diabetes outcome.

Qualitative data analysis

The interviews were audio-recorded and transcribed verbatim in Arabic before being translated into English. For data management and analysis, the framework method was used, which involves a combination of inductive and deductive approaches [84–87]. This method was deemed appropriate because of the need to both describe and interpret the diabetes self-management behavioral predictors. This method consisted of the following steps: (1) familiarization with the interview; during this step, the interviewer (first author) read the transcripts several times to produce an overall, general impression of the data; (2) coding; during this process, HB coded all transcripts by allocating text segments to multiple codes to account for the complexity of data and double-checked against the codes. FS and LM reviewed the codes to enhance the quality of the coding process [65,88–90]. Then, codes and sub-codes were grouped to form main themes and categories. A codebook was developed using predefined themes from the interview guide; additional codes and sub-codes that emerged during data analysis were added to the initial codebook [91,92]; (3) developing the analytical thematic framework; a coding tree was created to form the working analytical framework; (4) indexing; applying the analytical framework, during which the thematic framework was applied to all transcripts and supplemented with new emerging themes and categories; (5) charting data into the framework matrix, where participants' responses were summarized in a matrix for each health behavior; and (6) mapping and interpretation. To promote the reliability and validity of data during coding and analysis processes, thus rigor, data verification strategies were used [93]. This was achieved by (1) employing inductive and deductive methods,

the researchers HB, LM, and FS regularly and iteratively discussed the coding system and analysis to validate the consistency in the application of codes, data interpretation, and formulation of findings [93,94]; (2) using a common conceptual framework with a priory defined codes, which were specific to particular interview questions [65,89]; (3) performing concurrent data collection and analysis to ensure methodological coherence; and (4) checking for sampling adequacy and saturation. Moreover, in order to maintain consistency with the study aim, we applied an "ad hoc unitization strategy" by including theoretically relevant simultaneous and interpretative codes in the coding frame and in the analysis and interpretation of data [65].

RESULTS

Demographic characteristics and medical status information

Out of the 20 interviewees, 55% were Qatari, and the distribution of males and females was equal. The mean age was 21.6 years (SD = 2.6). Demographic and medical status information are shown in Table 2.

Pre-motivational factors

Awareness

Participants discussed topics related to their awareness of their behavior; awareness of risk perception of their own behavior; how these behaviors impacted their level of diabetes control; and awareness of the need to change their behaviors, if any. Participants who reported adherence to PA reported being adherent to HE [Quote #1], except for two cases where one patient was adherent to PA but not to HE, and vice versa [Quotes #2 and #3]. In relation to diet, the majority of participants indicated they were not following a dietary plan and that they were aware that they were non-adherent to HE; however, they did mention knowing how food affects their blood sugar levels. Some non-adherent respondents reported not being aware of the need to eat healthier; they remarked that they could eat whatever they wanted as long as they could adjust the insulin dose [Quote #4]. Similarly, many participants reported being aware that they were either inactive or non-adherent to the recommendations for performing PA. Some others indicated that they were already doing some kind of PA, which varied from walking during their working days to going to the gym. Several non-adherent participants realized that their poor HE habits and low level of PA had caused their diabetes to be uncontrolled [Quote #5]. Other reasons provided for poor and/or sub-optimal control were irregular sleep, carelessness, and overthinking.

Table 2. Main characteristics of the sample (n=20)

Characteristic	Number (%)
Adherence	
Adherents	5 (25)
Non-adherents	15 (75)
Gender	
Male	10 (50)
Females	10 (50)
Age, years	
≥17 - <18 (adolescents)	7 (35)
≥18 - 24 (young adults)	13 (65)
Nationality	
Qatari	11 (55)
Other Gulf Cooperation Council (GCC) countries	2 (10)
Other Arab countries	7 (35)
Education level	
Secondary	7 (35)
Graduate & above	13 (65)
Duration of diabetes	
1-5 year	3 (15)
6-10 years	3 (15)
>10 years	14 (70)
Evidence of late diabetes complications	
Yes	2 (10)
No	18 (90)
If yes, which	
Kidney	1 (5)
Eyes	1(5)
insulin administration device	
Injectable pen	9 (45)
Insulin pump	11 (55)
HbA1c Category across all age groups	
Optimal metabolic control	2 (10)
Suboptimal metabolic control	6 (30)
Poor metabolic control	12 (60)

Some respondents overestimated their level of diabetes control and were not fully cognizant of this. They considered themselves to have controlled diabetes, whereas actually, the results of their HbA1c indicated that they were either poorly controlled or had suboptimal control [Quote #6]. When participants were asked about the need to change their behaviors, if any, many non-adherent participants wished to increase activity levels and eat healthier. However, some of them indicated that they were not convinced of changing their behaviors regarding performing PA or HE because they failed to see a relation with diabetes control [Quote #7]. Other non-adherent participants indicated that their daily lifestyles were routines and habits that would be impossible to change [Quote #8].

Risk perception

Most adherent participants and some non-adherent ones recognized the susceptibilities of getting diabetes complications as a result of non-adherence to HE and PA as recommended. They also acknowledged that the risks of complications could be severe. Other non-adherents felt differently and indicated that complications from diabetes would be beyond their control and would happen anyway regardless of what they did, as it is their fate. Some other non-adherents did not link risks of non-adherence to PA, in particular to diabetes complications [Quotes #9 and #10]. Some respondents felt that the complications would happen at an advanced age. A few non-adherent participants thought that the complications would be serious only if they did not administer insulin as recommended or if their HbA1c became high, and thus did not link increased severity of risks to low adherence. One participant did not recall the types of complications of diabetes [Quotes #11 and #12]. Relevant quotes and respondents relating to pre-motivational factors are found in Table 3.

Table 3. Interviewee quotes: pre-motivational factors

Quote number	Quote and respondent
#1	*"I am physically active, I exercise daily. I started one month after being diagnosed with diabetes. I walk for 30-40 min a day; I cycle for another 30 min as well. In the gym I lift weights, on weekends, I also swim and play football with my friends. Regarding food, to be honest, at the beginning I didn't like to eat healthy. I used to be very mm.. what do you call "junkie" but since I'm more aware about this I have actually changed my eating habits. For example, I decreased portion size, and I have prevented myself from watching food advertisements. My mother cooks some dishes which are rich in carbs and oil, she would tell me to cook my own food. I cook oats and rice, I cook food with little oil, and I make sure to have salad and healthy food choices." (male, 24, adherent)*

#2	*"I am not into physical activity, I do not like physical activity, though I eat healthy so as not to gain weight. Three months ago, my doctor told me that my weight is above the normal range, since then I have been consistent in eating healthy and I will continue, I have lost almost 7 kg or even more, I want to be in good shape." (female, 19, adherent to healthy eating (HE) not to physical activity (PA)*
#3	*"No, I don't feel that I need to change anything. I do not feel that I have to eat healthy food because I am physically active." (male, 24, adherent to PA not to HE)*
#4	*"For me, there is no need to eat healthy, I can eat whatever I want as long as I count my carbs and increase insulin dose, there is no need to stop myself from eating what I want." (female, 18, non-adherent)*
#5	*"Ok, to be honest, I do not follow my doctor's recommendations and advice, my target goal is to reach A1c of 7 or less if it's possible, I know it's my mistake, I need to make healthy food choices and to do physical activity." (female, 24, non-adherent)*
#6	*"My diabetes is controlled, like the last appointment my A1C was around 8.9, so from then I have changed it, what I meant now it is 8.5. Yes, I'm happy with it, as a number I feel it's ok. The most important thing for me is to keep A1C under control to avoid diabetes complications, so 8.5 is Ok with me." (female, 19, non-adherent)*
#7	*"I do not feel that I have to eat healthy food. I eat anything, especially carbs, but also processed food and such things. When it comes to physical activities, I walk only on weekends for around 45 minutes. Whatever I do, my glucose will always be high. Sometimes I think that I am injecting the wrong dose, or maybe because I am under stress because of school exams and so many things to do." (male, 17, non-adherent)*
#8	*"What's the point? It's enough for me. I do not force myself. I have to change my lifestyle routine, my diet for diabetes. No –this is enough." (female, 17, non-adherent)*
#9	*"There is no effect of PA and a healthy diet on diabetes complications, but the glucose will be modified, it will not always be raised, even HbA1C might decrease. My lifestyle will be ok. The complications will occur anyway. I feel that no matter what I do, the complications will still occur." (female, 21, non-adherent)*
#10	*"Doing PA will not help in reducing complications, not that much, maybe a little. I mean, for example, walking will not reduce the chance of developing diabetes complications. I mean it will help but not that much. I do not feel it has a direct effect on diabetes." (male, 20, non-adherent)*
#11	*"They [diabetes complications] are not serious, no they are serious for people who actually do not take care of their diabetes, who do not take their insulin as they should, they are serious only if HbA1c results become high." (female, 19, non-adherent)*
#12	*"I don't know what diabetes complications are. I have forgotten diabetes complications a little bit. It's been a long time since I heard about diabetes complications when I first was diagnosed with diabetes. But I think my blood sugar improves with physical activity so… so I exercise sometimes to avoid the complications." (male, 23, non-adherent)*

Motivational factors

Attitude

Irrespective of whether participants were adherents or not, many respondents indicated that HE and PA were linked to health benefits (both physical health and mental/psychological health) and more general advantages. For example, they discussed the advantages of HE and PA on their general diabetes control, such as achieving good glycemic control, and being able to decrease insulin doses [Quote #13]. Some others mentioned preventing, delaying, or avoiding complications as advantages of HE and PA. Some physical health benefits that were recognized were: losing or maintaining weight, improving body image, fitness, and overall health.

In terms of psychological health advantages, respondents mostly mentioned enhancing their mood and living without worries. Additional general benefits for some interviewees were connected to health-related quality of life (HRQL), such as having a healthy life and the possibility of decreasing the chances of developing diseases. Participants also talked about general benefits relating specifically to performing PA [Quote #14]. Concerning healthy eating, the time needed to prepare and make healthy meals was mentioned as the main perceived practical disadvantage for non-adherents. Feeling deprived of their favorite food was the main psychological disadvantage for them. Participants who indicated that they were adherent to HE did not mention any disadvantages. Overall, adherent females reported having concerns about their weight and body image, which was a motivating factor to adhere to HE and PA for them.

Participants who performed PA regularly described physical disadvantages of performing PA, such as muscular pain, an increase in the risk of hypoglycemia and injuries. Non-adherent respondents also mentioned that fear of hypoglycemia (FoH) would hinder their adherence to PA. Time consumption was mentioned as the main practical disadvantage for non-adherents. Non-adherent participants also mentioned feelings of failure and low self-esteem resulting from their low adherence to PA in comparison with adherent patients [Quote #15].

Social influence

Social influence was perceived by the respondents as either positive (prompting the behavior), negative (discouraging), or neutral (no support). The forms of positive social influence the adherents received were emotional and practical, such as exercising with them, cooking healthy food for them, reducing sugary intake, and stopping buying soft drinks [Quotes #16 and #17]. The majority of adherents showed that they mainly got their support from their families, then from professionals, and in a few cases, from observing other adherents. Few participants who did not follow healthy diets or perform regular

PA admitted that they would sometimes accept the support and encouragement if given from close friends but not from their families. A few even said that they would listen to the advice about HE and performing PA but would not follow it [Quote #18].

Friends were mentioned as having a greater negative influence on non-adherent respondents than families and co-workers. Friends mainly encouraged negative behavior, such as encouraging them to either eat sugary and unhealthy foods with them when hanging out or get them to join them instead of going to the gym. They also said that the reasons for their friends' actions were a lack of knowledge about diabetes and the negative consequences of an unhealthy lifestyle on diabetes control. However, this did not stop them from resisting their friends' influence [Quotes #19 and #20]. Some non-adherent participants mentioned that co-workers and families exerted strong pressure to engage in being more active and eating healthier. Yet, this increased their resistance, resulting in doing the opposite [Quote #21].

Some non-adherent participants reported experiencing some forms of diabetes stigma, which had a negative influence on adherence to PA/HE and aggravated the emotional and social impact of diabetes. For instance, adolescents at school reported that some peers avoided interacting with them, thinking that they would not be able to have fun with people living with diabetes because of dietary and PA restrictions, regarding their diabetes as a burden because they had to look after them. A couple of adherents reported restrictions in participating in school activities by some teachers [Quote #22]. Other forms of stigmatization originated from parents and health care practitioners, amplifying a sense of blaming, guilt, and personal failure for not following HCP's advice, regardless of how much they tried [Quote #23]. This negative social influence elicited negative emotions in AYAs such as frustration, anger, and a feeling of being under the control of others. Non-adherent respondents more often mentioned feelings of low self-esteem and social isolation [Quote #24].

Self-efficacy

Several situations decreased feelings of self-efficacy in non-adherent participants. The first type of situation mentioned was related to social and cultural customs, prompted by the characteristics of the traditional diet and a lack of support from the environment [Quote #25]. A second type of situation was practical in nature, such as: facing difficulty in preparing healthy meals at home or in counting carbohydrates [Quote #26]. A third type of situation encompassed physical situations: non-adherent participants often mentioned encountering physical difficulties in finding suitable places offering healthy food when eating in restaurants or when traveling [Quote #27]. Easy access to unhealthy food was also indicated as facilitating non-adherence [Quote #28]. A fourth type of situation was personal and psychological. Frequently, participants' erratic lifestyles due to working or

studying conditions were mentioned as negatively impacting adherence, as they did not have the time or willpower to find or prepare healthy food. Preferences for unhealthy food accompanied with a dislike for the taste of healthy food were common among them [Quotes #29 and #30].

Concerning PA, a related set of situations were mentioned that often negatively impacted PA adherence. The first type was related to the physical environment. There was a general agreement among non-adherent respondents on the hindering effects of hot weather and infrastructure conditions, such as the availability of and ease of access to places to walk safely, like sidewalks, walking trails, and so on [Quote #31]. A second type concerned practical and personal situations. Time constraints were viewed as a major personal barrier (e.g., when being occupied with studying, work, or handling life matters). Non-adherent participants mentioned specifically fatigue and lack of sleep due to frequent urination as a result of hyperglycemia, and thus having no energy to engage in PA. Additionally, needing a detailed medical evaluation to determine their fitness to practice PA and the need to undertake additional examinations were viewed as complicated processes and barriers to joining gyms. Therefore, they either did not join or they had to deny that they had diabetes. Having babies/young children at home with no place to leave them during PA was mentioned by some mothers [Quote #32]. A third type was psychological in nature. Non-adherents talked about the overwhelming burden of balancing insulin, diet, and PA before, during, and after PA. A common psychological barrier pertaining to non-adherence to both HE and PA is derived from an intrinsic feeling of restriction, intolerance to routine and commitment, feeling down, boredom, and not seeing results [Quote #33]. FoH was linked specifically to PA.

The situations in which adherents found it easy to eat healthily were associated with social, practical, and psychological situations. For instance, eating with the family and having another family member who has diabetes made adherence easier. Other facilitators to HE were having no restrictions on eating, following an easy diet, and having a day off from the diet program [Quote #34].

The situations in which adherent participants found it easy to perform PA were associated with social, practical, physical, and psychological situations. The social situations were when they practiced with family or when they exercised in gyms because they felt supported by a trained coach and other trainees there. In particular, when the gyms were located near their homes [Quote #35]. Common psychological situations that facilitated adherence to both EH and PA were when they were in a good mood, felt motivated, and when located in their own environment [Quote #36 and #37]. Relevant quotes and respondents relating to motivational factors are found in Table 4.

Table 4. Interviewee quotes: motivational factors

Quote number	Quote and respondent
#13	*"Eating healthy and physical activity are good for all people including people living with diabetes. They can maintain my weight and give me happiness hormones. For my diabetes, since I started eating healthy and doing regular physical activity, I managed to decrease insulin doses. I think physical activity and diet might delay the complications of diabetes; they might determine your destiny for the next 50 years." (female, 23, adherent)*
#14	*"When I do PA continuously, I feel relaxed, my blood sugar level becomes normal, it decreases nervousness, my health, in general becomes better, all of that. HE and PA have helped me to live a normal life. I mean that my blood sugar level is controlled; I do not develop such complications and so on. Whenever I do PA and I eat healthy food, I will have a healthy life and I will feel better." (male, 24, adherent)*
#15	*"Performing PA needs time management and makes me feel low-esteemed because other people can achieve this, but not me." (female, 20, non-adherent)*
#16	*"My mother tries to cook food which is suitable for my diabetes and for all members of the family, not making two different meals. my mother hasn't used butter since I was diagnosed with diabetes, and in our home, we don't eat fried food, I think because my mother used to cook this food at home." (male, 24, adherent)*
#17	*"Both parents encourage me to perform physical activity, friends sometimes encourage me to participate in doing physical activity as a group." (female, 21, adherent)*
#18	*"Some of my close friends know that I have diabetes, there is no important reason for all of my friends to know that I have diabetes. Sometimes my close friends will say: don't give her a certain type of food because she has diabetes. Also, this might embarrass me. Yes, when they label me as a diseased person, I listen to them, though I don't follow their advice." (female,18, non-adherent)*
#19	*"All what my friends care about is having fun and hanging out, like: let's go to this café, it offers good cake, this restaurant makes a delicious burger. They stimulate me to eat unhealthy food, but without bad intentions. So, like maybe sometimes they do not think that this unhealthy food is not good for me, you know they don't know much about diabetes. At the end of the day, why can't I do the same, why is it only me? Why do I have to eat differently?" (female,18, non-adherent)*
#20	*"My friends encourage me to hang out with them instead of going to the gym. They rarely suggest going for exercise. It's not that they are doing it on purpose, because not all of my friends have appropriate and sufficient knowledge about the disease." (male, 19, non-adherent)*
#21	*"I feel tired because I have been doing everything in my power to control my diabetes, but my parents do not seem to appreciate my hard work. My mother and my father are always like this. I feel sad the most because I get tired, they always keep saying: health, health, take care of your health, take your insulin, go to the gym, do this, do not do that. They kind of force me to do things, this really upsets me and drives me to do the opposite." (male, 18, non-adherent)*

#22	*"My teacher said: 'You. I don't think you are allowed to participate in the match since you have diabetes.' I replied: 'You can't treat me this way. My mom allowed me to do it, this means that she is positive that I can actually control myself.' The teacher says, like: 'OK, you will participate under your own responsibility, if anything happens, we will not be responsible.' I really don't want to be treated like that, we are suffering enough because of diabetes, and on top of that to be treated like this. She talked about my diabetes in front of everybody, though I do not want other students to know that I have diabetes." (female, 17, adherent)*
#23	*"My doctor and my parents treat me like a child. When my tests readings are high, they keep asking questions to make me feel that it is my fault, have you been active? What have you been eating? They keep blaming me for my test results. They might do this because of their concerns, but this really makes me angry and frustrated, I am not a child anymore, I am old enough to take care of myself." (male, 17, non-adherent)*
#24	*"I want to exercise, but I don't have the motivation. It's because of the people around me, they never encourage me, they know I'm at risk of getting complications especially as I grow older, but still there is no support, this really annoys me a lot. That's why I prefer to stay alone most of the time." (male, 20, non-adherent)*
#25	*"Our traditional food contains high amounts of fat and carbohydrates like very sugary tea with milk, rice, sugary coffee. These are our popular kitchen ingredients. It's difficult to avoid such food." (male, 19, non-adherent)*
#26	*"I am not able to prepare healthy meals, because I am single, so I cook for myself. I cook food but salads need to be prepared on the spot. I don't have the energy or desire to prepare it right now. I prepare food for three days, three consecutive days, I feel that my diet could be better. Also, usually I find it difficult to count my carbs in the food I prepare." (male, 24, non-adherent)*
#27	*"When it comes to food it's really hard. I can't hold myself. I eat whatever I want. I can't go to a restaurant and eat just salad. Why would I go there then?" (male, 23, non-adherent)*
#28	*"The supermarket is like steps from my house. I go especially to buy soft drinks. I tried to take lemon juice instead of soft drinks, but I couldn't, so I end up taking both of them." (female, 17, non-adherent)*
#29	*"Sometimes when I see videos about people who follow a diet and lose weight, I get excited to look like them for a while. After that, I get busy with studying, and I feel I'm too lazy to do so. As a result, I end up doing nothing." (female, 18, non-adherent)*
#30	*"Eating healthy is hard. I don't like this kind of food. I don't like fruits and vegetables. I like sweets, I can't resist eating carbs, although it's top of the list of risky food for diabetes." (female, 20, non-adherent)*
#31	*"The weather is one part; another thing is the roads are not suitable for walking. Like if I want to walk from my home to the grocery store that would be very difficult. But (in..., where I was studying), you reach your destination in 10 minutes and the country roads are suitable for walking, where you find everyone walking with you. Sometimes, I go to walk in Aspire free walking area, but I need to prepare myself beforehand and that's the difference, where here you need to drive for at least 40 minutes to reach a proper place for walking, but there in … it's different. I just go out and walk." (male, 24, non-adherent)*

#32	*"My main problem is being committed to exercise, because I am not allowed to bring my baby with me to the gym." (female, 22, non-adherent)*
#33	*"When I see no improvement, for example, if I have planned to lose weight by doing PA and started to eat healthy, then three months have passed without achieving my target weight I feel like I didn't do anything and I give up." (male, 19, non-adherent)*
#34	*"I used to have one day off in my diet plan so I could eat whatever I wanted. I can eat in small portions without cutting down what I love to eat." (female, 21, adherent)*
#35	*"Although sometimes I feel that I'm not in the mood for physical activity, I encourage myself to go even when I'm not going to do something, gradually I find myself starting to exercise. So, I like to go to the gym because my coach motivates me." (female, 23, adherent)*
#36	*"It depends, if I have the intention and I'm in a good mood to eat healthy, then I will do it, otherwise, it's impossible for me to do it." (female, 17, non-adherent)*
#37	*"Well, when I was in my home country, I already adapted to the lifestyle out there. I managed to organize my time, performing PA and eating healthy was a normal thing, it was part of my daily life routine when I was there." (male, 21, non-adherent)*

Post-motivational factors

Action planning: preparatory and coping planning

Many non-adherent participants indicated wanting to control their diabetes and to achieve their goals through HE and performing more PA, but lacked self-efficacy and did not set clear goals or make action plans [Quote #38]. However, others mentioned making plans, but failed on plan execution, resulting in their plans failing to be realized [Quote #39]. Non-adherents relapsed more often and found it difficult to resist unhealthy stimuli. The main reasons for relapse provided were boredom, laziness, lack of motivation, and not seeing immediate results [Quotes #40 and #41]. Adherent participants did not make many action plans, but if they did, they were mostly linked to registering in a gym, cooking at home, or decreasing the size of food portions in an attempt to follow a diet [Quote #42].

Coping planning

Non-adherent participants did not make coping plans for the difficult situations they came across when trying to eat healthy; they mentioned relying on increasing the insulin dose to compensate for overeating unhealthy food. Other participants tried to make plans to cut down but not eliminate fast food [Quote #43].

When some adherent participants did make some sort of coping planning, these were mostly connected to plans to decrease portion size and substitute unhealthy food with healthy options, increase their level of PA to compensate for the consumption of extra carbohydrates consumed, and decrease the number of times they went to restaurants [Quote #44].

Similarly, non-adherent participants indicated not making coping plans for adhering to PA, resulting in performing PA inconsistently, sparsely, or never [Quote #45]. However, adherent participants reported making alternative plans, such as trying to manage time by compensating for days missed for PA; increasing the duration of PA; or doing different kinds of PA, such as walking in the shopping mall or swimming instead of vigorous PA [Quote #46].

Distal predisposing factors

Information factors

The majority of participants, irrespective of whether they were adherents or not, reported that the sources of information available to them were mainly from professionals at diabetes clinics (physicians and diabetes educators) and from the Qatar Diabetes Association. The second common sources were general internet websites, which were in the Arabic language, social media pages, TV, and newspapers [Quote #47]. A couple of adherent participants who used websites specialized in diabetes and traditional methods of media through reading books and journals had followed higher education (university level with medical backgrounds, e.g., pharmacy and nursing).

Some non-adherent participants mentioned friends, mothers, and coaches at gyms as sources of information. Some non-adherent participants looked for diabetes-related information from their friends without diabetes, who in turn used the internet or social media as sources of information. They explained that they did not want to engage in discussions about diabetes with other people living with diabetes, as this would cause them more stress [Quote #48].

Some adherent and non-adherent participants considered the information needed to be updated and modified, because they considered it was complicated, not specific to their situations, and mostly repetitive. They also suggested the need for more information on what type of exercises are suitable for T1D and on adjusting insulin dose around PA in order to avoid hypoglycemia [Quote #49].

Some participants suggested including PA teachers and other administrative staff in schools in the education about PA and T1D. Others stated that the information related to diabetes and PA was not available to some trainers in the gym. They either did not know how to deal with a hypoglycemic incident, did not have sugary food/drink in the gym, or kept pushing the participant to do more PA without taking their diabetes into consideration [Quote #50]. Relevant quotes and respondents relating to post-motivational and information factors are found in Table 5. The main findings are summarized in Table 6.

Table 5. Interviewee quotes: post-motivational and distal information factors

Quote number	Quote and respondent
#38	*"I tried to make a plan to control my diabetes, but I couldn't do it. Because it's so hard. I couldn't adapt. Because it's so hard. I don't like plans and I don't like setting goals that are difficult to achieve. If I push myself too hard, I will be the one getting hurt." (female, 20, non-adherent)*
#39	*"The question is, can I achieve this goal? I hope so, but logically, glucose levels for people with diabetes are always higher than normal people. To plan something, it's easy for me, but to act according to my plan, that's where I face many challenges." (male, 24, non-adherent)*
#40	*"I easily deviate from my plans, like if I go out with my friends, we won't go to have healthy food at a restaurant, of course, so I will have to eat unhealthy food like them. Also at home, I have to eat whatever is available, I don't have my own food. As I said, if I have supportive people surrounding me, the desire will come too. I mean having people there for me to support me." (male, 22, non-adherent)*
#41	*"It has been very rare that I walk or go to the gym. I don't pay attention to making healthy food choices when I eat. I just eat randomly, everything that I find in front of me. For example, I take my breakfast, lunch, and dinner without any specific meal plan. Two years ago, I planned to lose weight, after I gave birth. I gained 10 kilograms while I was pregnant and I want to lose this extra weight, but I'm not able to do so until now. My target goal is 'for my HbA1c to reach 7 or less if it's possible, and I know it's my fault because I need to control my eating behaviors and do physical activity." (female, 23, non-adherent)*
#42	*"Depending on what I know from my doctor, insulin always causes cells to store fat, which leads directly to weight gain, so my plan is to decrease my insulin dose intake through being physically active, and as a result, I eat small quantities." (female, 21, adherent)*
#43	*"I already cut down on fast food, for the past two years I used to eat fast food 14 times a week. Yes, now and for the past 5 months. I eat fast food 3 times a week, so it's a miracle for me." (male, 19, non-adherent)*
#44	*"Ya, I go to gatherings sometimes, I have an alternative plan, before I used to eat the whole plate, because I felt bad that it would be thrown in the rubbish, so I had to eat it all. But now I stopped doing that, I just eat like the size of my fist with plenty of fruits, vegetables, grilled food, and water." (female, 17, adherent)*
#45	*"During summer breaks I register in gym, but when the university starts, I stop going, because I am too busy. Even I do not have plans to exercise at home, because I am too busy with studying and exams." (female, 20, non-adherent)*
#46	*"I have a plan to do PA in late evenings during hot summer months, because it's too hot during the day to do activities outside the home. In winter I always exercise in the early mornings. Also, if it is too hot, I have a plan to go swimming instead of walking outside." (male, 24, adherent)*

#47	*"I don't rely only on the information provided during my hospital's appointments, because they are 4 months apart. I look at stuff on the internet as well. Common information across more than one website gives me some insight if the info is correct. For example, if I'm going to eat something new for the first time, I attempt to know the number of carbs online, but I try and I don't find it sometimes. I feel the search in English is more useful. There are more resources in English language." (female,19, non-adherent)*
#48	*"Sometimes I receive information from my friends. It's rare to find a friend with diabetes. Nowadays everyone knows about diabetes so I can receive information from anywhere. My friends get their info from WhatsApp or websites. For me, I rarely use the internet to get information." (male, 20, non-adherent)*
#49	*"I rarely have hypos. But, in the past ten days, I had one around 6-7 times. Yes, I usually go to the gym after eating and I should cut down my dose by one third if I'm going to go to the gym after an hour of eating. Before starting to have hypos, I didn't know that I had to decrease it. It needs to be more specific in the way that health professionals deliver the needed information for patients. When I see my doctor for routine check-ups I would prefer if she /he sit with me for a time and discuss all I need to do in detail, including the specific types of exercises that suit me." (male, 17, adherent).*
#50	*"The trainer at the gym kept pushing me to do more and more exercise, I had a hypo episode. I think trainers at gyms should be targeted in the education related to exercise and diabetes (male, 17, adherent).*

Table 6. Summary of findings

Theme	Main outcome
Pre-motivational factors	
Awareness	The majority of participants were cognizant of their own behavior towards healthful eating (HE) and physical activity (PA). Some non-adherents overestimated their level of diabetes control and others were not aware of the need to adjust their behaviors.
Risk perception	The majority of both adherents and non-adherents recognized the susceptibilities of getting diabetes complications as a result of non-adherence to HE and PA as recommended. Yet this was not enough to promote adherence among non-adherents. Some participants did not link increased risk to low adherence to HE and PA.
Motivational factors	
Attitude: advantages	Irrespective of whether they were adherent or not, many respondents believed the advantages of HE and PA were linked to health benefits (both physical health and mental/psychological health) and more general advantages. Nevertheless, unlike adherents, non-adherents' advantageous beliefs were not strong enough to bring them into action.

Attitude: disadvantages	Adherents mentioned the increased risk of injury and hypoglycemia being associated with adherence to PA and mentioned no disadvantages of HE. Non-adherents feared most PA-induced hypoglycemia. Dietary constraints and time consumption were mentioned as the main disadvantages to HE.
Self-efficacy	Non-adherents often encountered difficulties in adhering to HE and PA.
Social influence	Family impacted adherence mainly positively. Whereas peers impacted adherence negatively. Social environments have an important influence on adherence.
Post-motivational factors	
Action and coping planning	The majority of participants did not plan or execute relevant actions to realize the prescribed recommendations. They also reported sub-optimal goal setting, monitoring of self-care behavior and its outcomes, and maintaining behavior by resisting stimuli.
Distal predisposing factors	
Information factors	Information-seeking behavior varied among the participants. Mainly they sought information from health care providers and general internet websites. Specialized websites in the Arabic language are lacking.

DISCUSSION

The current study aimed to identify adherence towards HE and PA and the determinants of HE and PA in AYAs with T1D in Qatar. This study supports previous findings which showed that adherence to HE [95,96] and PA [73,96], was suboptimal. It is documented that non-adherence is a common problem in adolescents [97–99] and can continue until the mid-twenties [3,100]. Few people were adherent, and in general, those were the older participants. Previous data suggests that, compared to adolescents, young adults could be distinguished by cognitive capacity with more understanding of the consequences of actions [101] and more acceptance of their disease and self-care routine [102]. In the context of Qatar, the rapid socio-economic development and westernization of food habits played an important factor [56,59] and predicted unhealthy dietary habits among Qataris and residents [56]. Moreover, literature reviews from the Arab region revealed that physical inactivity was common among adults [103,104] and adolescents [104] general population. Some of the identified barriers were related to the specific cultural context of this region, such as the availability of and access to exercise facilities, hot weather, and lack of a social support system [103]. On the other hand, Ibrahim and colleagues (2018) found that sports facilities exist in most residential areas across Qatar [105]. However, there is a need for more data on the accessibility, utilization, and evaluation of sports facilities. Additionally, studies showed that Qatari students were less likely to be physically active

than non-Qataris [59] and children with T1D were doing fewer outdoor activities [61]. The high prevalence of physical inactivity was associated with socio-economic factors and sedentary behaviors, such as the presence of housemaids, prolonged sitting at work or school, and extensive leisure time on screens (e.g., watching TV, using a computer, or playing video games) [59]. Cultural influences remain an area for future exploration in future research. A couple of participants stated that they adhered to HE but not to PA, or vice versa, because of personal beliefs about the expected outcome of behavior and due to self-efficacy factors. Usually, adherence across domains of diabetes self-management behaviors is not consistent [99,106]. Griva et al. (2000) [107] found that generalized and diabetes-specific self-efficacy among AYAs with T1D were correlated only to adherence to diet but not to PA [107]. Similarly, Mozzillo et al. (2017) [31] found that adherence to PA was lower in AYAs with T1D compared to adherence to diet, reflecting the influence of the disease on daily functioning [31]. Hence, understanding why patients choose to be adherent to PA and not HE or vice versa is needed.

Pre-motivational factors: awareness and risk perceptions

In this study, the majority of participants reported being cognizant of their own behaviors towards HE and PA. Yet, some non-adherents thought it was acceptable to consume extra-sugary foods as long as they increased their insulin dose. Research demonstrates that engaging in compensatory beliefs can result in maladaptive behavior without a feeling of guilt [108]. Additionally, increasing the daily insulin dose leads to an increase in weight, which further worsens insulin resistance [109,110]. There is some evidence that overweight and obesity are increasingly prevalent in people living with T1D [111,112] and that the focus of patients and HCPs on carbohydrate intake prevailed over the attention paid to the overall HE [22,23,113]. Hence, it is essential to stress the importance of HE to maintain a healthy weight and reduce cardiovascular risks.

Some non-adherent respondents either overestimated their level of diabetes control or were not aware of the need to adjust their behaviors. Thus, they assumed that they were doing well in terms of the level of HbA1c they had achieved, and this did not prompt them to eat healthy or to engage in PA. This correlates with a prior study which found that AYAs with T1D lacked an understanding of the meaning and the implications of the HbA1c test [114] and with previous studies which validated cognition of the need to change behavior as an important predictor of HE [115] and PA behaviors [116]. Quite a few non-adherents reported that they were either intending to change their HE or level of PA or they were in the preparation stage, but there was no committed effort. Previous data showed that people living with T1D in the contemplation and preparation stages were less likely to follow a healthy lifestyle and dietary habits [115,117]. Further, subjects who are in the contemplation stage will not be ready to cope with the disadvantages of new behavior. Therefore, they are more likely to relapse or discontinue [118]. Hence, they may require

greater support to realize their actual level of diabetes control and their readiness for or stages of change.

In line with a previous study [119], we found that some participants did not adhere to HE and PA despite their foreknowledge about the risks associated with non-adherence. Joining their peers in social activities and maintaining their social image took priority over controlling their diabetes. While it is expected that higher risk perception should result in higher levels of adherence [120], some studies found that diabetes complications risk not only did not motivate adolescents with T1D to adhere, but were negatively related to adherence, due to low self-efficacy levels [121,122]. Plotnikoff et al. (2010) [123] found that coping appraisal variables (self-efficacy and response efficacy) were stronger predictors of intention to perform PA in people living with T1D compared to threat appraisal variables (perceived vulnerability and severity) [123]. We also found that some non-adherents did not link susceptibility to or severity of risks of complications to non-adherence. Some studies suggested that patients may continue unhealthy routines due to feelings that bad things will not happen to them [124] or not being convinced of immediate impacts on their health [125]. Previous results showed that AYAs with T1D engage in other risky behaviors, such as insulin and blood glucose monitoring non-adherence [3,126], alcohol use, illicit drug use, smoking, unprotected sex, and disordered eating behaviors [3,127]. Jaser et al. (2011) [127] reported that AYAs often have a lack of understanding and/or misunderstanding that these behaviors may risk their diabetes and health [127]. Beliefs about treatment effectiveness to control diabetes, treatment effectiveness to prevent complications, the perceived consequences and seriousness of diabetes were predictive of better dietary and PA self-management in adults with diabetes [128]. However, studies that examined personal models of diabetes in adolescents with diabetes showed varied results [128–130]. A study showed that the greater AYAs perceived their diabetes to be serious, the poorer their dietary self-care behaviors were (PA was not included in the analysis) [129]. Skinner et al., (2001) [130] found that the beliefs about treatment effectiveness to control diabetes has predicted better dietary but not PA self-care behaviors [130]. Neither beliefs about the seriousness of diabetes nor the treatment effectiveness to prevent long-term complications were predictive of HE or PA [130]. In another study, beliefs about treatment effectiveness to control diabetes and treatment effectiveness to prevent complications predicted better HE and PA behaviors, but the perceived threat of diabetes predicted poorer HE and PA [128]. Therefore, comprehensive education on the risks of non-adherence should be tailored to individual patients.

Motivational factors: attitude, social support, and self-efficacy

In the current study, non-adherents' advantageous beliefs, unlike adherents', were not enough to bring them into action. In contrast, some studies found that a more positive attitude improved adherence [131–133], while the perceived disadvantages of HE and

PA were a major factor affecting non-adherence [134,135]. Three potential explanations could be that: (1) other factors such as low levels of self-efficacy and/or negative social support influenced suboptimal adherence; (2) disadvantages outweigh advantages; according to some participants; failing to see immediate effects of HE and PA on diabetes control has led to discontinuation of healthy behavior. It is known that people living with diabetes may be more likely to change their beliefs and behaviors if they can see how their existing practices lead to healthy outcomes [125,136]; and (3) perhaps the affective component of attitude (emotions created by the prospect of performing a behavior, e.g., feeling deprived of food, or fear of PA-induced hypoglycemia and fear of injuries were more influential on intention to perform behavior than the instrumental component of attitude (cognitive consideration of how advantageous performing a behavior would be). Earlier studies found that respondents with dietary constraints [137,138] and with FoH [139,140] reported not adhering to HE and PA, respectively. Thus, encouraging AYAs with T1D to follow the recommendations of the State of Qatar National Physical Activity Guidelines (NPAG-Q) to seek specialized medical consultation and evaluation before exercising to determine the appropriate progress in the duration and intensity of PA, pre- and post-exercise meals is important to avoid hypoglycemia and injuries [141]. Past observations by other researchers [142,143] reported that measures of affective attitude were more predictive of intention than instrumental attitude. Clearly, further research is needed to examine the influence of attitude on behavior.

Regarding social influences, many non-adherent adolescents reported friends and family as mostly negatively affecting adherence, whereas adherents reported that having good health care and social support systems promoted adherence. Several studies demonstrated similar negative outcomes in social gatherings with peers [119,144]. On the other hand, a systemic review showed that peer involvement improved problem-solving and coping skills among people living with T1D [145]. Research has emphasized that family meal planning and gathering [146,147] and active family participation in PA [148,149] have improved adherence. However, other studies [98,150] found that family conflicts negatively impacted adherence. Thus, families' education and engagement to support a successful transition of self-management to AYAs and to avoid conflicts is needed. Also, the presence of a well-prepared health care support system increased trust in a provider's tailored advice and engagement in regular daily HE [151,152] and PA [2,153,154]. Our results indicated that exclusion from school activities has aggravated the emotional and social impact of diabetes, which confirms earlier results [155,156]. The International Society for Pediatric and Adolescent Diabetes (ISPAD) holds the position that adolescents must be able to manage their diabetes in the school setting without being excluded or discriminated [157]. Hence, educating the social environment to create a more supportive atmosphere for people living with diabetes should be enhanced.

Mirroring prior research, the results revealed a range of difficult situations, e.g., eating outside the home [38,158,159] or being busy [132,160–162]. Previous research conducted in Qatar demonstrated that the rapid socio-economic development and westernization of food habits also played an important factor in promoting unhealthy eating habits and a sedentary lifestyle [56,59]. Some difficult PA situations were related to the overwhelming burden of balancing insulin, diet, and PA before, during, and after PA, [26,160,163] and to the specific cultural context of this region, such as access to exercise facilities and a hot climate. In Qatar, despite the promising initiatives to promote PA at the national level, like formulating policies and organizing public sports activities such as "National Sports Day" and sports training at federation clubs [103,105], the prevalence of physical inactivity is high among the general youth population [103–105]. On the other hand, research has proven that people with T1D with high self-efficacy can motivate themselves [159,164], both directly through efficacy expectations and indirectly through perceived barriers [159], to make healthy food choices [164] and to incorporate PA into their daily routine [149,164,165]. Therefore, strengthening self-efficacy is a prerequisite for improving HE and PA adherence among this age group. Overall, given that motivation and intention are the immediate determinants of action [48] and increased patient motivation has been related to improving HE [44] and PA [166] adherence, it is crucial to assess what motivates AYAs with T1D to adhere to HE and PA recommendations.

Post-motivational factors: action and coping planning

Our results suggest that action and coping planning were lacking. Many non-adherents reflected on their planning as "implementation intentions" (such as "I plan to join the gym in the summer") rather than specified action planning. Detailed action planning should describe more than a mere behavioral intention [167,168]. Literature has shown that action planning [48,169] and coping planning [167,170] can be an effective technique to prevent relapse. Arau´jo-Soares et al. found that action planning and coping planning were predictive of changes in PA in a sample of healthy adolescents [167]. Rohani, et al. (2018) [171] found that action planning and coping planning predicted HE behavior among adults with type 2 diabetes [171]. However, less evidence is available on action and coping planning effects on HE and PA in people living with T1D [172], thus requiring future research. Non-adherent respondents reported inadequate abilities to maintain their efforts towards adherence to PA or HE for a longer period. This could be attributed to the observed deficiencies in coping planning.

Distal factors: information factors

Regarding information factors, all participants wanted information and diabetes self-management education (DSME) to be tailored to their circumstances and to be continuous. Focus-group interviews by Litchfield and colleagues [154] indicated that the barriers to PA were related to the level of education they got from HCPs. Some non-adherent

participants indicated having received contradictory messages regarding PA and HE. In a systematic review, some newly diagnosed T1D patients reported being advised by their HCPs not to exercise [173]. Therefore, it is important to coordinate the messages coming from a variety of sources. Many participants used the internet to look for information on HE and PA. However, these sites were not specific to diabetes and not targeted at AYAs. It is recognized that AYAs tend to use websites and other online resources to find information on diabetes management [12]. A noteworthy finding from the current study was that participants sometimes sought information from people without diabetes. A systematic review [174] revealed that friends and relatives were used as sources of information. Thus, information-seeking behavior from reliable sources should be fostered in AYAs with T1D.

Overall, this study has identified some factors that are known to influence behaviors involved in diabetes management. Furthermore, it has also highlighted determinants in the post-motivational (action planning and coping planning) which are limitedly investigated in T1D. The beneficial effects of these factors in increasing the likelihood of transition of intentions into actions have been demonstrated in various health conditions [170] and in type 2 diabetes [175]. Therefore, more research is required to gain further insight into these factors in T1D to optimize adherence and improve diabetes outcomes. Additionally, it has drawn attention to the needs of Arab patients with diabetes to have reliable educational material and resources in their native language.

Strengths and limitations

This study has some strengths and limitations. First, it has added to our in-depth understanding of the determinants of adherence to HE and PA in young people living with T1D in Qatar, owing to the specificity and depth of the subjective information generated. Second, to minimize researcher bias, all interviews were conducted by the same researcher, who did not have a relationship with the participants. Third, considering the large volume of information generated, adopting a framework analysis approach offered a systematic structure to easily manage, analyze, and identify themes [87].

This study also has some limitations. We recruited 20 participants based on some specific criteria for sample adequacy and verification of richness and saturation. However, it is still conceivable that our sample may not include certain categories. For instance, the views of young people who did not attend the follow-up appointments or were unwilling to participate were missed. These patients may have certain personality traits and views and are an important target for further research. A recent systematic review indicated that younger adults, those with dismissive behavior and preoccupied attachment styles or with anxiety and/or depression, and those who had not attended diabetes education were less likely to attend appointments [176]. Non-attendance was associated with higher HbA1c [176] and with lower adherence to a healthy lifestyle [139,177]. Research suggests

that young patients who are less inclined to disclose information regarding their diabetes are likely to be less adherent to diabetes management tasks and have a higher HbA1c [178]. Adolescents tend not to be open to talking about diabetes-related issues because of fear of discrimination and embarrassment. This leads to them missing opportunities to seek help regarding management, implicating the need for a more person-centered approach in T1D education. Nevertheless, it is suggested that the proliferation of qualitative research is the best way to ensure representation, rather than specifying such representation in samples [179]. Second, since saturation was deemed to be achieved, findings from this study may be transferable to similar groups. However, a larger sample size in a quantitative approach is needed to confirm our findings and increase generalizability. Third, while this study has highlighted specific determinants of non-adherence to HE related to insulin pump systems (e.g., some patients found insulin pumps have facilitated the use of corrective dose and gave them more freedom to eat whatever they wanted), we cannot draw enough conclusions on the effect of different types of insulin delivery devices on socio-cognitive factors (e.g., attitude, self-efficacy, etc.), and hence adherence to HE and PA. It was noted previously that insulin pumps offer users the flexibility to adjust insulin basal rates and boluses around exercise [180,181], but whether this has facilitated adherence to PA remains unclear. Therefore, more research is needed in this area to draw further comparisons and conclusions.

Conclusions and recommendations

The suboptimal adherence in AYAs to HE and PA requires more attention. Supportive actions are needed to encourage adherence to a healthy lifestyle to achieve benefits in terms of glycemic control and overall health outcomes, with a special focus on adolescents. Interventions are needed to foster motivation by addressing the relevant determinants to promote adherence to these two behaviors in AYAs with T1D. Such approaches targeting lifestyle modification using modern educational means are particularly important when adherence to HE and PA is pronouncedly low. This study has identified some salient factors for AYAs with diabetes, which can help HCPs identify patients who are most likely to not adhere to HE and PA. The findings encourage diabetes professionals to include friends, family members, and staff at schools and gyms in diabetes education around HE and PA. Additionally, to regularly review the awareness of AYAs with T1D about the risks of non-adherence and identify ways to increase this awareness in a non-threatening manner, review their abilities to make specific action plans to increase and be prepared to cope with challenging situations. Thus, to promote adherence to HE and PA.

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CHAPTER

3

Chapter 3

Determinants of adherence to insulin and blood glucose monitoring among adolescents and young adults with type 1 diabetes in Qatar: a qualitative study

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ABSTRACT

Background

Adherence to insulin and blood glucose monitoring (BGM) is insufficient in adolescents and young adults (AYAs) with type 1 diabetes (T1D) worldwide and in Qatar. Little is known about the factors related to being aware of non-adherence and the beliefs related to non-adherence in this group. This qualitative study investigated factors related to awareness of, and beliefs about non-adherence, as well as the existence of specific action plans to combat non-adherence using the I-Change model.

Methods

The target group was comprised of 20 Arab AYAs (17–24 years of age) with T1D living in Qatar. Participants were interviewed via semi-structured, face-to-face individual interviews, which were audio-recorded, transcribed verbatim, and analyzed using the Framework Method.

Results

Suboptimal adherence to insulin, and particularly to BGM, in AYAs with T1D was identified. Some AYAs reported to have little awareness about the consequences of their non-adherence and how this can adversely affect optimal diabetes management. Participants also associated various disadvantages to adherence (e.g., hypoglycemia, pain, among others) and reported low self-efficacy in being adherent (e.g., when outside home, in a bad mood, among others). Additionally, goal setting and action-planning often appeared to be lacking. Factors facilitating adherence were receiving support from family and healthcare providers, being motivated, and high self-efficacy.

Conclusions

Interventions that increase awareness concerning the risks of non-adherence of AYAs with T1D are needed, that increase motivation to adhere by stressing the advantages, creating support, and increasing self-efficacy, and that address action planning and goal parameters.

Keywords

type 1 diabetes, adolescent, young adult, insulin, blood glucose monitoring, adherence, qualitative research.

INTRODUCTION

Type 1 diabetes (T1D) is reaching epidemic proportions [1-3] with an annual rise of about 2-5% worldwide [1,4]. The exact incidence of T1D in young adults is unknown because reports do not usually distinguish between type 1 and type 2 diabetes in young adults, and available data primarily pertains to children and adolescents [1,2]. The Middle East (ME) region, including Qatar, has some of the highest T1D prevalence rates globally [5-7], with significant physical, social, and financial costs [8-10]. It is well known in the case of diabetes that T1D in itself constitutes a risk of developing complications, such as nephropathy, retinopathy, neuropathy, and cardiovascular disease [11,12]. The focus of the present study was late adolescents and young adults (AYAs), because of their unique developmental, social, mental, and physical characteristics and behaviors [13-15]. AYAs with T1D demonstrate a decline in diabetes self-care behaviors and deterioration of glycemic control and therefore are at an increased risk of developing early diabetes complications [14,15].

Insulin administration (IA) and blood glucose monitoring (BGM) either by self-monitoring of blood glucose (SMBG) or continuous glucose monitoring (CGM) practices are the key components of the diabetes self-care regimen for T1D. The association between insulin adherence and good metabolic control is well documented [16-18]. Large controlled clinical trials have demonstrated that intensive insulin treatment of diabetes can significantly decrease the development and/or progression of the complications of diabetes [12,19,20]. Similarly, evidence shows that SMBG [21-23] and CGM [23,24-26] can help patients with diabetes detect blood glucose levels and variability, thus adjusting insulin demands. They also provide safety by informing about hypoglycemia. Furthermore, studies have linked regular SMBG [27,28] and CGM [26,29] to better glycemic control. Schwandt et al. (2017) discovered that patients who self-monitored more than six times daily had lower hemoglobin A1c (HbA1c) than patients who monitored less frequently [28].

Findings have shown that insulin adherence among AYAs with T1D is poorer compared to younger children and adults [15,30]. AYAs with T1D tend to reduce or omit insulin doses intentionally or unintentionally [31-33]. They may also unintentionally increase the dose [34,35]. Other insulin adherence-related activities which AYAs with T1D often find to be challenging include carbohydrate (CHO) counting and dose adjustment [36,37]. Likewise, studies have demonstrated that regular SMBG [38-40] and CGM [26,29,38] are underutilized in AYAs. McCarthy and colleagues (2018) reported that emerging adults (age 18–25 years) were performing fewer daily blood glucose checks compared to older age groups (age 25 to ≥65 years) [32]. Data from the Juvenile Diabetes Research Foundation (JDRF) Continuous Glucose Monitoring (CGM) Study Group revealed that 30% of patients aged

15–24 years used CGM at least six days a week, compared with 50% of patients aged 8–14 years and 86% of patients older than 25 years [16,32].

Multiple factors influence adherence and non-adherence to the prescribed recommendations [41,42]. However, previous literature has focused predominantly on investigating selected factors, such as socio-demographic (e.g., age, gender, ethnicity, personality) [i.e., 43–46], socioeconomic (e.g., cost of treatment) [i.e., 43,45-47], and certain aspects of psychosocial factors including affect component (e.g., diabetes emotional distress, depression, anxiety) [i.e., 16,43,44,46-50], behavior components like eating disorders [i.e., 16,49] and interactions with family [i.e., 16,43,46,47] and healthcare system [i.e., 47], as well as cognition (e.g., knowledge and perception towards diabetes and insulin) [i.e., 45,48]. Other factors included the complexity of the insulin regimen [i.e., 47,51] and type of administration device [i.e., 16,46].

Studies that have used psychological/behavioral models to predict and improve treatment adherence have failed to consider all potentially relevant theory-based socio-cognitive factors in an integrated way [38]. Hence, a comprehensive understanding of the socio-cognitive determinants that predict insulin and BGM adherence among AYAs with T1D is needed to develop approaches that integrate these findings into more effective diabetes management programs and services. Within this context, the present study employed an integrative theoretical framework, the I-Change model (ICM) [52,53], because it considers numerous and multilevel influences on behavior at three distinct phases: awareness (cognizance, knowledge, risk perception and cues to action), motivational (attitude, social influence, and self-efficacy), and action (action planning and coping planning) (Figure 1). It also considers distal predisposing factors such as information factors (the quality of messages, channels, and sources used). ICM has been successfully used to predict and change treatment adherence behaviors in people with type 2 diabetes (T2D) [54-56]. The findings from this study are important for tailoring an education programme to improve IA and BGM adherence, and hence diabetes outcomes. They are also useful for diabetes policy strategies aiming to support patients' needs. Furthermore, few studies have looked at T1D patients in their late adolescence and early adulthood [57,58]. T1D studies are limited in the Middle East and North Africa (MENA) region, whereas cultural beliefs and practices are important determinants of diabetes self-management behaviors [59]. Therefore, this study aimed to explore adherence determinants to IA and BGM in AYAs, in the age range of 17–24 years within the context of their daily lives, their environment, and cultural and family dynamics in Qatar.

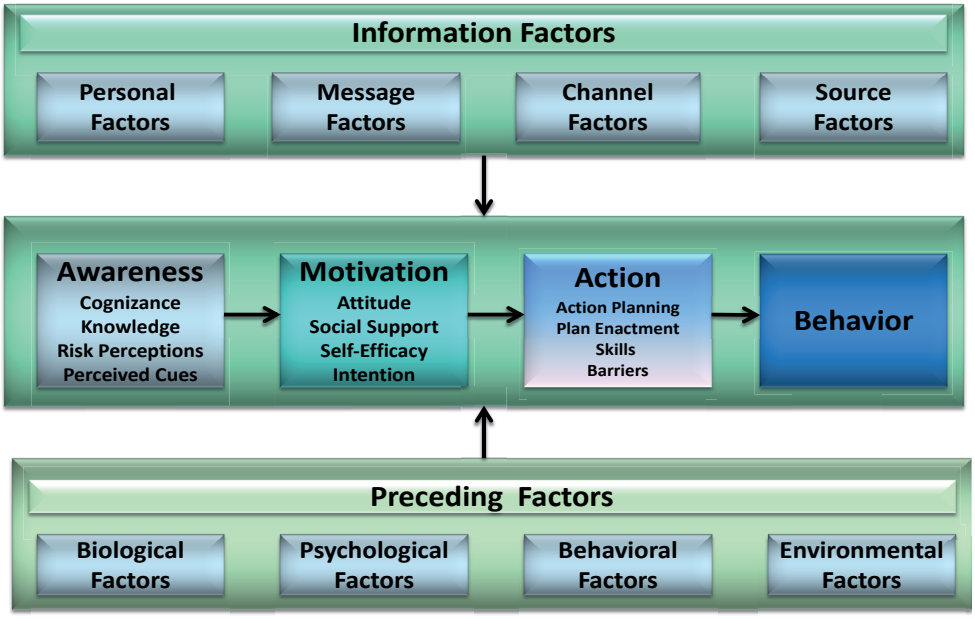

Figure 1. The I-Change model. This figure has been reproduced with permission from de Vries H. An integrated approach for understanding health behavior; the I-change model as an example. Psychol Behav Sci Int J. 2017;2(2):555-85. https://doi.org/10.19080/PBSIJ.2017.02.555585.

METHODS

Ethical approval

The Institutional Review Board (IRB), Medical Research Centre Committee-Hamad Medical Corporation approved the study (17017/17).

Research design

Semi-structured, face-to-face individual interviews were used. The rationale for using this method was to obtain a detailed description and an in-depth understanding of diverse participants' perspectives on subjects of interest [60,61], and encourage free discussion, especially when disclosing sensitive issues [62]. Data collection started in October 2017 and continued until January 2018, when 20 interviews were sufficient to achieve data saturation [51,63], and no further information could be added. This study was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) [64].

Participants and recruitment

Arab AYAs with T1D aged 17-24 years old receiving insulin therapy for at least two months prior to the study, and those using SMBG or CGM were eligible. Patients were treated in outpatient diabetic clinics at Hamad General Hospital, the main public hospital in Doha, Qatar. The exclusion criteria were gestational diabetes, secondary diabetes resulting from medical conditions or certain medications, such as corticosteroids, cognitive impairments, and drug and alcohol dependence. To ensure maximum variation sampling [65], the physicians purposively selected eligible patients who were attending the clinic and had varied experiences across the indicated age group, i.e., patients with optimal, suboptimal, and poor metabolic control [66,67], using HbA1c as an index of glycemic control over the previous two-three months [68]. The aim was to obtain varied participants' perceptions of their level of metabolic control and whether they linked this level to their adherence behaviors. Data on HbA1c was collected from patients' records. HbA1c levels were categorized into three levels of control based on the clinical practice guidelines' recommendations [23,69-71], with optimal control defined as <7.5% (<58mmol/mol), suboptimal 7.5-9% (58-75mmol/mol) and poor >9% (>75mmol/mol) in adolescents. In young adults, optimal control denoted <7% (<53mmol/mol), suboptimal 7-7.9% (53-63mmol/mol) and poor ≥8% (≥ 64mmol/mol). Purposive sampling continued in parallel during data collection. Patients who agreed to participate were referred to the principal investigator (HB), who explained the study in detail and obtained written informed consent forms from young adults aged 18 to 24 years and assent forms from adolescents under 18 years old, which included their carers' consents. Two patients declined to participate in the study, citing a busy schedule, but none of those who agreed to participate withdrew from the study.

Interview process and procedure

The first author (HB), trained in qualitative research and had no prior or post work relationship with the participants, used an open-ended and piloted interview guide during the interviews. The interview guide is available as Extended data (Appendix 1) [72]. ICM was used as the theoretical framework for developing the guide [52]. The interview discussion topics are represented in Table 1. Experts in qualitative research methodology, in the area of behavior change theories, and in T1D, guided the development of the guide. The interviews were held in private at the outpatient diabetic clinics and took approximately 60 minutes. Participants were assured that all information would only be used for research purposes. Permission to audio-record and to take notes was granted before starting the interviews, which were then transcribed in Arabic before being translated into English. During the interview sessions, probing questions were used to elicit information extraction, such as ("Can you tell me more? Would you give me an example? Would you explain that further?" among others). To ensure that the participants' answers were understood, the interviewer repeated the participants' words and confirmed the summarized main points of their responses with them. Prior to interviewing, we collected information on demographics, diabetes, and insulin history.

Table 1. Interview discussion topics

Topic	Discussion
Distal predisposing factors	
Information factors	related to the quality of messages, channels and sources used.
Pre-motivational section: awareness	
Cognizance	awareness of owns behavior: asking young people about their adherence to insulin administration (IA) and performing blood glucose monitoring (BGM) as recommended.
	awareness of level of diabetes control: weather their treatment regimen is controlled and why.
	awareness of need to change.
Knowledge	Factual and practical knowledge relating to IA and BGM, such as carbohydrates (CHO) counting, and dose adjustment based on CHO content and BGM results.
Risk perceptions	perceived susceptibility and severity of diabetes complications.
Motivations or intentions section	
Attitude	identification of advantages and disadvantages of adherence to IA and BGM as recommended.
Social influences	patients' recognitions of the support that they encounter from others in carrying out the behavior.
Self-efficacy	situations in which a person finds it easy/difficult to administer insulin/perform BGM as recommended.
Post-motivational section: action planning	
Preparatory planning	to help participants to undertake attempts towards IA and performing BGM as recommended.
Action planning	to help participant to realize the specific action plans stating when-where and how elements in the plan.
Coping or maintenance planning	plans on how to cope with difficult situations, barriers, and relapse.

DATA ANALYSIS

Demographic and clinical characteristics

Demographic and clinical characteristics were described using descriptive statistics and frequencies. Results were expressed as means (standard deviation [SD]) or percentage of total responses, such as the percentages of patients with optimal, suboptimal, or poor metabolic control. Participants were classified as adherents or non-adherents based on their responses during the interviews. Those who reported always or almost always ad-

ministering insulin or testing blood glucose as recommended were classified as adherents; those who did not were classified as non-adherents.

Thematic data analysis

The framework method was used to analyze the data thematically [73,74]. This method was chosen for the following reasons: first, it enables capturing different aspects of behavioral determinants; second, it guides systemic analysis through interrelated stages to describe as well as understanding the behaviors with their corresponding determinants. Third, it ensures transparency of data interpretations [75]. The analysis started with the familiarization stage, during which the coder (HB) read through all the transcripts and generated notes about common themes and other concepts from the data by considering each line and phrase. Firstly, a deductive theory-driven analysis was chosen. Based on this approach, a coding book was initially developed using the ICM described previously. The codebook was extensively reviewed by the authors HB, FS, and LM until agreement on the main codes and sub-codes was reached. All transcripts were coded manually in accordance with the coding book. The researchers HB, FS, and LM discussed the coding process to establish reliability [76]. The next stage was identifying the thematic framework (coding tree). During this process, codes were organized hierarchically based on how they related to one another, and additional emergent codes from the open discussions were added to the initial codebook and coding tree. An inductive approach was also used to generate meanings and to identify the patterns that could be grouped into themes and categories. During the final interpretation stage, mapping connections between the categories and the main themes aimed to look for similarities, differences, and patterns in the meaning of data. For example, the relationship between self-efficacy and coping plans; comparing participants' perceptions about their diabetes control and their HbA1c values. Validity and reliability were established through member checking during the coding process and investigator triangulation during data analysis [60].

RESULTS

Demographic characteristics and medical status information

Out of the 20 interviewees, 70% were Qatari, 55% were females, and 65% had diabetes for longer than ten years. The mean age was 20.5 ± 2.35. Demographic and medical status information are shown in Table 2.

Table 2. Main characteristics of the sample (n=20)

Characteristic	Number (%)
Adherence	
Adherents to insulin	7 (35)
Adherents to blood glucose monitoring	5 (25)
Gender	
Females	11 (55)
Age, years	
≥17 - <18 (adolescents)	3 (15)
≥18 - 24 (young adults)	17 (85)
Nationality	
Qatari	14 (70)
Other Gulf Cooperation Council (GCC) countries	2 (10)
Other Arab countries	4 (20)
Education level	
Secondary	10 (50)
Graduate & above	10 (50)
Duration of diabetes	
6-11 months	1 (5)
1-5 year	2 (10)
6-10 years	4 (20)
>10 years	13 (65)
Evidence of late diabetes complications	
Yes	2 (10)
Kidney complication	1 (5)
Nerves complication	1 (5)
No	18 (90)
Insulin administration device	
Disposable pen	4 (20)
Insulin pump	16 (80)
HbA1c Category across all age group	
Optimal metabolic control	1 (5)
Suboptimal metabolic control	10 (50)
Poor metabolic control	9 (45)

Distal information factors

AYAs with T1D most often asked healthcare professionals (physicians, diabetic educators, and dietitians) about information related to insulin and BGM. Many used general Internet websites as they indicated that diabetes-specialized websites in the Arabic language were deficient (Quote #1). They also sought information from friends without diabetes, parents, relatives, and trainers at the gym. Nearly all participants suggested that the information ideally should be simplified, updated, applicable to daily life, and refreshed. Female subjects wanted more information about pregnancy and child delivery. Others wanted to know more about cases that related to them to help them in the decisions they make on a daily basis (Quote #2). Others wanted more information about counting CHOs and what to do when blood glucose levels are very high.

Pre-motivational factors

Cognizance

Almost all participants reported being cognizant about whether they were adherents or not to injecting insulin and BGM as agreed with their HCPs. Quite a few participants indicated being adherent to IA on time. Still, some reported that they sometimes skipped insulin, either intentionally or unintentionally. A few others admitted that they were unadherent most of the time. Some AYAs, particularly females, deliberately omitted insulin doses to induce hyperglycemia for inpatient admission to avoid school exams or family conflicts (Quote #3). Very few females skipped or reduced insulin doses to control their weight (Quote #4). Irrespective of adherence to insulin, many participants were adherent to carbohydrate counting, apart from a few patients who either needed more education or more motivation to use the required information. Very few participants described themselves as adherent to healthcare providers' recommendations in terms of the frequency of SMBG and CGM. Two participants said that they would check their blood glucose before doing physical activity. The majority of patients reported testing randomly or rarely (Quotes #5 and #6).

The awareness of diabetes control levels varied between participants. Many of them, irrespective of whether they were adherents or not, believed that their diabetes was uncontrolled. Some reported that their T1D was fairly controlled (Quote #7). Some non-adherent AYAs perceived that their diabetes was controlled, but their perceptions were not consistent with their actual HbA1c levels; thus, they did not feel that they needed to adjust their adherence behaviors (Quotes #8 and #9).

The main changes few non-adherents wished to make were to manage their time effectively, care more about their health, be able to make diabetes decisions in general and control their HbA1c. Relating to IA, some non-adherents wished not to forget to admin-

ister or skip doses. Also, to be competent in counting CHO, while other non-adherents wished to perform BGM more frequently as recommended. A number of poorly adherent patients indicated that there was no need to change their adherence behavior at all. They stated that they did not accept the disease or the treatment; others believed that bringing their glucose levels near normal levels was impossible (Quotes #10 and #11).

Knowledge

Regarding knowledge, all adherents reported knowing how to calculate CHO and use the corrective dose, as well as how to obtain the necessary information from HCPs (Quote #12). However, a few non-adherents stated that they lacked the necessary knowledge to count CHO content, adjust insulin dose accordingly, and base decisions on BGM results (Quote #13), and a couple others reported lacking a certain level of knowledge about long-term complications of diabetes.

Risk perception

Nearly all adherents and many non-adherents reported being aware of the risks of developing short- and long-term complications resulting from non-adherence and acknowledged that these complications could have a severe impact on their health, like prolonged hyperglycemia, coma, blindness, and leg amputation (Quote #14). A few adherents, on the other hand, believed that adherence would delay severe long-term complications like renal failure; however, less severe complications like microalbunurea and short-term complications like hypoglycemia are unavoidable (Quote #15). Nonetheless, some non-adherents believed that whatever they did, the complications were unavoidable (Quote #16). Many non-adherents were more likely to be worried about the complications and hence avoided thinking about them. Others believed that the complications would not occur as long as they controlled their diabetes (Quotes #17 and 18). Some adolescent non-adherents believed they still had years to develop complications since they were still young, or according to their religious beliefs, everything that happens to them is destined to happen (Quotes #19 and 20).

Regarding BGM, very few adherents thought they were less likely to have complications because of regular testing. They could easily detect and act on hypo-or hyperglycemia (Quote #21). A number of non-adherents, however, did not associate the risks of their non-adherence with a level of diabetes control (e.g., detecting variations in blood glucose levels and linking these to possible causes and acting on them to bring blood glucose levels to a near normal level) or with diabetes-related complications (e.g., detecting unawareness hypoglycemia). These patients checked only when they felt the symptoms of hypo-or hyper-glycemia. Some others lacked the awareness to check even when they were experiencing hypoglycemia (Quotes #22 and 23) (Table 3).

Table 3. Interviewee quotes: distal information factors and pre-motivational factors

Quote number	Quote and respondent
#1	*"Basically, I get the info I need from my doctor. For example, if I administer insulin and my sugar is still too high, or sometimes when I administer a high dose of insulin and my sugar goes too low, I talk to him on WhatsApp to find out what I must do. For general information, I use the Internet, though it is very difficult to find trustworthy websites in Arabic." (female, 24)*
#2	*"I like to search for simple websites that are not complicated, where they provide simple explanations with pictures. I don't like it when they make it complex. I like a website that gives me information that I can benefit from, the things that I want to know about to apply it, not too much information." (female, 18)*
#3	*"Sometimes I do not administer my insulin for a whole day; I may skip my insulin for a whole day. I may depend only on my basal insulin without administering my bolus insulin. I know this is wrong, and it is hard to admit, but I sometimes do so to be admitted to the emergency room or hospital to get sick leave to miss going to school when I have an exam. My friend told me that she does the same to escape from her family fights." (female, 17)*
#4	*"To be honest; I know insulin causes weight gain. I have tried so many times to lose the extra weight I gained, but I could not. That's why I sometimes decrease the dose." (female, 18)*
#5	*"I check my blood sugar from time to time because I cannot take the glucometer with me. I test once every two days." (female, 20)*
#6	*"I do not check my blood sugar even if I feel it is low. Why check? Actually, I rarely check." (female, 22)*
#7	*"Mmm, why don't I have my diabetes under control?" OK, because I don't care, you know, not like I don't really care, but I'm careless, I deal with my diabetes as something insignificant, but it is not. I'm convinced of the importance of adhering to insulin and checking. I might even advise another diabetic person of what she should do, but when it comes to me, I could not adhere." (female, 20)*
#8	*"I believe my diabetes is controlled. I do not need to change anything; I feel I am good." (male, 23)*
#9	*"My diabetes is OK. I do not have any weaknesses in my actions. I only get easily bored from the daily routine of injecting and checking." (female, 19)*
#10	*"Nothing needs to be changed, because until now I have not accepted that I have to take insulin for the rest of my life, and I have to follow certain types of eating habits." (male, 17, with a HbA1c of 14%)*
#11	*"I have no weaknesses at all. I just like the way I'm right now, so I'm just going to continue like this. In any case, it is impossible to reach a normal person's sugar level because a diabetic patient's sugar level is always higher than normal persons." (female, 17, with an HbA1c of 8.5%)*

#12	*" I know how carbs can affect my blood glucose level and how to calculate my carbs in my meals and my insulin dose, I know for sure that I have to keep administering my insulin and checking my blood to control my diabetes, ... No problem for me. I can still contact my diabetes educator if I need anything." (male, 24)*
#13	*"So hard, you know, matching the food and the injection times. There has to be something wrong with my sugar levels, either high or low. I am not sure if I am counting carbs in the right way, I do not know how many units of insulin I should use. I am not sure how to apply the information about the grams of carbs in the meals to help me decide on how much or what to eat." (male, 19)*
#14	*"For sure, these complications frighten me; that's why I adhere to regular checking of my blood sugar, administering my insulin on time, and taking care of myself. I think that I am not at a high risk of developing diabetes complications with the way I am dealing with my diabetes, and I will do my best to avoid them." (male, 24)*
#15	"*If I maintain my blood sugar as my doctor told me to, then I do not think that I will experience any long-term complications. OK, short-term complications like hypoglycemia or a little bit of albuminuria, I can't actually completely prevent them, but then if I keep testing and keep adjusting the dose, then there won't be any long-term* effects.*" (female, 20)*
#16	*"Adherence to insulin and checking will only slow down the complication's appearance because everyone who has diabetes has a high risk of developing such complications. I am pretty sure that sometimes the major complications are not avoidable, but we try to delay them, to postpone them." (female, 19)*
#17	*"I know that the complications will be severe, like kidney failure, eye problems, etc. No one likes to have such complications. I wish that it wouldn't happen to me or to anyone else. I feel guilty, so I think about what might happen to me, but then I stop thinking, and I keep telling myself it won't happen to me. "You know, I sometimes avoid thinking about the complications because I am afraid of them." (female, 24)*
#18	*"I have asked many doctors from different countries, and all of them have told me that if my blood sugar is controlled, then I should not worry about the complications." (female, 21)*
#19	*"Diabetes may cause heart, kidney, and eye complications. I think that I have time until I develop any of these complications. I am still young." (male, 17)*
#20	*"I think if my A1c continues to be 8, the complications might occur in a few years, but if I manage to decrease it, then the complications will never happen to me. But if it remains at 8, then the complications will occur after 20-30 years, God forbid. Hmm, it has been a long time, maybe around 15-20 years. I think people who have their A1c at around 8 would get complications after the age of 50 or 40." (female, 17)*
#21	*"I usually check my sugar more often than normal people with diabetes, around 8-9 times daily. It is my health, you know, and you only have one health. If it goes away, it goes away, so I would rather be safe than sorry. Hence, I am less likely to have complications." (male, 24)*
#22	*"I really check whenever I feel tired, but I administer my insulin on time. I feel that there is no need for checking, it has nothing to do with helping me to control my blood glucose levels or prevent complications." (male, 20)*

#23	*"I do not check much, maybe once a week or when I need to check. Checking more will not prevent diabetes complications." (female, 17)*

Motivational factors

Attitude

Participants discussed the advantages and disadvantages of adhering to insulin from a physical, practical, and psychological perspective. All interviewees reported similar physical advantages, like controlling, normalizing, or decreasing blood glucose and subsequently avoiding symptoms of hyperglycemia, e.g., fatigue, dizziness, and frequent urination (Quotes #24). The main practical benefit identified by many adherents was improved quality of life for not being hyperglycemic all of the time. Adherents described specific benefits related to the practicality of using injectable devices; while some found injectable pens satisfactory and provided flexibility; others found insulin pumps to be more flexible (Quotes #25 and 26). Nearly all adhering participants agreed on the psychological advantages of adherence, like feeling relieved, not worried, not stressed, under control, and feeling like a normal person (Quote #27).

All interviewees reported similar physical disadvantages, like skin irritation and discoloration, muscle deformity, and hypoglycemia (Quote #28). Few students talked about the disadvantages of experiencing hypoglycemia the night before or while taking standardized tests, which have adversely affected their exam performances. They requested consideration of options to retake the test and to refund the test fees in case of inability to take the exam due to their diabetes (Quote #29). Weight gain was of particular inconvenience, especially among pump users because of the ease of use of corrective doses and the difficulty of losing weight (Quote #30). Non-adherents talked about the interference of insulin in their daily routine and found the process of injecting and CHO counting as tiring and time-consuming as the main practical disadvantages (Quote #31). Some non-adherents found the pump inconvenient because of life-interference, pain at the injection site, hassle, and the time it takes to prepare the pump (Quotes #32). All non-adherents discussed the psychosocial disadvantages relevant to diabetes care, including negative emotional reactions such as anxiety, depression, among others; ideals for weight; intolerance of regularity; fear of needles and testing, fear of hypoglycemia, which resulted in omitting insulin to avoid hypoglycemia; feeling the burden of counting CHO in their meals and synchronizing insulin dose with CHO content (Quotes # 33). Few female subjects mentioned their concerns about future marital relationships and the side effects of insulin on pregnancy and having babies. One male talked about his concern about erectile dysfunction.

Regarding BGM, very few adherents appreciated the advantages of providing assurance and safety through detecting hypoglycemia/hyperglycemia patterns and blood glucose levels (Quote #34). CGM's specific practical advantages were the ease and convenience of using sensors (Quote #35). Overall, many non-adherents doubted the role of monitoring in managing diabetes (Quote #36) and described physical, practical, and psychological disadvantages. The physical disadvantages included pain, while skin discoloration, irritation, and callus were particularly relevant among female non-adherents, such that they stopped testing altogether (Quote #37). Some non-Qatari individuals mentioned the cost. Practical disadvantages include frequency of testing, as it needs considerable time management and planning efforts; accuracy and practicality of use through the ability to interpret and act on results; and access to a glucometer. A few non-adherents found CGM inaccurate and described preparing the sensor as disturbing. Non-adherents illustrated psychological disadvantages linked to fear of pricking and negative feelings.

Social influence

To many adherents, family social influence was perceived as positive, especially when they were younger. However, as they grew older, they wanted to take more control over their diabetes, IA, and BGM. Many of them also appreciated the support they got from their healthcare team, especially the diabetic educators (Quotes #38 and #39). Several non-adherents accepted advice around diabetes from their close friends but not from their families; they felt family interactions were stressful and conflictual, which elicited guilt and overprotective emotions (Quotes #40 and #41).

While some adherents informed their friends about their disease and IA to help them when they were experiencing hypoglycemia events, non-adherents did the opposite because they did not want to be treated differently or with pity. Some felt that the interference of their friends had embarrassed or labelled them. Others justified that their friends were less supportive because they did not know much about diabetes and its complications. To avoid stigma, some skipped insulin or testing in public places (Quotes #42 and #43).

One of the emerged themes was social modeling, where some adolescents used traditional homeopathic medicines such as ginger, cinnamon, and pomegranate peel drinks or even bee stings to substitute insulin, just as their older relatives with diabetes did (Quote #44).

Self-efficacy

The situations which facilitated adherence for some adherents were using the pump and seeing positive results; also, when not surrounded by people and when supported by the healthcare system, when injecting or testing. Unlike non-adherents, the daily IA and BGM

of adherents became life routines with the long duration of diabetes (Quotes #45 and #46).

Non-adherents, particularly those using insulin pens and glucometers, highlighted a range of situations in which IA and BGM adherence were perceived to be difficult. These included, first, practical situations in which AYAs found it unpractical to take the insulin pen or the glucometer with them when they are outdoors (Quotes #47 and #48); second, social and cultural situations such as injecting or testing in public places because of people's curiosity and being judgmental or due to shyness or preference for maintaining a relationship over being adherent (Quotes #49 and #50); third, physical external environmental situations such as traveling, when engaged in social events, being busy. The internal physical situations were related to forgetfulness and sleep issues like feeling sleepy, having a different sleeping pattern, or sleeping (Quotes #51 and #52); fourth, psychological situations, e.g., being in a bad mood, low motivation, feeling restricted and occupied. All non-adherents reported being overwhelmed by their emotions due to the disease's long duration and the fact that it is incurable, which has negatively impacted their acceptance and adherence (Quotes #53 - #55) (Table 4).

Table 4. Interviewee quotes: motivational factors

Quote number	Quote and respondent
#24	*"Insulin helps to decrease my blood sugar. When my sugar is high, I will have no energy, and I will feel sleepy and dizzy, I can't study or go out. But, when my blood sugar is controlled, I will be able to resume my life normally." (female, 21)*
#25	*"Pen is more practical. I feel like a normal person as I can administer a dose only when I am planning to eat. With the pump, it takes a lot of time to prepare it and it causes pain." (female, 22)*
#26	*"It was hard without the pump, but then little by little I started to adapt when I started using the pump. I was relieved mentally. I was able to eat the same food other girls were eating, I was able to exercise like everyone else. Everything became better." (female, 24)*
#27	*"Adherence to insulin gives me mental relief, I will have enough sleep, I will feel relaxed and that my diabetes is under control, I will feel like a normal person." (female, 21)*
#28	*"I frequently have hypos. I drink juice and I eat chocolate when I have a hypo, so I will eat things that would increase my weight, I do not like to have hyperglycemia either." (female, 20)*

#29	*"Despite the moderate accommodations provided by testing agencies for diabetics during standardized tests, such as extra breaks, they are still very strict. For diabetics, for example, it is extremely difficult to request a test time extension. They do not consider retaking the test or refunding the test fee if we are unable to take it on the scheduled day due to having hypo or hyper the night before the exam, which will undoubtedly affect our performance during the test. We are treated in the same way as normal students, and this is not fair." (male, 17)*
#30	"*My diabetes has become controlled since I started using the pump. But, as I must inject myself only in my belly, this really upsets me, because it irritates my skin. So, I try to avoid skin irritation by switching between using the pen and the pump. Adding to this, insulin increases weight, especially with the pump, I can eat whatever I want, and I just enter the number into the pump to increase the dose, but consequently, I have gained 20 to 22 kilos since I started using it." (female, 18)*
#31	*"There is a lot of pressure because of the daily testing and insulin administration." It needs an extremely organized person. It takes a lot of discipline and self-control. So hard, even you know, with counting carbs in food and injections, it was not working. This is so frustrating." (female, 20)*
#32	*"I must check five times a day, I must inject four times daily, I must come to the clinic to check every three months, I should not eat so and so. All of that requires effort and takes time. When I ask my doctor a question, he says, "No, you cannot because you are diabetic. Sometimes, during the studying period, I return home late, I am too tired to change the needle, so I increased the insulin to lengthen the period that I need to change the needle. I do not have time to return home late, and I do not have time to do it." (male, 19)*
#33	*"Mentally, I feel I am a different person from my peers. The injection is something that will take away from you, your time, your life, and everything. Using insulin and checking my blood is more of a mental stress." (female, 17)*
#34	*"When I test my blood sugar 4-6 times a day, I will know about the pattern of my blood sugar levels, and I will act based on the results to prevent hypoglycemia and hyperglycemia." (female, 24)*
#35	*"See, I used to check around three times daily, but lately for the past two months I got the new device (..), so the testing is easy. You just need to scan, and that's it, so it's nice and convenient. The sensor with the pump is a great combination. It is just scanning, and I am done testing. Now I check in every two hours because it is simply a scan, so the process is easy." (female, 21)*
#36	*"Ok, everyone might think that I have to check my blood sugar more frequently and carry the meter with me all the time, to take care of my diabetes, but I think I am doing well in managing my diabetes, I feel that I am doing my best. Even if I have a hypoglycemic episode, why should I check? I already know from the symptoms that I am hypo." (male, 20)*
#37	*"Using the lancet hurts me psychologically. There was a time when I had to prick my fingers for a whole week, and it was painful. My fingers turned black, and then I decided to stop pricking my fingers, even though my blood was not coming out. So now I do it once, before breakfast." (female, 18)*

#38	*"My mother, she keeps advising me and nagging me. Before I was a child, but now I am old enough to take care of myself. She repeats the same advice again and again. " (male, 18)*
#39	*"My diabetic educator helps me with my daily insulin dose adjustments or self-monitoring, particularly with the availability of the helpline." (female, 24)*
#40	*"My parents are still blaming me all the time. I really got tired of them blaming me." (female, 21)*
#41	*"I do not like that my mother keeps asking me to administer my dose or to test my blood. I get nervous. For me, I don't like others to force me to do things. I will do the opposite." (male, 21)*
#42	*"You know, sometimes when a young man is administering an injection, it is not a good thing, especially if the people around you don't know that you are diabetic. Yaa, one time I was in the university, in my first year, the security called the police, because he saw me administering my injection. He thought I was a drug addict. People should be aware or educated about diabetes, but I can't blame them. Even yourself, if you saw a young person administering an injection, especially if you are not educated, or you are not aware of the diseases and the medication that should be injected, you will think the same way, I think". (male, 20)*
#43	*"The negative comments I hear are like stuff behind my back. For example, I hear someone saying, she is a poor girl because she has diabetes." So here is the problem: when I'm with them, they tell me it's fine, but behind my back, I'm a poor girl. That is why I don't like to inform people or friends that I'm diabetic, because no matter how they are mature, some will still look at it as a dangerous chronic disease. Others still, to this day, blame you for the disease, even though I have no control over it. I still feel that people are blaming me." (female, 21)*
#44	*"My auntie is also type 1 diabetic and she used to drink herbal tea instead of insulin like cinnamon, ginger, and pomegranate peel tea. I used to follow her advice and I thought that was something normal to do. You know, my friend told me she went to a traditional therapist and used bee stings. She advised me to go and see him, I might do." (female, 19)*
#45	*"Like sometimes when I see the sugar level is good, I feel proud and happy that it is good, so I continue to use insulin and to test." (female, 20)*
#46	*"After 22 years with diabetes, insulin administration and testing have become routine in my life." (male, 24)*
#47	*"I do not want my colleagues at work to interfere when I am administering my insulin or testing my sugar at the workplace, because I don't want to lose those who would interfere and ask personal questions, so they do not get offended if I am not willing to share my results with them or to talk about my diabetes. I know it is dangerous to postpone the injection time, but I used to do it rather than lose people who might interfere." (female, 24)*
#48	*"I do not use insulin if there is someone with me. I do not feel comfortable. I feel a little bit, let's say, embarrassed, but I do not want people to say that I am diabetic. Ahhh, to feel pity for me. Even in the presence of my school nurse or even my mother, I also feel shy in front of her. I do not feel comfortable." (female, 17)*

#49	*"I spend too much time on my mobile, leading me to forget about my insulin. Also, when I am at a party, it does not come to my mind at all to test and take my insulin. I get distracted by the event and the noises, so I forget. Although I know it is wrong, I still do not think about it." (male, 21)*
#50	*"I am the kind of person who tends to forget. I frequently forget to administer my insulin, but if insulin is placed in front of me, I will remember to take it, but if I forget to take it out of the fridge, I will miss my dose." (male, 17)*
#51	*"Like at night when I finish everything before I go to bed, suddenly I remember that I haven't checked my blood sugar since yesterday or I forgot to take my insulin or when I feel the symptoms of high sugar, then I would remember that I have forgotten to take my insulin. Of course, I act when I remember, but at the moment, I have to say it is just difficult; it requires being extremely organized. I mean, every minute you must be on some sort of schedule; diabetic schedule, studying schedule, you know, so you forget about one of the things." (female, 20)*
#52	*"When I get nervous, there are many things in my daily life which stress me out. All these stressors affect my diabetes and my psychological status. I keep thinking about everything. I know it is a problem because stress can increase my sugar, like I feel myself in a loop. It is hard for me to keep up with taking insulin and checking, like I check only once or twice because of other stressors." (female, 22)*
#53	*"I am not accepting the idea that I have diabetes. People will say, "she has diabetes, and I'm the only one who has diabetes. You understand, all my friends do not have diseases, but not me. People would tell me, "You shouldn't do this because you have diabetes, you see." Sometimes I feel like having to take insulin and to test is an obstacle for me, when sometimes I want to do something, but I can't because of insulin." (female, 17)*
#54	*"It might sound like a ridiculous reason, but my bag is too small to fit my insulin pen and the glucometer." (female, 22)*
#55	*"No, I don't check my sugar at school, just when I am at home. At school, never, only if I feel dizzy or hypo, I will go to the school nurse to check it for me, because I am not allowed to have the meter with me in the classroom." (female, 17)*

Post-motivational factors

Preparatory, action and coping planning

The majority of participants, irrespective of adherence, did not report having made preparatory or action plans to control their T1D, adhere to IA and/or BGM, or cope with problems. A few non-adherents considered increasing the frequency of SMBG, decreasing insulin dose, and not using the corrective dose on a regular basis, but they lacked structured plans (Quote # 56). Few others saw planning as an additional emotional strain because they would be preoccupied with their plans (Quote #57).

Concerning coping planning, only one newly diagnosed male used reminders to help him adhere to IA and SMBG (Quote #58). The vast majority of non-adherents did nothing to

cope with the difficult situations they encountered in IA, while some used maladaptive coping strategies by drinking herbal tea when they were in a bad mood to use insulin (Quotes #59 and #60). Further, setting goals, maintaining adherence, and the actual skills required (matching insulin dose with CHO content and interpreting BGM results and the ability to act on them) were reported by many non-adherents as areas where they needed improvement in. Routine intolerance and decommitment, having low desire, lack of intention and self-control, distraction, confusion about what to do, not feeling supported as they used to be when they were younger, and not seeing the results, were reported as common barriers to coping with adherence. (Quotes #61 - #63). Among the very few facilitating factors reported by adherents were that they kept themselves motivated and had a great deal of self-discipline (Quote #65) (Table 5).

Table 5. Interviewee quotes: post-motivational factors

Quote number	Quote and respondent
#56	*"I do not test enough in a day. I only test before eating. I will start to check two hours after eating. So, maybe that would help in reducing my A1c." (female, 24)*
#57	*"Planning is what makes diabetics frustrated. It keeps them thinking about diabetes. That is why I do not follow any plan. Why would I make it complicated? I will make it easy. Every time my healthcare team starts talking about how I should make plans and so on, this is upsetting and causes unnecessary headaches." (male, 23)*
#58	*"I was diagnosed with diabetes six months ago. For the first few weeks, it was difficult, but then I got the hang of it. I was sad when I was first diagnosed, but I learned how to make it part of my life by controlling it and managing my diet and exercise. When I was diagnosed, my A1c was 13. Now it is 6.7. I use a reminder on my phone to remind me to administer my insulin on time and to test 3 to 4 times daily. I would like to say that people should not feel abandoned when they get diagnosed and should not feel it is the end of the world. It is like a new beginning, and it will force you to be the best possible version of yourself. " (male, 17)*
#59	*"A friend recommended that I visit a herbal therapist who treats diabetic patients with pees. I also use pomegranate peel powder. My aunt advised me to use it, and it worked. I use it when I am not in the mood to have my shot." (female, 21)*
#60	*"When I am not in the mood to administer my insulin, I drink ginger or water, and my blood sugar level decreases." (female,19)*
#61	*"Right now, I do not have a plan. A long time ago, I planned a timetable for my meal plan, including what I had to eat in the morning, in the evening, and at night. It also contained my insulin shot timings. But I never committed to it. Mmmmmm I feel bored." (female,18)*
#62	*"Always when I do something and if I don't see immediate positive results, so this relapses me." (female, 24)*
#63	*"It needs effort and self-control; I do not have that energy to continue." (female,19)*
#64	*"You know, until recently, I felt a little lazy about administering my insulin, especially the injection before lunch." (female, 21)*

#65	*I feel tired and depressed. I used to have my sister's support. She used to take care of me. Now she is married." (male, 22)*
#66	*"It takes a lot of discipline and self-control. It is difficult in terms of the fact that it is challenging that you must struggle with what you like to do, but it is good in terms of learning self-control." (male, 17)*

DISCUSSION

The current study aimed to identify determinants of IA and BGM adherence among AYAs with T1D in Qatar. Our results confirm previous data indicating that IA and BGM adherence continues to be a problem in this age group.

Information factors

Nearly all patients wanted information provided to them to apply to their daily live and be refreshed more frequently. Consistent with other results [77], female subjects wanted more information about pregnancy and child delivery. Few non-adherents sought information from older relatives who recommended homeopathic medicines instead of insulin or from generic websites. A previous study among Qatari participants showed that 95% of them used Google as a search engine to look for health information, and the younger adults were using the Internet significantly more than older adults [78]. Evidence supports that lack of information [79] or irrelevant and false information can negatively impact diabetes management. International guidelines recommend that the information provided to patients should be structured, continuous, and accessible in a language that the patient understands and fulfils his/her needs [80,81]. Therefore, it is necessary to focus on improving information-seeking behaviors, understanding how the patient processes information, and translating this understanding into action so as to improve knowledge and facilitate positive self-care behaviors.

Pre-motivational factors: cognizance, knowledge, and risk perception

Concerning cognizance, this study showed that almost all adherents and non-adherents reported being aware of their behaviors. Yet, a few non-adherents did not have enough awareness that they needed to change their behaviors due to misjudgment about their level of diabetes control, misbelief about achieving target levels, or lack of acceptance of the disease and the treatment. Prior findings support the hypothesis that AYAs who accepted their disease were more adherent than those who did not [82,83], while those who did not achieve their target blood glucose levels felt powerless and under an impossible burden [84]. It is documented that knowing how the patient perceives his or her illness improves adherence [85,86]. Therefore, increased awareness, monitoring, and support for patients with diabetes, especially those with problems in psychological adaptation, are needed within different T1D care settings.

Regarding knowledge, our study confirms recent findings on the importance of periodically assessing the knowledge and readiness for education of patients with diabetes in clinic visits to meet the demanding nature of diabetes [87]. This is necessary because learning is more likely to be achieved when it is presented from the patient's perspective.

Concerning risk perceptions, our findings showed that few adherents perceived insulin adherence would delay long-term complications (like renal failure) but not short-term complications (like microalbuminuria). Researchers have found contradictory results relating risk perceptions of AYAs with T1D and adherence to DSM activities, emphasizing the need to identify short- and long-term complications when assessing risk perceptions of diabetes in AYAs [88,89]. Additionally, in this study, non-adherents indicated that they were not aware of the risks associated with non-adherence. Some groups, reported to deliberately omit insulin doses to induce hyperglycemia to get exam exemptions or avoid family problems. Previous research showed that female adolescents who experienced family problems were more likely to develop psychiatric problems and medication non-adherence [90]. Previous cases of deliberate insulin misuse to induce dysglycemia (hypoglycemia or hyperglycemia) have been observed in AYAs with T1D. Patients' motives varied, such as mental disorders like major depression or factitious disorder (FD) and/or suicidal ideation [31,34,91-93]. Induced hypoglycemia was also used to justify eating sweets and carbohydrate-rich meals [31]. Factitious dysglycemia should be considered a possible cause of brittle diabetes and requires specialist consultation [91,93]. However, the literature on FDs from the Arab region is limited [94,95], with only one report on Iraqi women with type 1 and type 2 diabetes [93]. More information is needed from the Arab region to clarify FD's clinical profile and implications for T1D. Our findings support results from earlier studies [96,97] indicating that some AYAs with T1D were not sufficiently aware of the consequences of their illness-specific risk behaviors, which could have a negative impact on optimal management and outcomes, such as severe hyperglycemia, diabetic ketoacidosis, and long-term diabetes complications. Further, similar to previous findings [98], other non-adherents believed that they were less vulnerable to complications because of inherent beliefs that they wouldn't suffer any negative outcomes or because complications would occur at an older age. Others, and in line with Garrett and colleagues' study (2014) [99] felt that complications were inevitable despite their best efforts. Moreover, a few non-adherents perceived the susceptibility and severity of risks associated with IA non-adherence as ongoing threats that were worrying and depressing, and they avoided thinking about them. These threats have previously been identified to affect AYAs' emotional well-being and adherence [100-102], and those who perceived their illness to be of greater severity demonstrated poorer glycemic control [103,104]. Yet, perceptions of risk and severity may encourage adherence [85,105,106]. A meta-analysis has shown that communicating threat messages has an effect on behavior only when efficacy is high [107]. Indeed, our results have addressed, similarly to other recom-

mendations [86,108,109], the importance of teaching AYAs about the potential long-term complications in a way that is not depressing or discouraging.

The findings indicated that the majority of non-adherents did not perceive being at risk because of non-adherence to BGM, and thus they rarely tested themselves. Previously, knowledge gaps regarding SMGB were identified [39,110,111]. A prior study found that patients who were less knowledgeable about the importance of glycemic control in developing diabetes vascular complications were less adherent to SMBG [112]. In summary, understanding awareness factors is a prerequisite for understanding individuals' engagement or disengagement in adherence behavior and should be continually evaluated and addressed in every health encounter.

Motivational factors: attitude, social influence, and self-efficacy

The majority of non-adherents reported not believing that adhering to the frequency of BGM as recommended would be advantageous. Similar findings are also reported in other studies [113,114]. It is also known that the psychological impact of a chronic illness alters an individual's attitude and affects medication adherence [115]. While national and international guidelines recommend that periodic psychological screening should generally be a routine part of diabetes management [116-119], it is clear that these recommendations are not yet being followed up sufficiently. It is important to develop communication strategies to convince non-adherent patients to adhere to the recommended frequency of BGM. This study also highlights AYAs' concerns about diabetes and its impact on pregnancy, marital life, and sexual dysfunction (SD). Previous research has discovered that AYAs with T1D have more conflicting marital relationships than their non-diabetic counterparts [58,90]. Studies from the Arab world [120,121] discussed the implications of diabetes on sexual life, usually considering SD in men and patients with T2D. AYAs with T1D have been given less attention, underlining the need for more exploration on this subject and in relation to insulin adherence in order to better understand these factors.

In our study, AYAs reported hypoglycemia before or during standardized tests to influence their concentration and performance, requesting the option to retake the test or be refunded. A systematic review reported that 23–39% of older children (>11 years) reported that they did not have the opportunity to repeat school exams again when they experienced hypoglycemic events before or during an exam [122]. Another systematic meta-review [123] has provided evidence that students with chronic illness often demonstrate worse school experiences and outcomes than students without chronic illness. While some countries have expressly defined legislative protections to support students with T1D [124-126] other countries have not. Additionally, these specific laws relating to the requested reasonable accommodations during exams vary from country to country. Therefore, international and national policies should provide unified guidance

to ensure that AYAs with T1D are not placed at a considerable disadvantage compared to students without diabetes. There is a need for further research into the perceptions and needs of students with T1D relating to exams in the Arab world.

In this study, adherents indicated that having good support from HCPs had motivated their IA adherence. They added that the availability of social media as a method of communication between the diabetes healthcare team and patients had empowered them in their daily decision-making. Prior findings indicated that the patient-provider relationship strongly impacts treatment adherence in AYAs with T1D [14,127]. AYAs with T1D also wanted to become more autonomous in their self-care decisions and behaviors with balanced family interactions, suggesting that the transition of diabetes responsibilities from pediatric to adult should be considered and evaluated for AYAs and their families in order to avoid family conflicts. Previous findings demonstrated that negative family reactions to self-care behaviors were found to be related to poor adherence and glycemic control [103,128]. Noser *et al.* (2017) found that diabetes-specific family conflict negatively influenced SMBG adherence in young adults with T1D even if they possessed high self-efficacy levels [129]. The national clinical guidelines [117] emphasize the delivery of diabetes self-management education (DSME) at transition points in care. However, more information on the details of the processes involved in the transition preparation period and on how to fully implement these processes needs to be addressed in further research. Our results revealed that key people in the patient's life and cultural factors affected the perception of the meaning of illness and its treatment. In a previous study, some adult patients with T1D commented that their family and friends provided incorrect information [130]. Hence, the sociocultural environment should be evaluated closely.

Our findings demonstrated that adherents showed higher levels of confidence in their ability to follow medical recommendations and expected more meaningful positive consequences for adherence. On the other hand, difficulty administering insulin and/or performing BGM as recommended has been reported in non-adherents as a result of low self-efficacy. Self-efficacy was previously identified as a significant predictor of relatively high adherence rates [42,131]. Therefore, self-efficacy promotion is important to help overcome the various barriers and, in turn, to improve adherence in Arab AYAs with T1D.

Post-motivational factors: action planning: preparatory and coping planning

Our results revealed that action planning was lacking for nearly all participants, whether adherent or not. Some non-adherents indicated that planning aggravates emotional strains. Previous studies highlighted the action planning construct as a prominent predictor of adherence to asmathtic [132] and antiretroviral [133] medication in AYAs. Additionally, goal setting was shown to improve SMBG [38]. It is therefore important that health

communication programs to foster T1D adherence focus on adequate action planning and goal setting for people with T1D in Qatar.

Strengths and limitations

The findings from this study can serve to design an educational program in which these psychosocial determinants can be addressed in a patient-centered approach. The strengths of this research are that, firstly, the face-to-face semi-structured approach with a researcher who did not have a relationship before and after the work helped AYAs communicate openly about sensitive issues such as SD, which would be generally difficult to address [134], particularly since it is influenced by different tribal and social attitudes in the Arab region [135]. Secondly, while a sample of 12 interviews demonstrated achieving saturation previously with a similar study nature and analytical approach [136–138], we examined the depth and richness of collected information using a saturation grid [139], and interviewing continued until saturation was deemed achieved with a sample of 20 interviews. Therefore, findings from this study may be transferable to similar groups. Thirdly, adopting a framework analysis approach offered a systematic structure to easily manage, analyze, and identify themes [140].

This study also has some limitations. Data collection was self-reported; therefore, reporting bias is possible. Although information about the magnitude of such bias is unavailable in most epidemiologic studies [141], there is a reasonably reliable self-report when questions are asked in a non-judgmental manner [66]. Second, although this study has highlighted specific determinants related to the different insulin delivery devices and BGM systems, more research is needed in this area to draw further comparisons and conclusions. Third, the views expressed in the interviews are less representative of the adherents' sample, particularly for BGM. Therefore, this study may not capture other important facilitators and experiences, highlighting the need for further research among adherents.

Conclusions and recommendations

First, concerning information needs, most respondents reported that they needed more information relevant to their daily lives and more Arabic language websites that provide simple diabetes, insulin, and CHO counting information. Second, concerning awareness, some non-adherents were not optimally aware of the need to change their behaviors, lacked the knowledge required to make decisions on insulin dose adjustments, and underestimated T1D risks. Third, concerning their motivation, many non-adherents reported a negative attitude towards adherence, which resulted from several perceived disadvantages that outweighed the advantages of adherence. They also reported a lack of social support and a low sense of self-efficacy. Fourth, most respondents lacked specific plans to prepare for and cope with adherence. In conclusion, increased efforts are needed for

people with T1D in Qatar to strengthen awareness, knowledge, and perceived risks of non-adherence as well as to realize a positive attitude, to strengthen social support and self-efficacy, and to enhance appropriate action planning. A comprehensive approach that takes into account the broader social context in order to minimize conflicts in families and to minimize stigma in the sociocultural environment is needed.

Data availability

Underlying data

The qualitative data that support the findings of this research are not publicly available due to concerns that the data could potentially reveal participants' identities. However, data are available to researchers upon request from the corresponding author (H.Burno@maastrichtuniversity.nl/hanoneh111@gmail.com) and with permission from the Institutional Review Board-Hamad Medical Cooperation for further academic research.

Extended data

Figshare: Extended Data Set: Appendix 1: The interview guide for "Determinants of adherence to insulin and blood glucose monitoring among adolescents and young adults with type 1 diabetes in Qatar: a qualitative study". https://doi.org/10.6084/m9.figshare.20368068.v2 [72].

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CHAPTER

Chapter 4

Socio-cognitive determinants affecting insulin adherence/ non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol

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ABSTRACT

Objective

This systematic review aims to investigate the key socio-cognitive determinants associated with adherence/non- adherence to insulin treatment in late adolescents and young adults in the age range of 17–24 years with T1D.

Methods

A pre-specified search strategy will be used to search for studies in the electronic databases and citation indexes: PubMed, EMBASE, Web of Science, and PsycINFO. Two researchers will screen the title and the abstract independently, then will read and critically appraise the full text of each included study. A third independent reviewer will resolve disagreements in data extraction until consensus. Data will be extracted using the Population, Exposure, Outcomes, Study characteristics framework. Study selection will follow the updated guideline for reporting systematic reviews (PRISMA 2020) and will take place from 15 October 2021 to 1 January 2022. The methodological quality and risk of bias of the observational studies will be assessed by the JBI Critical Appraisal Checklist for Cohort and JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies.

Results

A qualitative narrative synthesis will present the characteristics and the quality of studies and the outcomes of concern.

Conclusions

Based on the contemporary literature, this review will synthesize the evidence on the socio-cognitive determinants associated with adherence/non-adherence to insulin treatment in late adolescents and young adults in the age range of 17–24 years with T1D. The findings will help design patient-centered interventions to promote adherence to insulin in this age group, guide patients' consultations and diabetes self-management education (DSME) programs.

Protocol registration: PROSPERO ID: CRD42021233074.

Keywords

Socio-cognitive, insulin, adherence, non-adherence, type 1 diabetes, adolescents, young adults, systematic review

INTRODUCTION

Type 1 diabetes (T1D) is a global health problem with increasing prevalence at 3–5% yearly [1-3]. Although T1D sometimes appears during adulthood, it usually occurs during childhood or adolescence and is treated with insulin therapy. Despite the advancements in insulin administration systems, insulin adherence continues to pose a significant challenge for adolescents and young adults (AYAs) with T1D [4-7]. Adherence to insulin can be defined as administering the correct dose at the right time and/or frequency in accordance with a mutually agreed-upon treatment regimen [8,9].

Evidence suggests that the rate of insulin non-adherence in AYAs is high [4,10-12], ranging from 23-77%, with a higher rate in developing countries [13]. Research has demonstrated that non-adherence to insulin is associated with increased glycated hemoglobin (HbA1c) level [5,14], diabetic ketoacidosis [15], increased hospitalization [16], and long-term complications [15-17]. The latter includes microvascular and macrovascular complications leading to increased morbidity and mortality in people with T1D [4,8,17]. On the other side, the association between greater adherence and improved clinical outcomes in AYAs with T1D is evident [5,6,14]. Insulin non-adherence can occur intentionally or unintentionally and involves situations where adolescents and young adults did not fill their insulin prescriptions [17,18], reduced or omitted doses [4,7,19]. The latter may occur for various reasons, such as fear of hypoglycemia [20], weight control [4,7,19], interference with daily routine, forgetfulness [13], problems with coping with peers [21], and social stigma [22,23]. Sometimes AYAs unintentionally administered the wrong dose [21,24]. Due to the negative (health) consequences of sub-optimal adherence, it is imperative to understand adherence/non-adherence behaviors and their factors.

Medication adherence is affected by multiple interacting factors [4,25,26]. Some of these factors are relatively fixed factors, such as socio-demographic (SD) factors (e.g., age, gender, ethnicity, personality, etc.) [14,27-29] and socioeconomic (SE) factors (e.g., cost of treatment) [5,27-29]. For example, findings revealed that AYAs were the least adherent and had poorer diabetes control compared with children and older patients [4-7,18]. A systematic review among adolescents with T1D found that female sex was associated with non-adherence in more than one study [30]. Multiple studies involving T1D demonstrated eating disorders were more common in females than in males [31,32]. The prevalence of eating disorders increased with age, affecting up to 40% of young adult females with T1D [33]. Eating disorders were found to be associated with lower insulin adherence and higher HbA1c [11,19,34]. Other factors are either difficult to modify, such as certain affect psychosocial factors (e.g., diabetes emotional distress, depression, anxiety, etc.) [14,19,30,35] or partly unmodifiable such as medication regimen factors including the

complexity of insulin regimen [5,13,36], type of administration devices [4,14,27], and insulin side effects (e.g., hypoglycemia).

Certain factors, such as socio-cognitive factors, are, however, more likely to be modifiable [4,26,27]. Having insight into these modifiable factors can help to inform future interventions aimed at improving adherence through minimizing barriers and maintaining/promoting facilitators. There is a growing body of knowledge on the various psychological/ behavioral models used to examine the socio-cognitive factors that influence adherence to insulin [37]; still, all potentially relevant psychosocial factors were not yet considered in an integrated way [38]. Holmes and colleagues (2014) argue that within the theoretical models, researchers often focus explicitly on evaluating variables that are considered proximal (close) rather than distal to adherence behavior [39]. Hence, the I-Change model (ICM) [40] will be the leading theoretical frame for the present review (Figure1). The ICM integrates broader determinants of personal and environmental factors for the diagnosis of behavior, ranging from the individual 's degree of health literacy and knowledge to the social environment and setting for carrying out and maintaining the behavior. It distinguishes between pre- motivational factors (cognizance of one's behavior, knowledge, risk perceptions, and cues to action), motivational factors (attitude, social support, self-efficacy, and intention), post-motivational factors (action and coping planning), and distal information factors. This is particularly relevant for diabetes control as multiple empirical studies have shown that sets of interactively integrated factors account for variations in adherence to the prescribed recommendations [25,41,42].

Several studies have investigated and identified important socio-cognitive factors within adolescents and/or young adults. Some were related to pre-motivational factors such as knowledge and expectancies [43,44], perceived severity of the disease, perceived susceptibility or vulnerability to the disease process, perceived barriers/costs to the action, and cues to action [45,46]. Regarding motivational factors, results by de Weerdt and colleagues (1990) showed that attitude was an essential determinant of active self-care of AYAs along with features of their social environment [47]. Other studies showed positive correlations of perceived self-efficacy and outcome expectancies with insulin adherence [48,49]. Others identified the role of the social influence of family, peers, and the healthcare system on adherence [50-52]. Within the post-motivational factors, past studies demonstrated that the coping mechanism and appraisal of coping/ progress would modify the representation and/or coping behaviors [53,54]. Regarding distal information factors, studies highlighted considering features such as level, frequency, type, relevance to the recipient, and quality of information to provide personalized information to AYAs [55,56], and how the lack of information has impacted diabetes management negatively [57].

Systematic reviews that looked at socio-cognitive determinants of insulin adherence among people with T1D mainly focused on adults [i.e., 27,58,59]. The systematic/narrative reviews that did include adolescents and /or young adults did not exclusively relate to insulin adherence (investigated adherence to a range of diabetes self-management behaviors including diet, physical activity, self-monitoring of blood glucose and medication adherence [i.e., 28,30,60] and/or did not exclusively relate to T1D (included patients with either type 1 or type 2 diabetes), [i.e., 29,60-62] and/or focused mainly on a few determinants [i.e., 5,28,63]. Hence, the relevance of these findings for AYAs with T1D is unclear. One narrative review [5] specifically addressed insulin adherence in adolescents with T1D, considered mainly psychological factors (e.g., mood, anxiety, and eating disorders), social support factors, and interactions with healthcare system factors.

To date, a wide range of other socio-cognitive determinants such as those that predispose one to action (awareness factors and cues to action) and those that shift a person from being predisposed to action into an action state (clear action and coping planning and self-regulation skills) are not often investigated in the T1D systematic reviews. Overall, there is a gap in the systematic evidence that addresses the integrative socio-cognitive determinants of insulin adherence among late adolescents and young adults with T1D. Therefore, a comprehensive systematic evaluation of the evidence on the socio-cognitive determinants that predict adherence/non-adherence to insulin treatment among this age group is warranted. The findings will be important to guide patients' consultations and diabetes self-management education (DSME) programs. They may also help to develop tailored insulin adherence improving interventions aimed at improving diabetes outcomes in patients with T1D. Therefore, this review aims to identify the key socio-cognitive determinants influencing adherence/non-adherence to insulin administration in late adolescents and young adults in the age range of 17-24 years with T1D. In order to ensure the systematic search of available literature, the Population, Exposure, Outcomes (PEO) strategy [64,65] guided the formulation of the research question for this review.

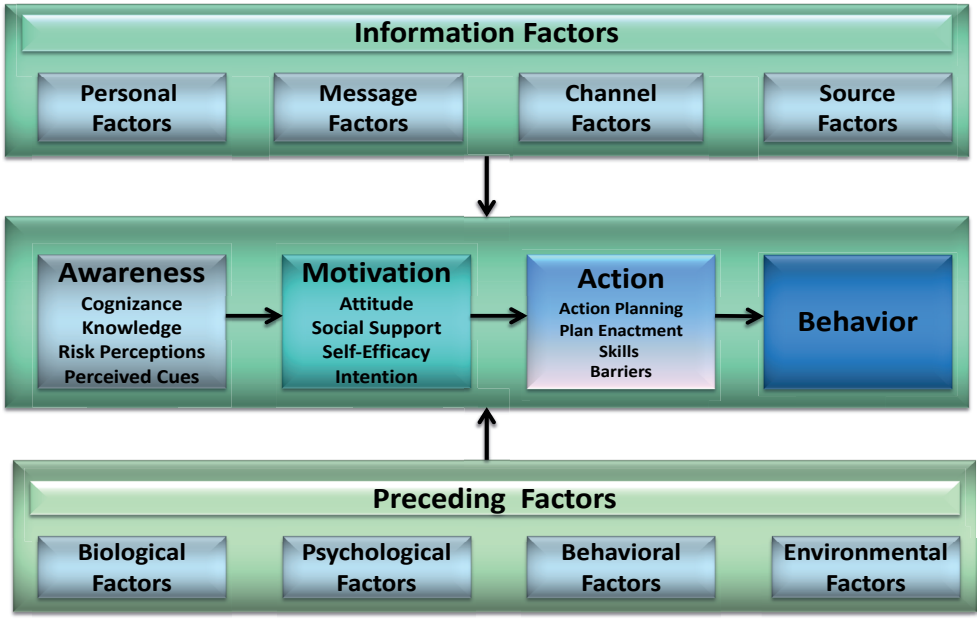

Figure 1. The I-Change Model. This figure has been reproduced with permission from de Vries H. An integrated approach for understanding health behavior; the I-change model as an example. Psychol Behav Sci Int J. 2017;2(2):555–85. https://doi.org/10.19080/PBSIJ. 2017.02.555585

METHODS

The methods of this systematic review have been developed and reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) [66] (see Annexure 1—PRISMA-P completed checklist) [67]. The study protocol is registered with the International Prospective Register of Systematic Reviews (PROSPERO) with ID: CRD42021233074.

Inclusion and exclusion criteria

Types of eligible studies

Studies will be selected for review if they were peer-reviewed cohort studies employing cross-sectional, longitudinal prospective, and retrospective cohort or mixed methods designs, published from 2000 to 2020 and written in English. Randomized and non-randomized comparative studies of interventions and studies investigating factors other than socio-cognitive determinants, such as only socio-demographic and/or only psychological factors will be excluded from the review. The reason for this is that these studies do not address the research question of interest. Besides, previous reviews [5,28,68-70] have provided evidence for them. Commentaries, letters, and editorials will also be excluded.

Population

Studies will be selected for review if they include adolescents and/or young adults in the age range of 17-24 years with a clinical diagnosis of T1D. There will be no restrictions on the gender or ethnicity of participants. Since adherence is dynamic in nature [71], there will be no restrictions on the duration of diagnosis with T1D. Patients with a clinical diagnosis of comorbid conditions (e.g., depression, hypertension); people with cognitive impairments; drug or alcohol dependence; people who intentionally overdose for suicidal attempts, and pregnant women will be excluded because each of these population groups has conditions that affect the nature of insulin adherence behavior.

Exposure variable(s)

Studies which investigated one or more of the socio-cognitive determinants associated with insulin adherence/non-adherence will be included. ICM guided the selection of the primary exposures of interest. Therefore, studies reporting on patient motivation, awareness of behavior and illness perception, awareness of risk perception, knowledge, cues of action, attitudes, self-efficacy, social influence, social norms, social modeling, action planning, coping planning, information, self-regulation skills, and service-related factors will be included in the review.

Outcome variable(s)

Studies which used the participants' adherence/non-adherence to insulin administration as the main outcome will be included. The secondary outcome will be the quantified association between any measured socio-cognitive determinant and adherence (if any). For more information about the outcome, please *see Appendix 3 in the extended data* [67].

Search strategy

A pre-specified search strategy will be used to search for studies in the electronic databases and citation indexes: Pub-Med, EMBASE, Web of Science, and PsycINFO databases. We aimed to achieve an optimal combination of databases to avoid missing relevant references [72]. The literature search will be limited to the English language and to articles published between 2000 to 2020 and will take place on 15 October 2021 until 1 January 2022. The emphasis was to complete study selection within approximately three months to ensure an-up to date systematic review before future studies on the same topic are conducted to avoid bias in the reported results [73]. A decision to identify studies only in the English language was undertaken due to time and budget resource limits [74,75]. The decision on publication years was undertaken, considering that the scope of this review is relatively broad in terms of the socio-cognitive factors of interest and because too narrow or too broad inclusion criteria can lead to an ineffective screening process [70], therefore, we attempted to balance the thoroughness of searching published articles within a timeframe which is not too narrow (to minimize bias of missing articles) [75], nor too wide (to

keep up-to-date with the most recent research evidence relating to systematic reviews in the social sciences [76] and the advancements in behavioral science in T1D) [77]. Reference lists from published studies and relevant reviews will be reviewed for additional papers not indexed in the databases searched, and when necessary, corresponding authors will be contacted for additional information [78].

A search strategy combining MeSH and EMTREE terms in PubMed and EMBASE, respectively, and free-text words (including term explosion) in the titles and abstracts will be used [79,80]. The list of systematically formulated search strings containing four index terms: (1) population, (2) exposure, (3) outcomes, and (4) study design is peer reviewed by SJ using the Press peer review of electronic search strategies guidelines and any necessary adjustments will be made before running the search [81]. The PubMed search strategy is available as *Extended data* (Appendix 1) [67].

Study selection

Study selection will follow the updated guideline for reporting systematic reviews (PRISMA 2020) [82] and will take place from October 15, 2021, to January 1, 2022. Duplicate records identified from database search will be first removed electronically in Endnote X9 following the method described by Bramer and colleagues (2016) [83]. Secondly, two researchers (HB and FS), working independently to minimize bias, will screen titles of all citations derived from the search. Thirdly, they will screen abstracts for eligibility. Finally, they will read and critically appraise the full text of each included study. During this process, the two researchers will discuss their findings; in case of uncertainty to either include or exclude the study, the full article will be read [84]. Furthermore, if any discrepancies in study selection between the two researchers still exist, a third researcher (LM) will be included in the discussion until consensus is reached.

Assessment of methodological quality and risk of bias

Two separate reviewers will assess the quality of the included studies using The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Cohort Studies and JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies [78]. The overall quality and risk of bias will be determined based on JBI guidelines [85]. A third reviewer will judge the disagreement, if any. These tools can be used to rigorously appraise the quality of observational studies by determining the extent to which a study has addressed the possibility of bias in its design, conduct and analysis [86]. JBI Critical Appraisal Checklists are depicted in Appendix 2 (*Extended data)* [67]. The number of positive answers to the questions will lead to the final score of the study. Studies will be classified as “high risk of bias (low quality)”, “moderate risk of bias (moderate quality)” and “low risk of bias (high quality)” if they score 0–3, 4–5, and 6–8 respectively, using the checklist for analytical cross-sectional studies, and 0–3, 4–7, and 8–11 respectively, using the checklist for cohort studies.

Data extraction

We will use the population, exposure, outcomes, and study characteristics framework to extract data. Two reviewers will extract data independently (HB and LM), a third independent reviewer (FS) will resolve disagreements in data extraction until consensus. Data will be extracted using a standardized and piloted extraction form adapted from Cochrane Public Health Group Data Extraction and Assessment Template [87]. The following three types of data will be extracted from selected studies: a) study data, b) outcome data, and c) study quality. Study data will include: 1) publication; 2) population; 3) study characteristics; 4) exposure; and 5) results and findings. Outcome data will relate to primary and secondary outcomes (see *Appendix 3 in the extended data*) [67]. Adherence is determined by using one or a combination of adherence to insulin measures (the commonly reported methods including the (adjusted) medication possession ratio, proportion of days covered (PDC), persistence, daily average consumption (DAC), and the Morisky Medication Adherence Scale (MMA) or by indirect methods such as using prescription claims, pharmacy/medical records or self-report questionnaires, visual analogue scale or by using cell-phone real-time assessment and computerized logbooks [17,88,89].

Data synthesis

Meta-analysis will not be performed due to the expected heterogeneity across studies, because of the variety of socio-cognitive determinants used in eligibility criteria and/or methods used to measure insulin adherence. Hence, a qualitative narrative synthesis will be performed and summarized in a table of findings using GRADEpro, which will present the characteristics and quality of studies, and the outcomes of concern [90].

DISCUSSION

This systematic review will be performed to critically examine relevant literature and report the socio-cognitive determinants associated with adherence/non-adherence to insulin treatment in late adolescents and young adults with T1D. The findings will help design patient-centered interventions to promote adherence to insulin in this age group, and guide patients' consultations and diabetes self-management education (DSME) programs.

Several systematic reviews have identified patient-perceived barriers as predictive of non-adherence to self-care recommendations in patients with type 1 or type 2 diabetes [27,62,91]. However, unlike our proposed review, findings from previously published systematic reviews were not specific to late adolescents and young adults, nor to type 1 diabetes, and/or to insulin adherence. Given, the hazardous consequences of non-adherence to insulin on diabetes outcomes [18], in addition to the availability of evidence which shows that psychosocial factors such as beliefs, attitudes, and motivation have a greater

influence on adherence than personality, metabolic, and demographic factors [92]. Moreover, patients' adherence to different domains of DSM is not uniform [6]. Therefore, our systematic review, grounded in theory, will fill this gap in the literature.

The proposed review is expected to have the following strengths. First, in order to enhance the performance and reporting of this systematic review, it will follow PRISMA 2020 guidelines [82], and will be conducted according to this reproducible protocol, which will provide evidence of the reliable conduct of the study [62,91]. Second, four databases will be searched, which include a specialized database in the fields of behavioral sciences to avoid missing relevant references [72] and to minimize selection bias [75]. Third, the validated JBI checklist tools will be used to assess risk of bias of the included studies which address both the validity and reliability of a study [93]. However, the review is expected to have a few limitations. The various direct and indirect adherence measures to insulin treatment may hamper the comparison of adherence rates across studies. Other relevant evidence may be missed due to excluding Gray literature and articles published in a non-English language [75]. Despite these limitations, the proposed review will provide a high level of systematic evidence on the subject of interest.

Extended data
Figshare: Extended Data Set: Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol. pdf,

This systematic review contains the following extended data:
• Appendix 1: PubMed Search Strategy
• Appendix 2: JBI _Critical Appraisal_Quality Assessment Checklists
• Appendix 3: Data extraction tool

Reporting guidelines
Figshare: PRISMA-P checklist for 'Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol', https://doi.org/10.6084/m9.figshare.15044151.

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CHAPTER

5

Chapter 5

Socio-cognitive determinants affecting insulin adherence/ non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review

This chapter has been submitted as:
AlBurno H, Schneider F, de Vries H, Al Mohannadi D, Jongen S, Mercken L. Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review. Submitted to Diabetes Metab Syndr: Clin Res Rev on June 22, 2023.

CHAPTER

6

Chapter 6

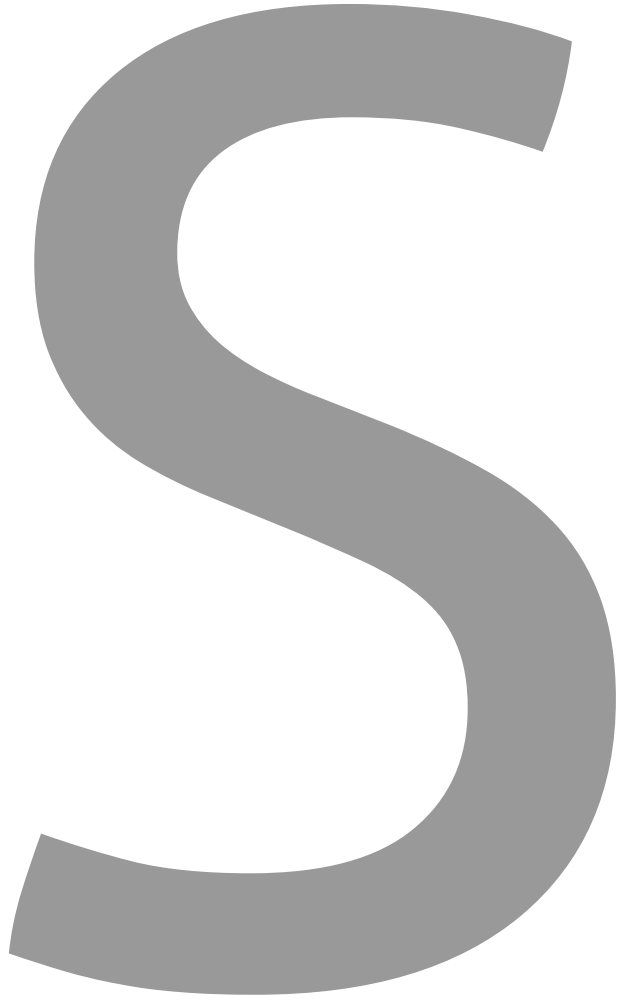
A Delphi study on the design and clinical adoption of internet-based interactive behavioral intervention promoting insulin adherence in adolescents and young adults

This chapter has been submitted as:
AlBurno H, Mercken L, de Vries H, Al Mohannadi D, Schneider F. A Delphi study on the design and clinical adoption of internet-based interactive behavioral intervention promoting insulin adherence in adolescents and young adults. Submitted to Inform Health Soc Care on June 13, 2023.

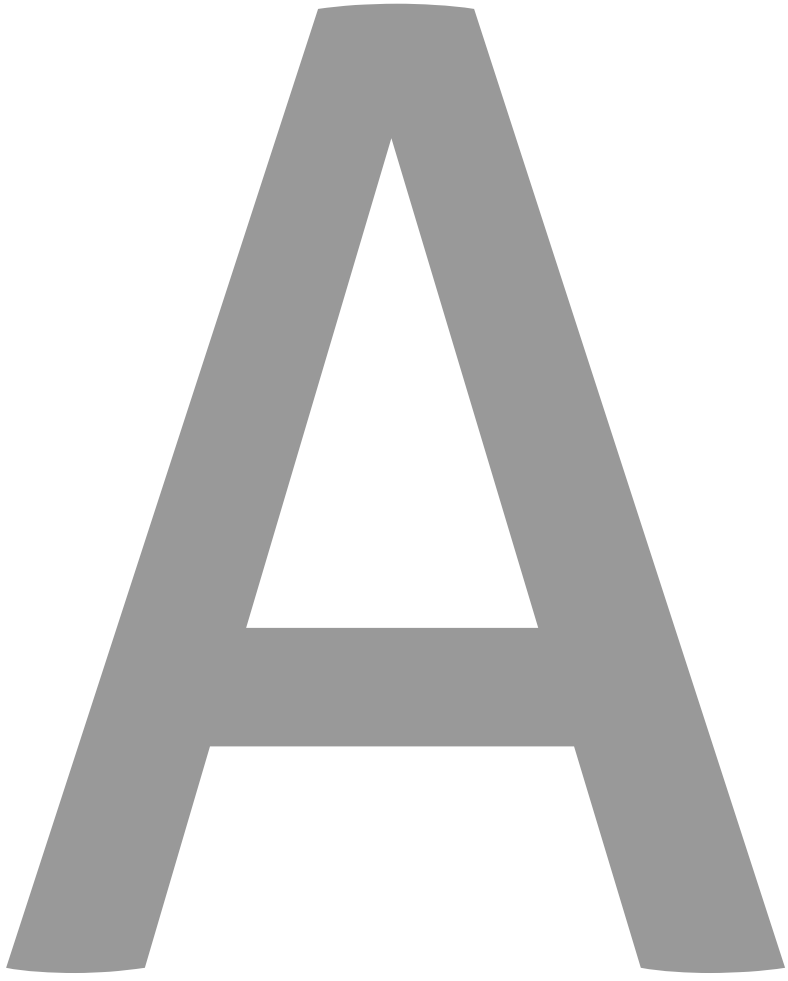
CHAPTER

Chapter 7

General discussion



Summary



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Publication list

PUBLICATIONS IN THIS DISSERTATION

AlBurno H, Mercken L, de Vries H, Al Mohannadi D, Schneider F. Determinants of healthful eating and physical activity among adolescents and young adults with type 1 diabetes in Qatar: A qualitative study. PLoS One. 2022;17(7):e0270984. https://doi.org/10.1371/journal.pone.0270984.

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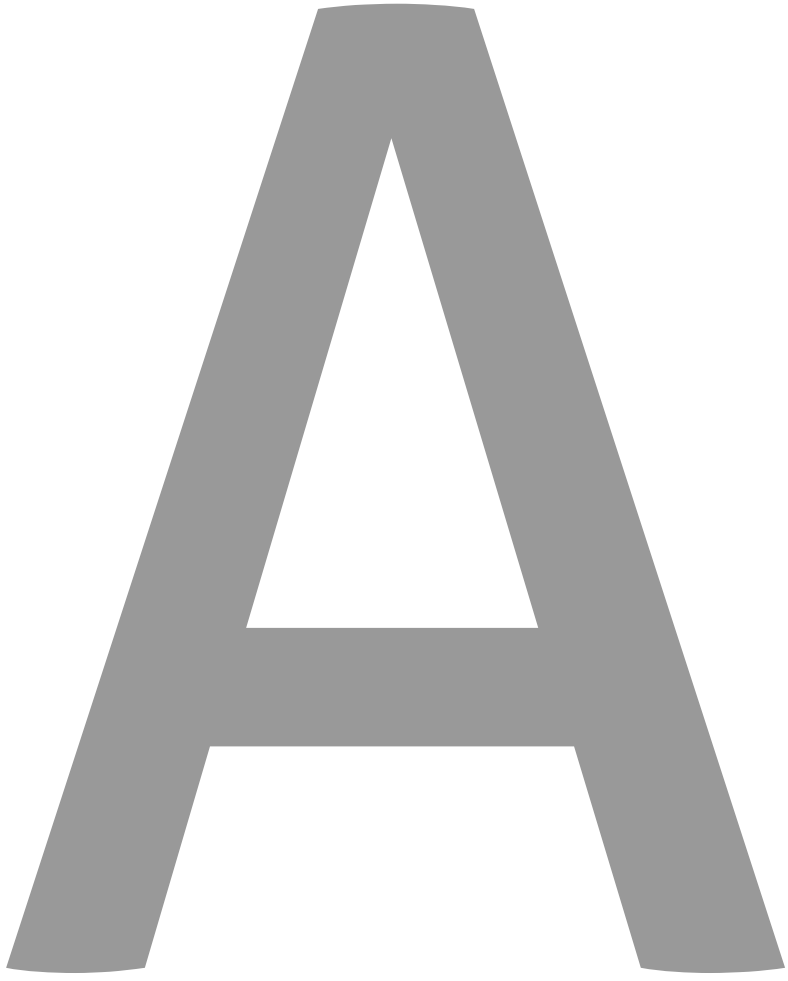
AlBurno H, Maurice H, Kheir N, Yousif, Al Sayed H, Al Lenjawi B. Knowledge, attitude and practice (KAP) of insulin- treated adult diabetic patients in the State of Qatar [poster presentation]. 2nd Qatar Petroleum Occupational Health (QPOH) Conference; 2013 November 19 – 21; Doha, Qatar.

AlBurno H, Mercken L, de Vries H, Al Mohannadi D, Schneider F. Enhancing insulin adherence in adolescents and young adults: a digital behavioral intervention approach, preparing content, and clinical adoption [poster presentation]. Qatar Health Congress 2023 and the Third Qatar Public Health Conference; 2023 November 21– 23; Doha, Qatar.



About the author

Hanan AlBurno, born on September 23rd, 1970, is a clinical pharmacist with a diverse background in academia, research, public health, project management, and clinical pharmacy. During her clinical pharmacy practice and interactions with patients, Hanan recognized a concerning suboptimal adherence to pharmaceutical care plans, in terms of medication management and healthy lifestyle behaviors among individuals with chronic diseases. This realization sparked a transformative journey for Hanan, igniting her passion for behavioral science and the pivotal role effective tailored communication plays in fostering behavior change to improve individuals' health.

After obtaining her Bachelor's degree in pharmacy at Jordan University in 1993, she decided to pursue an academic career and worked as a teaching and research assistant at the School of Pharmacy, Peta University in Jordan. She relocated to the United Kingdom and successfully completed the registration examination with the Royal Pharmaceutical Society of Great Britain in 2004, which entitled her to practice as a pharmacist in the UK. While working at BARTS and the London NHS, she expanded her professional experience and acquired clinical, research, and teaching expertise. Additionally, she actively participated in teaching sessions for MPharm students at the School of Pharmacy – London University.

In 2010, Hanan's dream of pursuing post-graduate studies became a reality when she embarked on a two-year pre-master's program offered by Queen's University-Belfast. This was followed by a one-year research master's program in Clinical Pharmacy, from which she graduated with Distinction in 2012. Throughout her career journey, Hanan maintained a profound interest in research and academia, with a particular focus on health behavior, which inspired her to apply for a Ph.D. research project that employs the Integrative Change Model (ICM) as a theoretical model for behavior change and the role of eHealth applications in this area. To complement her clinical research knowledge and skills, she completed a one-year clinical research training program offered by Harvard T.H. Chan School of Public Health in 2017.

Currently, she is working as a Health Programs Manager at the Ministry of Public Health (MOPH) in Qatar. During her work at MOPH-Qatar, she took the initiative to plan, organize, and coordinate collaborative projects with national and international organizations. These projects supported young adults' engagement in society and raised their awareness of higher education in healthcare professions and research endeavors. She has also been actively involved in strategic health projects aimed at building the capacity of healthcare

professionals and improving the health of the population. In order to ground her career in project management, as it is a core skill needed for every health program, she obtained certification as a Project Management Professional (PMP) in 2020.

Looking ahead, Hanan aspires to work at an academic institute to pursue her post-doctoral research in the fields of health behavior and eHealth. Her goal is to advance knowledge in this field, furthering the understanding of effective behavior change strategies to improve individual health outcomes.