

AMERICAN UNIVERSITY OF BEIRUT

TYPE 1 DIABETES IN EMERGING ADULTS IN LEBANON:  
A MIXED METHODS STUDY

by  
AMANI ALI AL BAYRAKDAR

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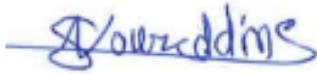
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AMANI ALI AL BAYRAKDAR

Approved by:



---

Dr. Samar Nouredine, Professor  
Hariri School of Nursing, AUB

Advisor



---

Dr. Laila Farhood, Professor and Interim Dean  
Hariri School of Nursing, AUB

Chair of Committee



---

Dr. Houry Puzantian, Assistant Professor  
Hariri School of Nursing, AUB

Member of Committee



---

Dr. Mona Nasrallah, Associate Professor  
Department of Internal Medicine, AUB

Member of Committee



---

Dr. Hala Tfayli, Associate Professor  
Department of Pediatrics and Adolescent Medicine, AUB

Member of Committee



---

Dr. Huda Abu-Saad Huijer, Professor and Dean  
Faculty of Health Sciences, University of Balamand

Member of Committee



---

Pamela Martyn-Nemeth, Associate Professor  
Department of Bio-behavioral Nursing Science,  
University of Illinois Chicago

Member of Committee



---

Dr. Kevin Joiner, Assistant Professor  
Department of Health Behavior and Biological Sciences,  
University of Michigan

Member of Committee

Date of dissertation defense: April 27, 2022

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# ABSTRACT

## OF THE DISSERTATION OF

Amani Ali Al Bayrakdar

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Title: Type 1 Diabetes in Emerging Adults in Lebanon: A Mixed Methods Study

Emerging adults (EAs) with Type 1 Diabetes (T1D) have poorer diabetes-related outcomes than other age groups, partly due to suboptimal diabetes self-care. No studies have addressed this vulnerable population in Lebanon nor in the Middle East. Filling this gap is needed, considering the unique sociocultural environment and healthcare system of Lebanon, which may influence the health outcomes of this population.

The purpose of this mixed methods study was to describe the experience of EAs living with T1D in Lebanon. The study also aimed to describe their diabetes-related health outcomes, and identify their sociodemographic and clinical predictor variables, while identifying the role of self-care and social support in this relationship. The study's conceptual model was guided by the Transition, Emerging Adulthood, and Self-Care in Chronic Illness theories.

The study sample consisted of 90 EAs aged 18-29 years with T1D, out of whom 15 participated in the qualitative interviews. Participants were recruited from diabetes clinics and through social media, and data were collected via semi-structured individual interviews. The survey data included sociodemographic and clinical characteristics, diabetes distress (Type 1 Diabetes Distress Scale), social support (Diabetes Care Profile - Social Support scale), and self-care (Self-Care Inventory-Revised scale).

Thematic qualitative analysis was used to identify the themes that describe the experience of the EAs. The overarching theme was "Living with T1D during emerging adulthood: the complex balance of a chemical reaction", within which the changes that the EAs with T1D experience, the facilitators and barriers of performing adequate self-care, and their ability to reach equilibrium are described. The five main themes included "Breaking of Bonds: Changes and Taking Ownership of their Diabetes", "The Reactants: Factors Affecting the Diabetes Experience", "The Catalysts: Facilitators of Self-Care", "The Inhibitors: Barriers to Self-Care", and "Aiming for Equilibrium".

The sample had a median age 21 (IQR, 19–25) years, mean diabetes duration of 10.3 ± 4.6 years, and 61% were females. Over two thirds (70 %) had HbA1c levels ≥ 7%

(median HbA1c 7.7, IQR 6.6, 8.4); 81.1 % reported a mean diabetes distress score of  $\geq 2$ , indicating moderate to severe diabetes distress; and half of the participants reported at least one acute diabetes complication during the past 6 months. The participants had good levels of diabetes self-care and high levels of social support. HbA1c was predicted by insulin treatment type, age at diagnosis, and self-care, while as diabetes distress was predicted by diabetes knowledge, blood glucose monitoring type, self-care, and social support. Moreover, the incidence of acute diabetes complications was predicted by level of education of the head of household, and self-care was predicted by treatment site, age at diagnosis, and diabetes knowledge. The mediation and moderated-mediation effect of our model was supported, with self-care mediating the association between diabetes knowledge and diabetes distress, and social support moderating this mediation.

The study findings were analyzed from the integrated approach of mixed methods studies and meta-inferences were developed. The study findings validated the suggested framework and provided insight to the clinicians on the experiences of EAs with T1D living in Lebanon to develop future interventions.

# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	1
ABSTRACT .....	2
ILLUSTRATIONS .....	9
TABLES .....	10
ABBREVIATIONS .....	11
INTRODUCTION .....	12
A. Background .....	13
1. Diabetes Etiology, Types, Treatment, and Complications .....	13
2. Diabetes Prevalence .....	15
3. Emerging Adulthood.....	17
B. Significance .....	20
1. The Burden of Diabetes .....	20
2. Transitioning into Emerging Adulthood in Individuals with T1D .....	21
3. Emerging Adults with T1D in Lebanon .....	24
C. Purpose of the Study .....	28
1. Study Aims .....	28
LITERATURE REVIEW .....	30
A. Health Related Behaviors in EAs with T1D.....	30
B. Diabetes-Related Health Outcomes in EAs with T1D.....	31
1. Glycemic Control and Diabetes-Related Complications .....	32

2.	Psychological Health: Depression, Diabetes Distress, and Quality of Life....	33
C.	Diabetes Self-Care .....	36
D.	Variables Affecting Diabetes-Related Health Outcomes in EAs with T1D.....	38
1.	Gender.....	38
2.	Living Situation .....	39
3.	Healthcare Services.....	39
4.	Social Support.....	41
E.	Research in the Middle East and Lebanon.....	45
F.	Summary.....	47
<b>THEORETICAL FRAMEWORK .....</b>		<b>50</b>
A.	The Middle-Range Theory of Transition.....	50
1.	Nature of Transition.....	51
2.	Transition Conditions/ Facilitators and Barriers.....	53
3.	Patterns of Response .....	54
4.	Nursing Therapeutics .....	55
B.	The Middle-Range Theory of Self-Care in Chronic Illness .....	55
1.	Key concepts of the Theory of Self-Care in Chronic Illness .....	56
2.	Processes Underlying Self-Care .....	57
3.	Intended and Unintended Outcomes of Self-Care .....	58
4.	Factors Affecting Self-Care .....	59
C.	Conceptual Framework of the Study .....	60
D.	Conceptual and Operational Definitions of Key Concepts.....	62
1.	Sociodemographic and Clinical Variables.....	62
2.	Diabetes Self-Care .....	62
3.	Social Support.....	63
4.	Diabetes Distress.....	63
5.	Glycemic Control.....	64

6. Acute Diabetes Complications.....	64
E. Research Questions and Hypotheses .....	65
<b>METHODOLOGY .....</b>	<b>67</b>
A. Study Design.....	67
B. Sample .....	70
1. Sampling Design.....	70
2. Sample Inclusion/Exclusion Criteria .....	70
3. Recruitment.....	70
C. Data Collection .....	74
1. Quantitative Data Collection and Research Instruments .....	74
2. Pilot-test of the Questionnaire .....	85
3. Qualitative Data Collection .....	87
D. Ethical Considerations .....	89
E. Data Analysis .....	91
1. Sample Size Estimation .....	91
2. Qualitative Data Analysis .....	92
3. Quantitative Data Analysis .....	101
F. Data Integration and Presentation.....	104
<b>RESULTS .....</b>	<b>106</b>
A. Sample Characteristics.....	106
1. Sociodemographic Characteristics of the Study Participants .....	106
2. Clinical Characteristics of the Study Participants.....	108
B. Qualitative Findings: The Experience of EAs Living with T1D .....	110
1. The Thematic Map.....	113

2.	Breaking of Bonds: Changes and Taking Ownership of their Diabetes .....	115
3.	The Reactants: Factors Affecting the Diabetes Experience.....	117
4.	The Catalysts: Facilitators of Diabetes Self-Care.....	126
5.	The Inhibitors: Barriers to Diabetes Self-Care .....	129
6.	Aiming for Equilibrium .....	132
7.	Summary .....	142
C.	Quantitative Results .....	145
1.	Psychometric Testing of the Study Instruments (DCP-SS, SCI-R, and T1DDS).....	145
2.	Descriptive Analysis of the Diabetes-Related Outcomes .....	147
3.	Predictors of Diabetes-Related Health Outcomes .....	149
4.	Mediation Analysis of Self-Care on the Association between Predictors and Diabetes-Related Health Outcomes .....	167
5.	Moderation Effect of Social Support on the Association between Diabetes Self-Care and Diabetes Outcomes .....	170
6.	The Moderated Mediation Model .....	174
7.	Summary .....	176
D.	Mixed Methods Results: Data Integration .....	177
1.	Summary of the Integrated Findings .....	184
<b>DISCUSSION AND CONCLUSION.....</b>		<b>187</b>
A.	Discussion.....	187
1.	Demographic Characteristics of the Participants.....	187
2.	Clinical Characteristics and Health Outcomes of the Participants .....	189
3.	The Experience of EAs Living with T1D in Lebanon.....	190
4.	Diabetes-Related Health and Associated Factors .....	198
B.	Limitations .....	211
C.	Implications for Knowledge, Practice, and Research.....	213
D.	Conclusion .....	216

APPENDIX A.....	219
APPENDIX B.....	236
APPENDIX C.....	238
APPENDIX D.....	239
APPENDIX E.....	242
APPENDIX F.....	243
APPENDIX G.....	256
REFERENCES.....	258

## ILLUSTRATIONS

### Figure

1. Conceptual Framework.....	61
2. Mixed Methods Concurrent (Convergent) Triangulation Study Design.....	69
3. Qualitative a priori Conceptual Framework Guided by the Transition Theory.....	93
4. Thematic Map of the Experience of EAs Living with T1D in Lebanon.....	115
5. Mediation Model of Self-Care on the Age at Diagnosis – HbA1c Association...	168
6. Mediation Model of Self-Care on the Diabetes Knowledge - Diabetes Distress Association.....	170
7. Moderation Model of Social Support on the Association between Self-Care with Diabetes Distress (A), And HbA1c (B).....	171
8. A Statistical Model of the Moderation Effect of Social Support on the Association between Self-Care and Diabetes Distress.....	172
9. The Interaction between Social Support and Self-Care on Diabetes Distress Scores .....	174
10. Moderated Mediation Models of the Indirect Effect of Diabetes Knowledge on Diabetes Distress through Self-Care, Moderated by Social Support.....	175

# TABLES

## Tables

1. Self-Report Measurement Tools of Diabetes Distress, Diabetes Self-Care, and Social Support.....	76
2. Coding Framework.....	94
3. Descriptive Statistics of Demographic Characteristics.....	106
4. Descriptive Statistics of Clinical Characteristics.....	108
5. Characteristics of the Qualitative Study Participants.....	112
6. The Themes, Subthemes, and Categories.....	143
7. Reliability Analyses of the DCP-SS, SCI-R, and T1DDS.....	145
8. Descriptive Statistics of Diabetes-Related Outcomes.....	147
9. Associations of HbA1c and Diabetes Distress with Select Variables.....	150
10. Associations of Acute Diabetes Complications with Select Variables.....	153
11. Association of Self-Care Scores with Select Variables.....	155
12. Regression Models of Main Predictors on HbA1c.....	158
13. Regression Models of Main Predictors on Diabetes Distress.....	160
14. Logistic Regression for Acute Diabetes Complications.....	163
15. Regression Models of Main Predictors on Self-Care.....	165
16. Conditional Effects of Self-Care on Diabetes Distress at Values of Social Support.....	173
17. Indirect Effect According to Social Support Levels.....	176
18. Joint Display of the Quantitative and Qualitative Findings with Meta-Inferences.....	178

## ABBREVIATIONS

T1D: Type 1 diabetes

T2D: Type 2 diabetes

EA: Emerging adults

MENA: Middle East and North Africa

CCC: Chronic care center

CES-D: Centre for epidemiological studies–depression

DQOL: Diabetes-related quality of life

DKA: Diabetic ketoacidosis

IBD: Inflammatory bowel disease

SCI-R: Self-care inventory-revised

DGP: Diabetes care profile

T1-DDS: Type 1-diabetes distress scale

# CHAPTER I

## INTRODUCTION

The prevalence of Type 1 Diabetes (T1D) worldwide is consistently on the rise (Findley et al., 2015; Sheehan et al., 2015). In 2000, the global estimate of diabetes mellitus prevalence in individuals aged 20-79 years was 151 million. Estimates have since tripled to reach 463 million in 2019, which is around 9.3% of the adult population. T1D accounts for 10% of the global total diabetes cases, including 1.1 million children and adolescents under the age of 20 with T1D worldwide (International Diabetes Federation [IDF], 2019). Due to the continuous medical advancements in chronic disease management, around 90% of children with chronic conditions including T1D, are expected to transition into adulthood (Farrell et al., 2018). This transition is rapidly becoming a major concern for health care providers due to its reported negative consequences on the health of young adults (Jones et al., 2017; Peters & Laffel, 2011).

Emerging adulthood has been defined as a developmental stage between the ages of 18 up to 29 years that is distinct from adolescence and adulthood (Arnett, 2011). This stage is characterized by changes in the individual's independence at various levels (financial, self-management, social), the emergence of risky behaviors, and shifts in family relationships, among other changes (Arnett, 2000). Emerging adults (EAs) with T1D face the added burden of the daily management requirements of their disease, resulting in a substantial negative impact on their health (Hanna, Weaver, Slaven, et al., 2014; Miller et al., 2015; Peters & Laffel, 2011; Ramchandani et al., 2019). Accordingly, EAs with T1D are prone to experience deterioration in glycemic control (Bryden et al., 2001; O'Hara et al., 2017), increased occurrence of acute complications (Bryden et al., 2001; Pedersen-Bjergaard & Thorsteinsson, 2017), as well as

psychosocial, emotional and behavioral challenges (Baucom et al., 2015; Lašaitė et al., 2016). The emergence of chronic complications that may go undetected or untreated during this phase (Zoffmann et al., 2014) and early mortality as a result of the acute and chronic complications of T1D (Laing et al., 2005; Peters & Laffel, 2011), were also noted in this population.

## **A. Background**

### ***1. Diabetes Etiology, Types, Treatment, and Complications***

Diabetes mellitus is a metabolic disease characterized by hyperglycemia that results from inadequate insulin secretion, insulin action, or both. The risk of developing diabetes can be a result of several factors including age, obesity, ethnicity, a family history of diabetes, and other environmental factors. The pathogenic processes involved can include autoimmune destruction of the insulin-producing  $\beta$ -cells of the pancreas, or abnormalities that result in resistance to the action of insulin. Insufficient insulin secretion or reduced tissue responses to insulin lead to hyperglycemia. The most prominent symptoms of hyperglycemia include polyuria, polydipsia, weight loss, blurred vision, and polyphagia (American Diabetes Association, 2020a).

The two major types of diabetes are type 1 and type 2 diabetes (T2D). T2D is the most prevalent category, accounting for around 90% of individuals with diabetes. This type happens secondary to a combination of resistance to insulin action and an inadequate compensatory insulin secretory response (American Diabetes Association, 2020a). In patients with T2D, damaging levels of hyperglycemia can be present without clinical symptoms for a long period before diabetes is diagnosed. Treatment of T2D varies according to each individual's characteristics. Glycemic control can be achieved

with nutritional management, weight reduction in overweight and obese individuals, exercise, and/or oral glucose-lowering agents. As the disease progresses and the residual insulin levels decrease, exogenous insulin might be needed for adequate control and survival (American Diabetes Association, 2020b).

T1D is an autoimmune disease that is triggered by a cellular-mediated autoimmune destruction of the  $\beta$ -cells of the pancreas, resulting in severe insulin deficiency. The rate of  $\beta$ -cell destruction is variable during the disease trajectory. Infants and children usually experience more rapid  $\beta$ -cell destruction rates than adults. Individuals with T1D usually present with diabetic ketoacidosis (DKA) as the first manifestation of the disease (American Diabetes Association, 2020a). The etiology of this process is thought to be a result of genetic, environmental, and autoimmune predispositions that are still poorly defined (Atkinson & Eisenbarth, 2001). T1D was previously considered to be a disorder affecting only children and adolescents, hence the term “juvenile-onset diabetes”. However, recently immune-mediated diabetes was found to occur at any age (American Diabetes Association, 2020a; Atkinson & Eisenbarth, 2001). The pharmacologic treatment of T1D consists of lifetime exogenous insulin replacement to stabilize blood glucose at normal or near-normal levels. Insulin therapy can be administered through multiple injections or continuous subcutaneous infusion using the insulin pump and is essential for survival. The newer generation of insulin pumps is the automated insulin delivery system, known as the ‘closed-loop/artificial pancreas’ system. These pumps are associated with higher time-in-range levels, lower hypoglycemia levels, and better sleep in patients with T1D (Lal et al., 2019). However, this technology, which is not available in Lebanon, is still novice and studies that can assess the longitudinal benefits in terms of glycemic control, emergence

of chronic complications, and psychological health impact are still needed. In conjunction with insulin therapy, non-pharmacological treatment of T1D consists of lifestyle interventions such as physical exercise, nutritional therapy, and frequent blood glucose monitoring (Atkinson & Eisenbarth, 2001; Pickup, 2012).

Improper management of T1D can result in life-threatening short- and long-term complications. Short-term complications include ketoacidosis and non-ketotic hyperosmolar syndrome (related to hyperglycemia), and hypoglycemia (American Diabetes Association, 2020b). Chronic levels of hyperglycemia can also result in long-term damage of the blood vessels, causing microvascular and macrovascular complications. This chronic damage eventually leads to injury of various organs, especially the eyes (retinopathy), kidneys (nephropathy), nerves (peripheral and autonomic neuropathy), and the heart (atherosclerotic cardiovascular, peripheral arterial, and cerebrovascular disease) (Ahmadiéh et al., 2019; American Diabetes Association, 2020c, 2020d). Moreover, high rates of cognitive dysfunction has been associated with T1D (Shalimova et al., 2019), as well as the evidence of and progression of vascular dementia and Alzheimer disease in patients with diabetes (American Diabetes Association, 2020b). This phenomenon can be attributed to the effects of altered glucose metabolism on the brain, in addition to cardiovascular and microvascular complications and increased inflammatory cytokine expression related to diabetes (Shalimova et al., 2019).

## ***2. Diabetes Prevalence***

Diabetes mellitus is the seventh leading cause of death in the United States (Centers for Disease Control and Prevention [CDC], 2020). The prevalence of diabetes

mellitus is on the rise worldwide according to estimates by the World Health Organization (WHO) and the International Diabetes Federation (IDF, 2021; WHO, 2020). In 2021, the IDF reported 536.6 million adults with diabetes aged 20-79 years worldwide. This number is projected to reach 783.2 million by year 2045, with the majority of cases occurring in low- and middle-income countries (IDF, 2021). This striking increase is believed to be related to lifestyle changes resulting from globalization and urbanization. In Lebanon, the IDF reported 396,100 individuals with diabetes aged 20-79 years, constituting 5.8% of the total population (IDF, 2021). However, a recent national survey of 17,832 persons of all age groups showed a reported diabetes diagnosis prevalence of 7.95% (95% confidence interval [CI] =7.55-8.35) (Bou-Orm & Adib, 2020).

T1D accounts for around 10% of diabetes cases worldwide, with over 1.2 million children and adolescents under the age of 20 with the disease, and 149,500 new cases diagnosed each year. The IDF reported an estimated 3% annual increase of T1D cases worldwide (IDF, 2021). In the MENA region, there are 192,500 reported cases of T1D aged 0-19 years, with 25,000 new cases each year (IDF, 2021). Within the region, Algeria, Morocco, and Saudi Arabia had the highest prevalence rates of T1D per 100,000 population per year, with 50,800, 43,300, and 28,900 cases respectively (IDF, 2021). In Lebanon, the IDF reported a prevalence of 600 patients with T1D within the 0-19 year age group, with 100 newly diagnosed cases each year, but no data are available on those above the age of 20 years (IDF, 2021). There is no official diabetes registry for T1D in Lebanon. However, in their national survey, Bou-Orm and Adib (2020) estimated a 0.1% prevalence of T1D in the population in Lebanon, and a 1% prevalence of T1D among all diabetes cases. With an estimated population in Lebanon

of around 6.8 million (United Nations, 2019), the T1D population will be at around 6,800 individuals. Given a total age distribution in Lebanon of individuals between 20 and 29 years old of around 17.2% (United Nations, 2019), a calculated estimate of the number of patients with T1D within this age range would be around 1,170 cases.

### ***3. Emerging Adulthood***

As noted above, T1D may occur at any age among the youth, but the majority of patients is diagnosed during childhood. One age group that is gaining interest in this T1D population includes emerging adults (EAs). The concept of 'Emerging Adulthood' is not new. In fact, some developmental theories have explored this unique stage in an individual's life albeit under different terminologies (Arnett, 2000). Erikson discerned a period between adolescence and young adulthood that includes some characteristics of both stages. This period is characterized by the exploration of adult commitments and responsibilities while continuing with the experimentation of adolescence (Erikson, 1968). Similar to Erikson's conception, another developmental theory by Levinson (1978) declared the ages 17-33 as the phase that prepares the individual for adulthood. During this stage, the individual endures substantial amounts of change and instability while striving for the independence of adult life (Levinson, 1978).

More recently, Arnett (2000) argued that the developmental pathways into adulthood that were presented by previous theories have been altered to become multifaceted and less clear, due to the major demographic and sociocultural changes that have taken place in industrialized societies. Arnett (2000) argued that demographic and psychosocial factors that mark the transition to adulthood, such as median age of first marriage, parenthood and career development, are being attained at older ages now

than in the past (Arnett, 2000). Accordingly, the Emerging Adulthood theory defined a distinct period of the individual's life spanning between ages 18-25 as the "emerging adulthood" phase. Arnett later stated that this age range could span up to the age of 29 years, depending on the factors highlighting the initiation of the adulthood phase such as a longer and more widespread education, lower birth rates, and higher median ages of marriage and parenthood (Arnett, 2011). During this period, individuals perceive themselves as outgrowing the adolescence stage, leaving behind the dependency associated with it, but not reaching adulthood with its responsibilities and decision-making demands yet. Arnett (2000) stated that:

Emerging adulthood is neither adolescence nor young adulthood but is theoretically and empirically distinct from them both.... Having left the dependency of childhood and adolescence, and having not yet entered the enduring responsibilities that are normative in adulthood, emerging adults often explore a variety of possible life directions in love, work, and worldviews. (p. 469).

Emerging adulthood is characterized by five distinctive features: the age of identity explorations, the age of possibilities, the age of feeling in-between, the self-focused age, and the age of instability (Arnett, 2000; Reifman et al., 2007). *Identity exploration* involves the individual seeking independence and autonomy. Emerging adulthood is the age of *possibilities* since it is the time where educational choices, job opportunities, relationship choices and other commitments are accessible. EAs feel *in-between* because they perceive themselves as being in the grey area between adolescence and adulthood. As they take on greater responsibility, EAs need to have a good *self-focus* in order to cultivate the knowledge, skills, and self-understanding necessary to prepare them for adulthood. The above four dimensions can be overwhelming and might have a negative impact on the EAs as they deal with this change, an aspect coined the *age of instability* (Arnett, 2000; Reifman et al., 2007).

Risky behaviors constitute another hallmark of the emerging adulthood phase (Arnett, 2000). Studies have documented several risky health behaviors such as reckless driving, substance abuse, engagement in unprotected sex, tobacco smoking, irregular sleeping patterns, and inadequate physical activity among EAs (Arnett, 2000; Bachman et al., 1996; Palladino et al., 2013). These behaviors can be explained as a function of the identity exploration characteristic of emerging adulthood and the need to engage in a variety of experiences made feasible due to the decreased parental monitoring, while not yet having the constraints of the adulthood role (Arnett, 2000).

In his theory, Arnett (2000) argues that the emerging adulthood phase is socially shaped and is most common in industrial and postindustrial societies. Accordingly, this developmental period differs across societies with diverse demographic characteristics, socioeconomic statuses or cultures. In industrial and postindustrial societies, entry into adult roles and responsibilities is typically postponed until well past the late teens (Arnett, 2000; Reifman et al., 2007). In many societies, marriage and parenthood are usually considered determinants of the ages when one enters the emerging adulthood phase. In the USA, the median age of marriage for men and women is 29.3 and 27.1 years, respectively. In Lebanon, a survey conducted in 2007 reported the mean age of marriage for men to be 32.3 and for women 28.3 years, respectively (United Nations, 2017). In addition, the average age at first birth in Lebanon was reported to be 29.3 years in 2001 (NationMaster, 2020). The high ages at marriage and parenthood in Lebanon would deem Arnett's emerging adulthood period of 18-29 years applicable within the Lebanese population.

In conclusion, EAs survive an unstable period in their lives as they prepare for adulthood and may engage in risky behaviors as a manifestation of this instability.

Having to manage an illness such as T1D during this period would add an additional challenge that this population needs to face.

## **B. Significance**

### ***1. The Burden of Diabetes***

The primary treatment of T1D consists of insulin replacement therapy aimed at achieving near normoglycemia. Nevertheless, insulin therapy does not always provide the metabolic regulation necessary to avoid the short- and long-term complications of the disease (Atkinson & Eisenbarth, 2001). Intensive diabetes treatment is necessary to avoid diabetes-related complications, including testing blood glucose levels at least four times a day, daily adjustments of insulin doses, following a healthy diet and exercise routine, and regular visits to diabetes health care services (Atkinson & Eisenbarth, 2001). The burden of T1D and its management have been well documented and can affect the individual on personal, social, and economic levels (American Diabetes Association, 2020e). In fact, living with T1D has been associated with reduced quality of life (Hanna, Weaver, Slaven, et al., 2014; Hood et al., 2014), increased disease-related distress and depressive symptoms (Baucom et al., 2015; Darwish et al., 2018; Lašaitė et al., 2016), as well as challenges in diabetes management or adherence to treatment (Hynes et al., 2016; Ramchandani et al., 2019).

The burden of managing T1D affects the individual as well as the family. Parents of children with T1D often experience feelings of distress over the health of their children (Whittemore et al., 2012). Parents report concerns about the negative consequences of the teenager's self-management, the financial burden associated with the disease, and health insurance coverage (Ersig et al., 2016). Later on, as children

transition into adulthood, parents battle with feelings of blame, guilt, anxiety, and unrealistic expectations as they relinquish control over their child's diabetes management (Suris et al., 2017). The parental burden and difficulty in handing over the control can lead to conflict with the EAs, which in turn is associated with worsening glycemic control (Campbell et al., 2019).

Lastly, diabetes exerts a considerable social and economic burden on both the patients and the health care system, often due to increased prevalence of the disease, its high treatment costs complications, and lost productivity (Bommer et al., 2018). The social and economic indirect costs of diabetes include labor-force drop out resulting from disability, mortality, absenteeism, and reduced work productivity (IDF, 2021). In 2021, the IDF estimated that the annual worldwide total diabetes-related health expenditure was USD 965 billion. This economic impact is projected to increase to USD 1,027 billion by 2030, and USD 1,053 billion by 2045 (IDF, 2021). This upsurge is attributed to the increased prevalence of the disease and the increased cost per person with diabetes (American Diabetes Association, 2020f).

In summary, the management of T1D is multifaceted, with significant effects on the patients and their parents, and a financial burden on the healthcare system.

## ***2. Transitioning into Emerging Adulthood in Individuals with T1D***

Emerging adulthood is a critical time where individuals often experience several changes on the physical, geographical, economical, and emotional levels as they transition from adolescence towards adulthood (Arnett, 2000). During this phase, individuals strive for autonomy (Arnett, 2000) and start assuming responsibility for their diabetes management (Iyengar et al., 2019). EAs with T1D increasingly perform

self-care activities that were typically performed or supervised by their parents during childhood and adolescence. Such activities include monitoring blood glucose levels, adjusting insulin dosage, scheduling health care appointments, securing the needed medications and supplies, and managing sick days (Palladino et al., 2013). Self-care, which is associated with improved glycemic control in patients with T1D (Pillay et al., 2015), has been found to be suboptimal in the EA population, possibly attributed to the developmental challenges faced by the EAs during this phase (Majumder et al., 2016; Vallis et al., 2018).

The developmental changes, coupled with the complex nature of diabetes management, pose a challenge for the individuals in achieving glycemic control (American Diabetes Association, 2020e). During late adolescence and emerging adulthood, patients with T1D have lower proportion of individuals with the recommended HbA1c levels than any other age group, with HbA1c levels peaking during this time and gradually declining by late emerging adulthood (McKnight et al., 2015; Miller et al., 2015). Feltbower et al. (2008) reported that mortality rates were 4.7-fold more in those with T1D aged 15-29 years compared with those aged 0-14 years. Nearly half of the deaths (44%) occurred because of diabetes complications, 22% were attributed to accidents or suicide, and 16% to drug misuse (including insulin) (Feltbower et al., 2008). Another longitudinal study in Finland that examined mortality trends among patients with early onset (age 0-14 years) and late onset (15-29 years) T1D and causes of deaths over time, showed an increase in the standardized mortality ratios in patients diagnosed at the age of 15 to 29 years. The increase in mortality was due to an increase in alcohol and drug related mortality and acute complications of diabetes (Harjutsalo et al., 2011).

Likewise, the burden of the chronic nature of the disease has been associated with some psychological consequences in EAs with T1D, such as depressive symptoms, diabetes-related distress, and reduced quality of life (American Diabetes Association, 2020g; Hanna, Weaver, Slaven, et al., 2014). Individuals with T1D are more likely than those without the disease to suffer from depressive symptoms (Baucom et al., 2015; Gendelman et al., 2009). Diabetes distress is the term used to define the disease-specific emotional and behavioral consequences related to diabetes and its management (Fisher et al., 2012). Diabetes distress levels peak during emerging adulthood more than at any other point in the individual's lifespan (Lašaitė et al., 2016).

Another change that EAs have to deal with is the transfer from pediatric to adult healthcare services. Emerging adulthood falls between adolescence and adulthood, rendering the pediatric and adult healthcare providers ill equipped to cater to the needs of this population in a developmentally appropriate manner (Michaud et al., 2018; Ritholz et al., 2014). Consequently, many EAs receive less than optimal care for their developmental needs (Peters & Laffel, 2011). In fact, the EAs' lack of rapport or satisfaction with adult healthcare providers affected their clinic attendance during the transition from pediatric to adult diabetes clinics (Farrell et al., 2018; Michaud et al., 2018). Poor clinic attendance can result in a "gap in care", during which many EAs experience deterioration in glycemic control, as well as the emergence of short and long-term diabetes complications (Peters & Laffel, 2011; Pyatak et al., 2017).

The challenges discussed above render emerging adulthood a remarkably risky phase in the lives of individuals with T1D, with detrimental physical and psychological health consequences. Investigators have identified personal factors such as knowledge and self-care, social factors such as social support, and healthcare system variables such

as the presence of programs to facilitate transition from pediatric to adult diabetes healthcare services, which may influence health outcomes during this transitional phase (Hanna, 2012). Yet, there are inconsistent findings on the degree of influence these variables have on these outcomes in different settings. Understanding this unique phase in individuals with diabetes is crucial for health care providers to be able to deliver tailored care and support to this population.

### ***3. Emerging Adults with T1D in Lebanon***

The condition of the Lebanese population with T1D is not far-off from the global situation in terms of prevalence of the disease and its management challenges. However, it would be naïve to assume that the experience of the EAs with T1D and the factors affecting their diabetes-related health outcomes are identical across cultures. The cultural context plays a central part in the care of this population since the major factors involved constitute a manifestation of cultural and healthcare practice influences. Self-care for instance is a reflection of both the culture and the healthcare system practices, while social support can reflect the collectivist nature of the Lebanese culture.

The effects of ethnicity on diabetes related outcomes in EAs with T1D were noted in previous work. Butler et al. (2017) reported a moderating effect of ethnicity (non-Hispanic Whites, Hispanic Whites, and African Americans) on the association between stress and diabetes outcomes, with Hispanics demonstrating a stronger association between diabetes stress and poorer glycemic control than non-Hispanic Whites. The authors attributed this ethnic impact on the fact that in the Hispanic culture, EAs are more likely to reach the emerging adulthood milestones, such as having greater autonomy, more responsibilities towards others, and becoming parents earlier than the

non-Hispanic Whites (Butler et al., 2017). Campbell et al. (2019) further demonstrated the effect of ethnicity in a study of 79 EAs with T1D. Caucasian participants reported lower parental involvement in their T1D management than non-Caucasian participants do. In addition, Ramchandani and colleagues (2019) stressed the importance of replicating their qualitative study of the perceived challenges of diabetes management faced by EAs in ethnically and/or culturally diverse populations.

Lebanon is considered a collectivistic culture, where there is a high level of interdependence among the individuals in the society, and where individuals identify with their families or close communities and duties and obligations determine their behaviors (Green et al., 2016). The significant differences between the West and Arab cultures are mainly reflected through the effect of family involvement in the management of patients with diabetes. In two samples of Arab American people with T2D, family understanding of food choices predicted the perceived importance of diabetes self-management (El Masri et al., 2020), and the family acted as both a facilitator of diabetes management and a source of distress to the patients in another study (Fritz et al., 2016). However, there is very limited research that focuses on the significant ethnic and cultural effects on living with T1D globally and within the Arab or Lebanese context, especially during the different developmental stages.

Another major difference between the West and the Lebanese contexts is the difference in the healthcare systems that govern the care for patients with T1D. In Western countries, the EAs struggle with transitioning not only from adolescence to adulthood, but also from pediatric to adult healthcare services. This situation causes diabetes complications that affect the development and wellbeing of these patients, and so adequate interventions are needed to prevent such complications. On the other hand,

once diagnosed with T1D in Lebanon, the majority of patients younger than 18 years, are referred to the Chronic Care Center (CCC), a non-governmental medico-social institution and a member of the IDF organization that provides treatment for patients with T1D and thalassemia (Chronic Care Center, 2020). Patients visit this center every 2 to 3 months for assessment, evaluation of treatment protocol, glucose monitoring, diabetes self-management skills training, and nutritional treatment. Patients follow up at the center almost free of charge up until the age of 21 years, after which regular fees apply. In the center, patients are followed up by pediatric and adult endocrinologists. Except for physicians, the same healthcare team members at the center, such as diabetes nurse educators, dietitians, and social workers, provide care for patients of all age groups. Even though the CCC continues to provide healthcare services for patients after the age of 21 years, the healthcare follow-up rates and the health status for those who leave the CCC are not known. Patients who are not followed-up at the CCC are usually cared for by pediatric or adult endocrinologists at other primary or secondary care services.

In Lebanon, we are not aware of any research that assesses the nature or consequences of emerging adulthood in patients with T1D. Two groups of investigators provided recommendations for this age group based on literature reviews and professional opinions for patients with thalassemia (Musallam et al., 2008) and sickle cell disease (Inusa et al., 2020) in Lebanon. However, those studies only focused on the EAs' transition from pediatric to adult healthcare services, which is not relevant to the T1D population in Lebanon since there is usually no clear distinction between pediatric and adult endocrinology clinics, and patients are mostly cared for by adult endocrinologists due to the scarcity of pediatric endocrinologists (personal

communication, pediatric and adult endocrinologists). Thus, the experience of the Lebanese EAs with T1D in Lebanon and the factors that are associated with their diabetes-related health outcomes are unique and remain unidentified. Due to this gap in knowledge, there is a critical need to explore the experiences of the EAs with T1D in Lebanon, describe the diabetes-related health outcomes of this population, and identify the variables associated with those outcomes.

In summary, EAs with T1D are a unique vulnerable population known to have poor health outcomes in terms of glycemic control, mortality, psychological health, and disrupted access to healthcare. There is a need to fill the gap in knowledge about this population in Lebanon, where the cultural, social, and healthcare system variables are different from the West, and where no knowledge exists regarding this population neither in Lebanon nor in the MENA region. This study will provide insight into the experience of the EAs with T1D while focusing on culturally specific factors at play during the transitional phase. Moreover, the literature supports the significance of the personal and social variables, but provides limited research that explores diabetes self-care abilities and social support as essential factors that influence diabetes-related health outcomes in the Lebanese population. This study will explore the association between sociodemographic and clinical variables and glycemic control, acute diabetes complications, and diabetes distress as influenced by social support and diabetes self-care. By doing so, we will be able to determine the most prominent variables associated with diabetes-related health outcomes within the Lebanese population.

This study will add to the current clinical knowledge by providing healthcare professionals with a better understanding of the specific needs of EAs with T1D in Lebanon from the perspective of patients, which is a fundamental step in planning

standards of care that are tailored to the Lebanese context. The results of this study will provide the grounds on which care models can be planned, implemented, and tested for effectiveness in optimizing disease related outcomes.

### **C. Purpose of the Study**

The purpose of this mixed methods study is to describe the experience of EAs with T1D in Lebanon and their diabetes-related health outcomes. This experience includes any changes that the EAs passed through during this transition period, as well as their perceived challenges and the available support systems present during this developmental phase. In addition, the study aims to explore the most prominent sociodemographic and clinical variables that predict glycemic control, acute diabetes complications, and diabetes distress among the EAs with T1D in Lebanon, and explain the role of self-care and social support in this relationship.

#### ***1. Study Aims***

The aims of this study include:

*Aim 1:* To explore the experiences of EAs living with T1D in Lebanon, including the perceived changes, challenges, and available support systems during this developmental transitional phase.

*Aim 2:* To describe the diabetes-related health outcomes, namely current glycemic control and diabetes-related distress - as primary outcomes, and acute diabetes complications (acute hypoglycemia and DKA experienced over the last six months) - as a secondary outcome, among EAs with T1D in Lebanon.

*Aim 3:* To identify the sociodemographic and clinical predictors of diabetes-related health outcomes among EAs with T1D in Lebanon.

*Aim 4:* To test the effect of diabetes self-care on the association between the sociodemographic and clinical predictor variables and diabetes-related health outcomes among EAs with T1D in Lebanon.

*Aim 5:* To determine the influence of social support on the association between self-care and diabetes-related health outcomes among EAs with T1D in Lebanon.

## CHAPTER II

### LITERATURE REVIEW

A comprehensive literature review was conducted to provide an overview of current knowledge on EAs with T1D. The literature search addressed emerging adulthood, diabetes self-care, social support, and diabetes-related health outcomes. An electronic search of CINAHL, MEDLINE, PubMed, and the Cochrane Library databases was used. Key words used in the search included: diabetes mellitus, type 1 diabetes, chronic illness, prevalence, outcomes, transition, emerging adulthood, self-care, self-management, glycemic control, diabetes distress, social support and Lebanon. The studies examining T1D in emerging adulthood are presented in Appendix A.

#### **A. Health Related Behaviors in EAs with T1D**

Emerging adults with T1D face unique challenges in managing a rather demanding disease while going through the exploration, experimentation, and risk taking behaviors of this developmental period. In fact, the effects of the risky behaviors while transitioning into emerging adulthood was explored in a 2-years longitudinal study of 197 high school seniors with T1D aged 17–18 years (Lee Tracy et al., 2019). The authors examined risky behaviors (smoking, drinking alcohol, and withholding insulin) and diabetes outcomes across three time points. Health-risk behaviors increased during this transitional period and predicted negative changes in diabetes-related outcomes. For instance, alcohol consumption and insulin withholding behaviors increased over time and were associated with poor adherence to treatment and high HbA1c levels. Another 1-year longitudinal study that explored risky behaviors among 239 EAs aged 17–18 years (122 without diabetes and 117 with diabetes) supported the

theory of emerging adulthood's claims of an increase in risky behaviors during this phase (Palladino et al., 2013). At baseline, 31.7% of participants consumed alcohol, 15.9% reported binge drinking, and 28.4% smoked. Those behaviors significantly increased over one year to 50.9%, 33.5%, and 36.6%, respectively. There was no difference between the two groups in terms of engaging in those risky behaviors. It is worth noting the alarming nature of these findings, since engaging in these risky behaviors can lead to greater and more severe negative health consequences for those with T1D.

Emerging adults are mostly aware of the need to practice good diabetes control. However, their developmental needs, such as the need to blend in, seeking autonomy, and feeling normal, sometimes take priority over their disease management. In a qualitative study by Ramchandani et al. (2019), "attempting to blend in with peers" was considered an additional burden to diabetes management, where EAs reported having to "sacrifice their perfect HbA1c level" for the sake of feeling like regular college students. The EAs reported "the desire to be normal or to fit in, privacy/ secrecy about their diabetes, fear of hypoglycemia, and just giving up for a moment" as reasons for mismanaging their disease (Ramchandani et al., 2019). In summary, EAs perform risky behaviors increasingly over time, occasionally influenced by their peers, which translates into worse diabetes health outcomes.

## **B. Diabetes-Related Health Outcomes in EAs with T1D**

In a systematic review, O'Hara and colleagues (2017) reported clinical variables such as glycemic control and diabetes complications; behavioral variables such as self-care practices and adherence to clinic follow-up visits; and psychological variables such

as diabetes distress, depression and quality of life, to be the most commonly studied outcomes in young adults with T1D.

### ***1. Glycemic Control and Diabetes-Related Complications***

The developmental transition into emerging adulthood have been associated with worsening glycemic control and the risk of developing acute and long term complications in people with T1D (Peters & Laffel, 2011). According to diabetes registries, EAs with T1D have suboptimal glycemic control, with only a limited number being able to achieve the recommended HbA1c targets (Feltbower et al., 2008; McKnight et al., 2015; Miller et al., 2015). Two cross-sectional studies of 49 EAs and 406 young adults with T1D reported mean HbA1c level of  $8.3 \pm 1.6$  and  $8.2 \pm 1.5$  respectively, which is above the recommended level of 7 % for this age group (Hendricks et al., 2013; Zoffmann et al., 2014). Moreover, the authors of two longitudinal studies reported a significant worsening in HbA1c levels over time, from late adolescence into emerging adulthood in EAs with T1D (Baucom et al., 2015; Bryden et al., 2001). In fact, the data from diabetes registries reflected worse levels of glycemic control during emerging adulthood than at any other time in the lifespan of individuals with T1D (McKnight et al., 2015; Miller et al., 2015).

In addition, the emergence of diabetes related complications have been evident in this population. A longitudinal study that tracked 76 adolescents with T1D over eight years reported several long-term complications and serious events developing during the emerging adulthood years (Bryden et al., 2001). Thirty-one percent of the participants had recurrent hospital admissions secondary to diabetic ketoacidosis (DKA), and 4% suffered from serious events such as death, brain damage, and cognitive

impairment resulting from DKA or severe hypoglycemia. As for long-term complications, 25% of males and 38% of females developed severe retinopathy, nephropathy, and hypertension (Bryden et al., 2001). Another cross-sectional study of 406 young adults with T1D aged 18-35, showed that more than one in four participants had at least one diabetes long-term complication, including renal, neurological, and eye complications (Zoffmann et al., 2014).

## ***2. Psychological Health: Depression, Diabetes Distress, and Quality of Life***

The chronic nature of T1D, the burden of its management, and the fear of its short- and long-term complications often lead to negative emotional and psychological consequences among patients (Fisher et al., 2012; Peters & Laffel, 2011). In a retrospective-cohort study, patients diagnosed with T1D during childhood and adolescence (n= 1302) were compared to age and sex-matched non-diabetics (n=6422) for approximately 17 years for the incidence of psychiatric disorders (Cooper et al., 2017). The risk of psychiatric disorders was 2.3 times higher in the diabetes group compared to the control group. Those with diabetes were at increased risk of anxiety, as well as eating, mood, personality, and behavior disorders. Moreover, the pediatric HbA1c level was identified as a risk factor for anxiety, mood, and eating disorders. Such negative psychological consequences of diabetes can eventually lead to symptoms of depression (Baucom et al., 2015; Cooper et al., 2017; Hislop et al., 2008), reduced health related quality of life (Bronner et al., 2020), and diabetes-related distress (Butler et al., 2017; Lašaitė et al., 2016) among the EA with T1D.

A number of investigators reported positive associations between psychological health, adherence to diabetes management and glycemic control among EAs with T1D

(Baucom et al., 2015; Butler et al., 2017; Downie et al., 2021; Hislop et al., 2008). In a two-year longitudinal study of 197 late adolescents with T1D, participants reported mean scores on the Centre for Epidemiological Studies–Depression Scale (CES-D) above the cutoff score for clinically significant depressive symptoms. Greater depressive symptoms were correlated with poorer diabetes management adherence and poorer glycemic control (Baucom et al., 2015). In another study, 49.1% of 287 EAs (18-35 years) with T1D had diabetes distress levels above the clinical cut-off score, and higher distress scores predicted poorer blood glucose practices (Downie et al., 2021). The high prevalence of depressive symptoms and psychological stress, and their significant positive correlations with HbA1c were also highlighted in two studies of EAs with T1D (Butler et al., 2017; Hislop et al., 2008).

Contrary to the above findings, some investigators found no or minimal effect of diabetes on the psychological health of EAs with T1D. For instance, Palladino and colleagues (2013) reported no differences in depressive symptoms between EAs with and without diabetes. However, in that study, EAs with diabetes reported lower levels of life satisfaction and life purpose than their counterparts. Similarly, Hendricks et al. (2013) reported psychological well-being and quality of life scores within normal ranges among EAs with T1D. Furthermore, Hanna, Weaver, Slaven, et al. (2014) reported that the demands and burden of diabetes care did not affect diabetes-related quality of life (DQOL) in EAs with T1D during their first year following high school graduation. In fact, the results showed good DQOL among the EAs, with minimal worries, moderate levels of life satisfaction, and fair to good reported health status. Moreover, although participants had poor mean HbA1c levels (mean  $9.1 \pm 2.1$ ), no associations were detected between glycemic control and DQOL, worry about diabetes,

or life satisfaction. On the other hand, diabetes management was positively associated with better perceived DQOL, whereas living independently of parents was negatively associated with DQOL (Hanna, Weaver, Slaven, et al., 2014).

Lately, the term ‘diabetes distress’ has been more commonly used to reflect the emotional response toward the unpleasant stressors related to diabetes (Fisher et al., 2012). Diabetes distress peaks during the emerging adulthood phase more than at any other point in the individual’s lifespan. In a cross-sectional study, Lašaitė et al. (2016) reported significantly worse diabetes distress levels in EAs than adolescents, with 28% of the EAs reporting diabetes distress scores over the cut-off limit regardless of diabetes control. Likewise, a sub analysis of the DAWN 2 survey conducted in 17 countries across four continents, examined the differences in psychological variables between EAs aged 18-30 years and adults aged >30 years with T1D (Vallis et al., 2018). The findings showed that even though perceived health status, quality of life, well-being and depression were significantly better in the EAs group, diabetes distress was significantly higher among the EAs group. Additionally, EAs had greater levels of anxiety and fear of living with diabetes, feeling overwhelmed and worried about the future, and finding that diabetes takes up too much time (Vallis et al., 2018).

Regardless of the inconsistent findings, the literature supports the claim that the prevalence of psychological morbidity is relatively high among EAs with T1D, which may influence their self-care and subsequently glycemic control. Such findings highlight the significance of psychological screening and providing proper psychological support to EAs with T1D. Moreover, the above findings support the distinction between depressive disorders and diabetes-related distress. Relying on overall quality of life or depression scores can be misleading and may lead to faulty

conclusions regarding the psychological effects of the disease on the EAs (Rassart et al., 2015; Vallis et al., 2018). Thus, it is more relevant to address the disease-specific psychological impact on the EAs with T1D through examining diabetes distress.

### **C. Diabetes Self-Care**

Diabetes self-care education is a key component of the management of diabetes, as it is expected to promote glycemic control, reduce complications, and improve quality of life (American Diabetes Association, 2020g). Disease management relies heavily on the individual's knowledge and implementation of self-care behaviors (Riegel et al., 2012).

Self-care behaviors for T1D include activities such as adjusting and administering daily insulin injections or the use of an insulin pump, frequent measurement of blood glucose levels, monitoring dietary intake, routine physical activity, and regular health checks (American Diabetes Association, 2020f). EAs with T1D experience a decrease in parental monitoring and involvement, and assume more responsibility for key tasks related to their daily self-care activities (Wiebe et al., 2016). However, the challenges of the disease, coupled with the ones related to this unique developmental phase, can reflect negatively on the EA's ability to perform adequate diabetes self-care (Montali et al., 2022). This finding was reflected in a qualitative study of EAs with T1D aged 19-30 years, where the emerging adulthood transition was portrayed as an unsettling time, with a disruptive effect on habits and routines related to diabetes self-management (Hanna & Hansen, 2019). Moreover, due to the challenges that characterize this phase, EAs do not consistently employ adequate self-care

behaviors to maintain good health and prevent diabetes related complications (Peters & Laffel, 2011).

Several studies portrayed the suboptimal self-care practices of EAs with T1D, reflecting the continuous struggle in managing their disease during this developmental transition (Hendricks et al., 2013; Ramchandani et al., 2019; Vallis et al., 2018). In a qualitative study, 22 young adults reported that the barriers to self-care included disease characteristics and social stigmatization, whereas social support, diabetes education and multi-professional teams in diabetes centers facilitated their self-care. The results also indicated that diabetes technology acted as both a barrier and a facilitator of self-care (Montali et al., 2022). On the other hand, Majumder et al. (2016) reported that EAs showed increased autonomy in performing diabetes self-care practices and improved diabetes problem-solving skills. Self-care through problem solving predicted better glycemic control at 1-year follow-up, indicating a buffering effect of these skills on the deterioration of glycemic control during this period (Majumder et al., 2016).

Self-management programs are often considered part of the interventions within the preparation for transition, to aid EAs achieve optimal health status (Egan et al., 2015; Schultz & Smaldone, 2016). However, the findings regarding the effects of implementing such programs on diabetes-related health outcomes among the EAs are inconsistent. Some studies reported improved diabetes-related health outcomes with programs that included diabetes self-management education (Egan et al., 2015; Pyatak et al., 2017). In contrast, a recent systematic review and meta-analysis with 1,002 participants (15-39 years old with T1D and T2D) by Wong et al. (2020) showed no effect of such programs on diabetes health outcomes (HbA1c levels, body mass index, depression, diabetes-related distress, diabetes related quality of life, overall self-care,

diabetes knowledge, and self-efficacy). Thus, future self-management interventions should be tailored to the specific needs, preferences, and concerns of the EAs with T1D.

In summary, challenges in self-care are common in EAs with T1D, especially as it comes at a time when the patient is dealing with the transition to adulthood and its concurrent developmental tasks. However, the optimal intervention to promote self-care in this population is yet to be identified.

#### **D. Variables Affecting Diabetes-Related Health Outcomes in EAs with T1D**

Several variables were identified that affect the health outcomes of EAs who have T1D. The most prominent variables include demographic, healthcare, and social variables, and are discussed below.

##### ***1. Gender***

The literature provides inconsistent findings on the influence of gender on diabetes-related health outcomes and complications among the EA population. Data collected from 300 individuals with T1D aged 18–30 years indicated that females had significantly higher HbA1c, body mass index, and HDL-cholesterol levels than males. Smoking and sexual dysfunction, however, were more prevalent in males (Maiorino et al., 2018). Investigators also reported gender differences in the psychological health outcomes, with significantly higher distress levels and negative emotional consequences of T1D in EA females compared to males (Lašaitė et al., 2016). In another study, females were more likely than males to involve others in their care, report worrying when going out with peers, and worrying about managing their diabetes and hypoglycemia episodes (Ramchandani et al., 2019). Moreover, male EAs were more

likely to have lower diabetes specific family conflict than females (Campbell et al., 2019). On the other hand, gender was not associated with any diabetes-related health outcome in other studies of EAs with T1D (Hislop et al., 2008; Zoffmann et al., 2014).

## ***2. Living Situation***

During the emerging adulthood period, leaving the parents' house and living independently is another transition that can influence diabetes-related outcomes. In a longitudinal study of 197 EAs, those who did not live with their parents demonstrated a significant increase in depressive symptoms over time than those who did (Baucom et al., 2015). However, another study reported an inconsistent effect of leaving the parents' home on glycemic control, whereby some participants reported worsening levels of HbA1c upon leaving home while others reported improving levels (Ramchandani et al., 2019). These inconsistent findings reflect the presence of confounders that may account for the association between the living situation and diabetes related outcomes.

## ***3. Healthcare Services***

The majority of the literature on EAs with T1D focused on their transfer from pediatric to adult healthcare services (Agarwal et al., 2017; Egan et al., 2015; Pyatak et al., 2017; Schultz & Smaldone, 2016). This literature addressed the challenges faced by the EAs during this situational transition and described interventions that might ease this process. Such interventions included transition programs that involved joint pediatric/adult clinics, transition coordinators with phone support, dedicated transition clinics, and self-management education programs (Egan et al., 2015; Schultz &

Smaldone, 2016). The American Diabetes Association recommended the application of such intervention programs during this phase (Peters & Laffel, 2011). Several studies explored the impact of implementing transition programs on diabetes-related health outcomes among the EA population. These transition programs helped maintain glycemic control and reduce diabetic ketoacidosis episodes, as documented in a systematic review (Schultz & Smaldone, 2016). Likewise, structured transition programs reduced HbA1c, severe hypoglycemia, and emergency department visits; however, there was no effect on psychological health (Levy-Shraga et al., 2016; Pyatak et al., 2017). Therefore, structured programs that provide care coordination, support and education to patients are likely to have a positive impact on the EAs as they move from pediatric to adult health care.

Patient-healthcare provider relationship is another factor that can influence the transition experience of the EAs with T1D (Joly, 2015; Kelly et al., 2018; Ramchandani et al., 2019). In an integrative review of one quantitative and ten qualitative studies, Joly (2015) reported three major themes that characterized the healthcare transition experience of EAs with chronic illnesses: “it’s like falling off a cliff”, “the paradox of independence”, and “it takes a village”. EAs viewed the adult healthcare system as an unfamiliar world where the care received is lacking or inadequate and is often “fragmented and disease-centered” (Joly, 2015). Another qualitative study of 21 EAs with T1D further highlighted the significance of patient-healthcare provider communication, where participants declared “a desire to have a connection with their diabetes provider” during this phase (Ramchandani et al., 2019). Furthermore, Kelly and colleagues (2018) reported that patient-provider communication moderated the effect of transition readiness skills on adherence to treatment. Transition readiness skills

were associated with better adherence among those with higher patient-provider communication, but lower adherence among those with low patient-provider communication (Kelly et al., 2018).

Overall, the healthcare system support is mainly reflected through adequate preparation and knowledge transfer, continued involvement of the pediatric healthcare providers during the transition, and good communication with the adult healthcare providers.

#### ***4. Social Support***

The literature on parent and peer support for EAs within the context of T1D underscores the changing nature of this relationship, and its influence on diabetes-related health, general health behaviors, and psychological well-being (Goethals et al., 2017; Kelly et al., 2018; Markowitz et al., 2016; Vallis et al., 2018).

##### ***a. Parent Support***

Relationships with parents change during emerging adulthood (Arnett, 2000). During this period, some individuals can easily navigate through the changing family dynamics and support. However, over- or under-involvement of parents in their children's diabetes care may hinder the successful mastery of adult roles and reflect poorly on the EAs' diabetes health outcomes (Hanna, 2012).

Some studies explored the emerging adult-parent relationship's association with diabetes management and glycemic control. A longitudinal multicenter study of 182 EAs with T1D showed that participants had relatively low levels of parent-youth conflict, increased shared responsibility with their parents for diabetes care, and

increased parental support of their autonomy during the first year after high school graduation (Hanna, Weaver, Stump, et al., 2014). However, higher levels of HbA1c were correlated with more parent–youth conflict. The authors also reported moderately high levels of tangible aid from parents, such as keeping track of supplies, making appointments, and paying for diabetes treatment (Hanna, Weaver, Stump, et al., 2014). These findings reflect the residual need for parental support, as these EAs did not yet reach the adulthood phase (Arnett, 2000).

Another longitudinal study by Campbell et al. (2019) explored family functioning in the context of diabetes-related family conflict and responsibility for diabetes care with 79 EAs with T1D and their parents. Study participants reported low baseline diabetes-specific family conflict and the level of conflict did not change across the one-year study period. However, both parent-reported and emerging adult-reported parental involvement in diabetes care levels decreased over the study duration. After controlling for demographic variables, more diabetes-specific conflict and greater parent responsibility levels predicted worse glycemic control. The study findings come in congruence with a previous study on EAs (Markowitz et al., 2016) but in contrast with results of another study where parental involvement in early adolescence has been associated with better glycemic control (Radcliff et al., 2018).

On another note, increased independence in diabetes self-care and adherence to treatment was found to be fostered by supportive parental relationships. However, the benefit of this support was highest when individuals were able to regulate the level of parental involvement (Wiebe et al., 2018). In a cross-sectional study of 521 patients (aged 14–25 years) with T1D and 752 parents, parental involvement was associated with poorer treatment adherence when perceived as controlling by the participants,

while better responsiveness from parents was associated with improved treatment adherence (Goethals et al., 2017).

Other studies highlighted the effect of the emerging adult-parent relationship on the psychological outcomes of the patients with T1D. Parental relationships were found to be important to the psychological well-being of EAs with T1D (Helgeson et al., 2014), and living with parents was associated with better quality of life in EAs (Hanna, Weaver, Slaven, et al., 2014). The positive effect of parental support on psychological health, but not treatment adherence and glycemic control, was also documented in a longitudinal study of adolescents and EAs with T1D (Raymaekers et al., 2017). Conversely, controlling parental behavior and parental conflict often resulted in increased stress, and negatively affected the mental well-being of the EAs (Celik et al., 2015; Chiang et al., 2020).

In summary, the findings of the above studies highlight the importance of parental involvement in the care of their children during their emerging adulthood phase. However, caution should be exercised against critical and intrusive control by parents due to its negative associations with adherence to treatment, disease management, and health outcomes. The influence of parental support depends on how it is perceived by the EA.

#### b. Friends/Peers Support

During emerging adulthood, parental involvement decreases, while interaction with peers and romantic partners increases (Arnett, 2000). Consequently, peer support for EAs with T1D plays an important role in their diabetes management independently from their parents (Pihlaskari et al., 2018; Vallis et al., 2018; Wiebe et al., 2018).

Perceived diabetes-specific peer support during emerging adulthood was found to facilitate diabetes management in a longitudinal study of 211 high school seniors with T1D, and was associated with better adherence one year after finishing high school, after controlling for levels of adherence and perceived peer support at baseline (Pihlaskari et al., 2018). Likewise, in a longitudinal study of 217 participants, Kelly et al. (2018) reported that friend knowledge/ helpfulness moderated the effect of self-management skills on adherence to treatment, such that adherence was highest when low self-management skills occurred in the context of high friend knowledge and helpfulness. Another study examined the effect of diabetes-specific peer support on diabetes-related health outcomes in 317 college students (aged 18-30 years) with T1D, where peer support was considered present if the participants were members of a local university-based diabetes student organization (Saylor et al., 2018). Participants who were members of the organization were significantly less likely than non-members to report increased levels of isolation, depressive symptoms, and diabetes-related anxiety. Additionally, members reported decreased frequency of hypoglycemic events and lower HbA1c levels since joining the student organization. However, there were no differences between members and non-members in severe hypoglycemia and DKA incidents during the college years (Saylor et al., 2018). In two qualitative studies, EAs reported a significant impact of peers with diabetes on their physical and emotional well-being, which they attributed to sharing experiences and knowledge, as well as feeling a sense of acceptance and belonging (Abdoli et al., 2017; Montali et al., 2022).

On the other hand, unpleasant or conflicting relationships with friends negatively affect the health and behavioral outcomes of the EAs. In a sample of 117 EAs with T1D, conflict with friends predicted an increase in depressive symptoms, perceived stress,

bulimic symptoms, and drive for thinness, in addition to increased alcohol use and binge drinking (Helgeson et al., 2014). Moreover, data from a qualitative study highlighted the suboptimal peer support received by 14 participants aged 15-28 years with T1D. The inadequate peer and public support resulted in the EAs experiencing daily diabetes management distress, feeling alone and unsupported in their diabetes care, and fearing the negative social perceptions of the disease (Habenicht et al., 2018).

In summary, research findings highlight the importance of peer support for EAs with T1D, with an effect on self-management skills and diabetes-related outcomes. However, findings on these effects are limited and inconclusive, as confounded by the quality of peer relationships in terms of perceived support and conflict.

#### **E. Research in the Middle East and Lebanon**

There are very few studies that evaluated the emerging adulthood transition experience in individuals with diabetes or other chronic illnesses in Lebanon or the Middle East region. A consortium of experts from different regions including the USA, Europe, the Middle East (including Lebanon) and Africa, provided a global perspective of the pediatric to adult healthcare transition for patients with sickle cell disease (Inusa et al., 2020). The experts presented a global overview of the transition practices, discussed the challenges commonly faced during this period, and provided recommendations for practice. Several between-countries differences were highlighted, including the age at transfer to adult care and the different healthcare system practices across countries. These differences reflect cultural and demographic variations, which make Western guidelines inappropriate when taken out of the cultural or country context. Nevertheless, the review highlighted best healthcare transition practices, which

contributed to the development of the six “SICKLE recommendations”. Similar to the American Diabetes Association recommendations of healthcare transition in patients with diabetes (Peters & Laffel, 2011), the SICKLE recommendations included skills transfer, increasing self-efficacy, coordination of transition, knowledge transfer, linking to adult services, and evaluating readiness to transfer. Another review by Musallam et al. (2008) described the changes individuals with thalassemia go through during their transition into adulthood. The authors stressed the importance of providing age-specific medical and psychological assessment and care during this developmental stage (Musallam et al., 2008).

Only one cross-sectional study in the Middle East described the situational pediatric to adult healthcare transition practices implemented by gastroenterology services in patients with inflammatory bowel disease (IBD) in the Kingdom of Saudi Arabia (KSA) (Al-Jahdali et al., 2017). Although 79% of the gastroenterologists rated transitioning as being “very important”, only 26% of the medical centers in KSA followed an institutionally developed protocol guiding the transition of IBD patients to adult care. This discrepancy reflects the lack of transition practices from pediatric to adult health care at the national and institutional levels in KSA despite the consensus on the significance of transition as a health concern among individuals with IBD (Al-Jahdali et al., 2017).

The paucity of studies in Lebanon and the Middle East region and the different cultural context than the West, draw the attention to the dire need for studies in the region.

## **F. Summary**

In summary, emerging adulthood is a crucial developmental milestone that has become a rising concern for patients with T1D, their parents, and the health care providers. The empirical literature supports the notion that EAs with T1D are a unique population with personal, sociodemographic, clinical, and social factors influencing their diabetes management and health outcomes in an unusual way. The challenges faced during this developmental transition place the EAs at a greater risk for developing disease-related complications and psychological morbidity.

Nevertheless, there are several inconsistencies in the reviewed literature. These inconsistencies could be the result of some conceptual and methodological weaknesses and limitations of the studies done on this population. To begin with, very few studies (Egan et al., 2015; Hanna, Weaver, Slaven, et al., 2014; Joly, 2015; Palladino et al., 2013; Zoffmann et al., 2014) were based on theoretical or conceptual frameworks. Using theory-based research leads to a better understanding of the problems experienced by the EAs, as well as the mechanisms by which they can reach optimal health outcomes.

In addition, studies were inconsistent regarding the age of the EAs. For example, some authors reported results on participants from late adolescence into the emerging adulthood stage (i.e. 15-25 years), other studies included participants with ages between 18-25 years, while others extended this age range up to 30 years. It is important to have a consistent definition of the age group assigned to the 'Emerging Adult' terminology due to the effect developmental stages have on the thought processes and self-care management abilities of the patients. Besides, comparing outcomes between studies will become challenging with this hazy age border. However, a uniform definition may be

challenging at this point due to the different ages at which the determinants of this developmental transition occur across cultures.

Moreover, several studies had some methodological weaknesses. First, most of the studies used cross-sectional designs (Butler et al., 2017; Hendricks et al., 2013; Hislop et al., 2008; Lašaitė et al., 2016; Zoffmann et al., 2014), which reduces the verification of causal relationships between variables and the ability to track changes over time during the transition. Second, some authors reported sampling biases in their studies, limiting generalizability of the findings to the population (Campbell et al., 2019; Hanna, Weaver, Slaven, et al., 2014; Hendricks et al., 2013; Palladino et al., 2013; Pihlaskari et al., 2018; Ramchandani et al., 2019; Rassart et al., 2015). Other noted sampling concerns include small sample sizes, as well as not providing power analysis for the statistical analyses done (Bryden et al., 2001; Egan et al., 2015; Hendricks et al., 2013; Hislop et al., 2008; Majumder et al., 2016; Pyatak et al., 2017; Rassart et al., 2015). Low sample sizes can reduce the power of the study and increase the margin of type II errors (Wilson Van Voorhis & Morgan, 2007).

Third, attrition and missing data rates were not mentioned or properly managed in several studies (Bryden et al., 2001; Hendricks et al., 2013; Hislop et al., 2008; Lašaitė et al., 2016; Zoffmann et al., 2014), which can lead to the possibility skewed or biased results.

Finally, the internal validity of the results of some studies were compromised due to the lack of evidence of the validity and reliability of their measurement tools (Bryden et al., 2001; Lašaitė et al., 2016; Pihlaskari et al., 2018; Pyatak et al., 2017; Saylor et al., 2018), or using instruments with low reliability scores (Rassart et al., 2015). In fact, the authors of two systematic reviews reported that the majority of the

studies in this population were of medium to low quality in terms of methodology, sampling, controlling for confounders, and acknowledging biases (O'Hara et al., 2017; Schultz & Smaldone, 2016).

Overall, analysis of the reviewed research highlighted its implications as well as its limitations, suggesting the need for conducting high quality research within this population. Several authors emphasized the social and cultural variation in the determinants of diabetes-related health outcomes in the EAs. This finding validates the need to determine the transition experience of the EAs with T1D in Lebanon, with the ultimate goal of improving glycemic control and providing high quality care and support to this vulnerable understudied patient population.

## CHAPTER III

### THEORETICAL FRAMEWORK

In the Emerging Adult theory, Arnett (2000) provided the definition and described the attributes of emerging adulthood, which is a period of transition from adolescence to young adulthood. On the other hand, the Transition Theory provided a more elaborate theory on what happens during (any) transition, including its relation to health (Meleis et al., 2000). Moreover, T1D is a chronic illness where self-care is key to glycemic control; thus, the framework for this study will address both the transition during emerging adulthood and self-care behaviors during this phase.

One model that could be used in this study is one of the ecological models that examines the influence of individual, community, society, and policy on health behaviors. However, these models are very broad, and go beyond the aims of the proposed study. In such models that are usually used in studies of health behaviors, there are multiple layers of influence that are studied but the interaction between the various constructs is usually not clear or well defined (Sallis & Owen, 2015). Based on the above, we chose a conceptual framework of the study that is inspired by the Middle-Range Theory of Transition (Meleis et al., 2000), and the Middle-Range Theory of Self-Care in Chronic Illness (Riegel et al., 2012). These theories are described below.

#### **A. The Middle-Range Theory of Transition**

Transition is a time during which changes in an individual's life cause instability and render the individual vulnerable to delayed or ineffective coping (Meleis & Trangenstein, 1994). Chick and Meleis defined transition as "passage from one life phase, condition, or status to another" (1986, p. 239). Meleis later developed a middle-

range theory of Transition where transition was conceived as a central concept in nursing and defined as “complex multidimensional processes that both cause and affect changes in life, health, relationships, and environment” (Meleis, 2010, p. 359). This theory acknowledged the complexity of transitions and focused on a guided approach of care for anyone in various types of transitions. The goal of a successful transition is to achieve well-being, a reformulated identity, and role mastery. Meleis’s transition theoretical framework focuses on four components: the nature of transitions, transition conditions, patterns of response, and nursing therapeutics (Meleis et al., 2000).

### ***1. Nature of Transition***

The nature of transition includes the *types*, *patterns*, and *properties* of transition. *Transition types* can be developmental, situational, health/illness, or organizational. Transitions are not mutually exclusive events (Meleis et al., 2000). Individuals can experience different *patterns* of transition, as they are faced with multiple transitions simultaneously that can overlap and be related to one another (Meleis et al., 2000). This is highly relevant in the EAs with T1D as they experience developmental, health/illness, situational, and organizational transitions concurrently. The EAs are transitioning developmentally as they move from adolescence into young adulthood, gaining independence and autonomy while becoming more liable for their own decisions and health (Arnett, 2000). The EAs are also transitioning situationally as they start college, a new job, or engage in a relationship/ marriage. The move from pediatric to adult healthcare systems/clinics would constitute the organizational transition that the EAs face at this stage. Most importantly, the simultaneous occurrence of these transitions might be overwhelming to the EAs and can result in sudden or gradual changes between

states of wellness and illness (Meleis et al., 2000). Among the EAs with diabetes, this health-illness transition is reflected in their deteriorating diabetes-related health outcomes and occurrence of diabetes-related complications during this phase (Bryden et al., 2001; Hendricks et al., 2013; Zoffmann et al., 2014).

The five essential and interrelated *properties* of transitions include awareness, engagement, change and difference, transition time span, critical points and events. Awareness is the perception of change of the individual undergoing the transition; it is the acknowledgement that a person is undergoing transition. Engagement is when the individual participates in the transition process. Critical events, disrupted interaction with others or routines, and changes in perceptions and identities that the EAs face, characterize the transition process. The transition time span is the movement over time, starting at the beginning of change (anticipation, perception, or demonstration of change), passing through a critical period characterized by instability, confusion, and distress, and ending in a period of stability (Meleis et al., 2000). The individual in transition must be aware of the process of transition and the changes occurring during this phase.

Researchers identified how these properties can affect the EAs with T1D. Two systematic reviews showed that the involvement of the EAs with T1D in their diabetes management and having enough time to adapt to the transition resulted in positive diabetes-related health outcomes (Farrell et al., 2018; Findley et al., 2015).

## ***2. Transition Conditions/ Facilitators and Barriers***

The interaction with the environment surrounding the transition and the stability of this environment affect the transition process and outcomes (Meleis, 2010).

Transition conditions are divided into personal, community, and social conditions.

The *personal* conditions consist of meaning, cultural attitudes, socioeconomic status, participation, and knowledge. The individual's meaning or the perception of the change process and its consequences, his/her cultural beliefs, and socioeconomic status can act as either facilitators or barriers to positive transition outcomes. Preparation for the transition should be anticipatory and should include providing the EAs with diabetes with the knowledge and skills needed to prepare them for assuming autonomous self-care. Inadequate knowledge and skill during transitions may adversely influence health outcomes (Meleis, 2010).

The *community and social systems* reflect the resources within the environment that shape the transition process. The community condition is the support acquired from family members, partners, and friends. The social systems include the availability of resources, such as healthcare systems or services, which can either hinder or facilitate the transition (Meleis et al., 2000). In a systematic review, Hynes et al. (2016) reported that the availability of transitional programs, involvement of young adults, provision of support and information during transition, and communication between pediatric and adult care services act as factors that can assist the EAs in achieving favorable health outcomes during this transitional phase. In addition, social support, both parental and peer involvement, was found to be associated with self-management, adherence to treatment, and diabetes-related health outcomes among the EAs with T1D (Kelly et al., 2018; Pihlaskari et al., 2018; Wiebe et al., 2018).

### ***3. Patterns of Response***

Meleis et al. (2000) differentiated between a healthy and unhealthy or ineffective transition. The transition theory identifies two patterns of response: process indicators and outcome indicators. *Process indicators* include feeling connected to and interacting with key persons, caregivers, and the health care professionals; location and being situated within the new life in terms of time, space and relationships; and developing confidence and coping by being independent in managing the chronic illness. *Outcome indicators* include fluid integrative identities that are reflected through mastery of new skills and behaviors needed for the transitioning individuals to cope with their changing condition. The level of mastery, resolution of distress, and restoration of disrupted relationships indicate the extent to which a successful transition is achieved. Fluid integrative identities reflect the identity changes that the individual passes through during the transitional process (Meleis et al., 2000).

The literature on the impact of emerging adulthood transition on individuals with T1D revealed results that are congruent with Meleis's proposed outcomes, namely the outcome indicators patterns of response such as mastery of skills (self-care) and resolution of distress outcomes. Several studies focused on glycemic control, diabetes related hospitalization, and clinic attendance as indicators of transition success (Agarwal et al., 2017; Levy-Shraga et al., 2016; O'Hara et al., 2017). Other studies focused on psychological well-being, quality of life (Pyatak et al., 2017; Sequeira et al., 2015), and diabetes distress (Lašaitė et al., 2016). Moreover, in a qualitative study, stakeholders identified diabetes knowledge/skills, integration of care into the emerging adult roles, balance of parental involvement with autonomy, and "ownership" of self-management as significant outcomes during transition (Pierce et al., 2017).

#### ***4. Nursing Therapeutics***

The theory identifies transition as a dynamic time where nurses provide the proper therapeutics required to achieve positive health outcomes. Nursing therapeutics include assessment of transition readiness, preparation for transition, and continuous assessment and evaluation of the transition outcomes. The assessment of the individual's readiness to change should involve a multidisciplinary approach to identify all the elements involved in transition. The preparation for transition mainly consists of educating the individual and ensuring adequate training for assuming new responsibilities and skills. Continuous reassessment and evaluation of the individual's transitional trajectory involves creating a suitable time-plan for the adaptation to new roles, and supporting the creation of a healthy environment in which transition occurs, to aid in the identity reformulation of the transitioning individual (Meleis et al., 2000). A consensus statement highlighted the significance of proper assessment and preparation of transitioning EAs with T1D (Peters & Laffel, 2011). Assessment and preparation strategies for EAs with T1D included the implementation of transition programs and having care coordinators, which resulted in achieving positive diabetes-related health outcomes (Agarwal et al., 2017; Egan et al., 2015; Levy-Shraga et al., 2016; Wafa & Nakhla, 2015).

#### **B. The Middle-Range Theory of Self-Care in Chronic Illness**

Managing chronic illnesses is a challenge to the patients' health and well-being. Patients with chronic illnesses have to perform complex behaviors in order to manage their symptoms, reduce the incidence of complications, and maintain a good quality of life. These behaviors comprise the concept of Self-Care. Riegel et al. (2012) proposed a

Middle-Range Theory of Self-Care in Chronic Illness, which was based on the situation-specific Theory of Heart Failure Self-Care (Riegel & Dickson, 2008). This middle-range theory was also guided by Orem's general Theory of Self-Care Deficit (Orem, 1991), with the distinction of this theory by focusing on chronic illness. Riegel et al. (2012) defined self-care as "a process of maintaining health through health promoting practices and managing illness" (p. 195). The theory addresses key concepts of self-care, the processes that underlie self-care, intended and unintended outcomes of self-care, in addition to the factors that affect self-care.

### ***1. Key concepts of the Theory of Self-Care in Chronic Illness***

Three key concepts that help define and understand self-care in chronic illness include self-care maintenance, self-care monitoring, and self-care management. *Self-care maintenance* is defined as the "behaviors performed to improve well-being, preserve health, or maintain physical and emotional stability" (Riegel et al., 2012, p. 196). These behaviors include lifestyle or treatment adherence practices recommended by healthcare professionals, family members, or the patients themselves. Adaptation is often needed to accommodate any changing conditions that can affect self-maintenance behaviors (Riegel et al., 2012).

*Self-care monitoring* is "a process of routine, vigilant body monitoring and surveillance for changes in signs and symptoms" (Riegel et al., 2012, p. 196). The goal of self-care monitoring is to detect the occurrence of physical or emotional changes related to the chronic illness; it should be performed in a systematic, routine, and timely manner in order to produce the best outcomes. Self-care monitoring is necessary for

effective self-care management because patients cannot decide to treat a symptom unless they are able to recognize it and evaluate its significance.

*Self-care management* is the “response to signs and symptoms when they occur” (Riegel et al., 2012, p. 196). It involves the evaluation of the symptoms or changes detected in self-care monitoring, and the implementation and evaluation of the actions needed to manage those changes. In some cases, self-care management requires the assistance of healthcare professionals (Riegel et al., 2012).

Studies on self-care behaviors among EAs with T1D concur with the three concepts of the Self-Care Theory for Chronic Illness. Self-care maintenance (such as following a healthy lifestyle and adhering to medication regimen), self-care monitoring (such as frequent blood glucose monitoring), and self-care management (such as treating hypoglycemia and hyperglycemia episodes) are essential in acquiring optimal health outcomes (American Diabetes Association, 2020g). Moreover, the adaptation to change discussed in the Self-Care Theory is especially relevant in emerging adulthood due to the developmental and autonomy changes taking place during this time (Arnett, 2000). Failure to adapt to these changes leads to failure in performing adequate self-care practices during the emerging adulthood phase (Hendricks et al., 2013; Vallis et al., 2018). In addition, emerging adulthood was found to be an unsettling time that has a disruptive effect on habits and routines, negatively affecting diabetes self-care practices (Hanna & Hansen, 2019).

## ***2. Processes Underlying Self-Care***

Riegel and colleagues (2012) described decision-making and reflection as the two processes that underlie self-care practices. During self-care management of symptoms,

decision-making is needed to determine the responses required to manage the signs and symptoms. On the other hand, reflection is linked to knowledge. Patients should have the appropriate knowledge and skills to perform self-care that is reflective of their condition and needs. Reflection happens when patients are knowledgeable about their self-care needs, perform self-care with thought about the meaning of their signs and symptoms, and make good decisions about what to do in case of abnormal signs or symptoms. Reflective self-care can be learned, and healthcare professionals play a role in this process by providing patients with needed health education (Riegel et al., 2012). Self-management educational programs during the transition into emerging adulthood have been associated with improved outcomes in individuals with T1D (Agarwal et al., 2017; O'Hara et al., 2017).

### ***3. Intended and Unintended Outcomes of Self-Care***

The Self-Care theory describes intended and unintended outcomes of self-care. *Intended outcomes* include illness stability, better health, well-being and quality of life, as well as lower anxiety levels and an increased sense of control over the illness. In addition, self-care can decrease health care costs through reduced morbidity and hospitalization rates (Riegel et al., 2012). The *unintended outcomes* of self-care include delay in seeking treatment, which happens when patients perceive high levels of control leading to self-deception, and deny needing assistance. In addition, the need to perform self-care and guilt when failing to follow treatment recommendations can lead to increased treatment burden. Moreover, self-care could increase treatment costs by motivating patients to seek care even when it is not needed (Riegel et al., 2012).

Studies of EAs with T1D reported intended and unintended outcomes of self-care. Self-care predicted better glycemic control (Majumder et al., 2016) and was positively associated with diabetes quality of life (Hanna, Weaver, Slaven, et al., 2014) in EAs with T1D. On the other hand, EAs reported bearing “a burden of the disease”, reflected in their continuous struggle in performing adequate diabetes self-management (Ramchandani et al., 2019).

#### ***4. Factors Affecting Self-Care***

Riegel et al. (2012) identified several factors that affect self-care in patients with chronic illness, such as experience and skills, motivation, confidence, habits, functional and cognitive abilities, cultural beliefs and values, support from others, and access to care.

*Experience, skills, habits, and motivation to perform self-care* activities are essential as patients must be able to plan, set goals, make decisions, and be driven to achieve their goals. *Functional and cognitive abilities*, and *confidence* in the ability to perform self-care behaviors, are prerequisites for performing such behaviors. There is a noted effect of *cultural beliefs and values* on self-care. Self-care is more salient in individualistic cultures where independence is valued, and less salient in collectivist cultures where support from others is more pronounced. Nevertheless, although self-care may be performed solely by the patient, *support from others* such as family or friends is needed. Lastly, having *access to adequate health care services* facilitates self-care and promotes health outcomes of patients with chronic illness (Riegel et al., 2012). It is worth noting the inclusion of cultural beliefs and values as factors affecting self-care in the Self-Care in Chronic Illness theory, whereby the authors stated the need for

culturally relevant studies to reflect the differences in self-care practices and their respective effects on health outcomes between different cultural groups (Riegel et al., 2012).

As noted in the literature review, exploring the above factors within the context of emerging adulthood in individuals with T1D highlighted their impact on self-care. Self-management educational programs, social support (parental and peer), and healthcare providers' support and communication were positively associated with self-care practices in the EAs with T1D (Helgeson et al., 2014; Kelly et al., 2018; Pihlaskari et al., 2018).

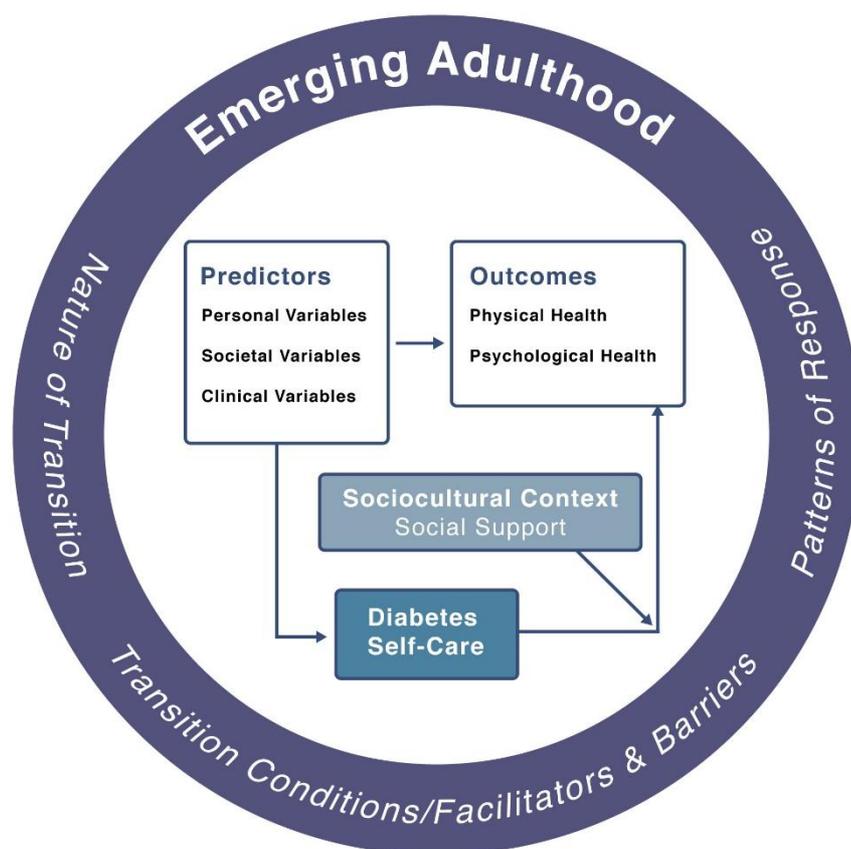
### **C. Conceptual Framework of the Study**

The definition of transition as a “complex multidimensional processes that both cause and affect changes in life, health, relationships, and environment” (Meleis, 2010, p. 359) is adopted in the proposed study of EAs. Meleis and colleagues (2000) described several variables that influence the transition process, thus affecting the health of the transitioning individual. Within the emerging adult with T1D, these variables can be categorized as personal, societal, and healthcare system variables. The theory further considers physical and psychological health as outcome measures during transition. Similarly, in the theory of Self-Care in Chronic Illness, Riegel et al. (2012) described the personal, social, and healthcare factors affecting self-care, as well as the outcomes of self-care practices on the health and well-being of patients with chronic illnesses. In this study, a conceptual framework guided by the middle-range theories of Transition (Meleis et al., 2000) and Self-Care in Chronic Illness (Riegel et al., 2012) is developed (Figure 1). This framework focuses on key predictor variables, which include personal,

societal, and clinical variables. The main outcome in this framework is diabetes-related health, measured through physical health (HbA1c, hypoglycemia, and DKA) and psychological health (diabetes distress).

**Figure 1**

*Conceptual Framework*



In this study, we aim to understand the nature of the association between the identified predictors and diabetes health outcomes. Based on Riegel’s description of the factors affecting self-care and its reported outcomes, and its reflection in the reviewed literature, we propose self-care to act as a mediator between clinical and

sociodemographic variables, and diabetes related health outcomes. We also propose that social support, which is one of the factors affecting self-care according to the Self-Care Theory in Chronic Illness and the reviewed literature, moderates the association between diabetes self-care and diabetes health outcomes. The cultural, physical and value-laden context that defines emerging adulthood in the Lebanese population with T1D is captured in the circle surrounding the study variables, as it is assumed to underpin and explain all the studied associations.

## **D. Conceptual and Operational Definitions of Key Concepts**

### ***1. Sociodemographic and Clinical Variables***

Several sociodemographic and clinical variables will be addressed in this study such as age, gender, duration of diabetes, living arrangements, social status, educational level, occupation, medical insurance, duration of diabetes and comorbidities.

### ***2. Diabetes Self-Care***

*Theoretical Definition:* Self-care is defined as “a process of maintaining health through health promoting practices and managing illness” (Riegel et al., 2012, p. 195). Diabetes self-care is “the daily regimen tasks that the individual performs to manage diabetes” (Weinger et al., 2005, p. 1346). This disease-specific definition will be used in this study.

*Operational Definition:* Diabetes self-care will be measured by the Self-Care Inventory-Revised tool (Weinger et al., 2005). The SCI-R is a 15-item self-report measure of diabetes self-care activities developed for use among adults with T1D and

T2D. The tool addresses self-care actions related to diet, medication administration, exercise, managing low glucose levels, and preventative/routine aspects of self-care.

### **3. Social Support**

*Theoretical Definition:* Social Support is defined as an “exchange of resources between at least two persons, aimed at increasing the well-being of the receiver” (Shumaker & Brownell, 1984, p. 11).

*Operational Definition:* Social support will be measured by the Social Support subscale from the Diabetes Care Profile (DCP), which is an instrument that assesses the social and psychological factors related to diabetes and its treatment (Fitzgerald et al., 1996). The Social Support scale is a self-report measure that includes a global social support subscale and two subscales measuring desired social support and received social support.

### **4. Diabetes Distress**

*Theoretical Definition:* Diabetes distress is the unique emotional and behavioral challenges generated by the stressors related to diabetes and its management (Fisher et al., 2012).

*Operational Definition:* Diabetes Distress will be measured by the Type 1 Diabetes Distress Scale (T1-DDS). The T1-DDS is a 28-item scale that measures diabetes-related emotional distress in adults with T1D (Fisher et al., 2015).

## **5. Glycemic Control**

*Theoretical Definition:* Glycemic control reflects the adequacy of diabetes management and the effectiveness of diabetes-care practices among individuals with diabetes (American Diabetes Association, 2020b).

*Operational Definition:* A recent indicator for glycemic control is the ‘time-in-range’ concept, which is the time spent in the target range between 70 and 180 mg/dl (Beck et al., 2019). However, this indicator will not be feasible in this study since it requires participants to be on continuous glucose monitoring, which is not currently feasible in the Lebanese population. To that effect, glycemic control will be measured by the self-reported last HbA1c value of the participant, which is an estimate of the average glucose bound to hemoglobin values over the prior 2 - 3 months and is a commonly used indicator of glycemic control.

## **6. Acute Diabetes Complications**

*Theoretical definition:* Acute complications of diabetes arise from the rapid increase or decrease in blood glucose levels. Such complications can be life threatening and require prompt attention and treatment (American Diabetes Association, 2020b). These include hypoglycemia and diabetic ketoacidosis.

*Operational definition:* Acute complications will be measured in the study by asking the participants to self-report the number of DKA and severe hypoglycemia events experienced over the last 6 months. Severe hypoglycemia events, also known as ‘level three hypoglycemia’, are defined as hypoglycemia events involving altered mental and/or physical functioning that require assistance from another person for recovery (American Diabetes Association, 2020b). The individual is asked to recall if

his/her blood sugar was low in a way that he/she could not move or focus enough to get treatment by him/herself for it. DKA is defined as the presence of ketones in the urine in addition to any of the signs of DKA including blood glucose  $\geq 250$  mg/dl, extreme thirst, polyuria, nausea, vomiting, abdominal pain, feeling tired, fruity-smelling breath, fatigue, rapid breathing, and difficulty concentrating or confusion (Kitabchi et al., 2009).

The study will address the above concepts from the perspective of the EAs living with T1D. The qualitative component of the study will explore the emerging adulthood experiences living with the disease, including changes that EAs' experience in their diabetes management, social interactions, relationship with their families and health care services, among other changes; as well as exploring the challenges they face and the resources available to them during this period.

### **E. Research Questions and Hypotheses**

This study will address the following research questions:

Research question 1 (Aim 1): What is the experience of EAs living with T1D in a Lebanese sample?

Research question 2 (Aim 2): What is the status of diabetes-related health outcomes, namely the current levels of glycemic control (HbA1c), psychological distress (Diabetes Distress), and the frequency of acute diabetes complications (DKA and severe hypoglycemia) experienced over the last six months, among EAs with T1D in Lebanon?

Research question 3 (Aim 3): Which demographic and clinical variables predict diabetes-related health outcomes among EAs with T1D in Lebanon?

Research question 4 (Aim 4): What is the effect of diabetes self-care on the association between sociodemographic and clinical predictor variables, and diabetes-related health outcomes among EAs with T1D in Lebanon?

Hypothesis: Diabetes self-care will mediate the relationship between sociodemographic and clinical predictor variables and diabetes-related health outcomes among EAs with T1D in Lebanon.

Research question 5 (Aim 5): What is the effect of social support on the association between diabetes self-care and health outcomes, among EAs with T1D in Lebanon?

Hypothesis: Social support will moderate the association between self-care and diabetes-related health outcomes among EAs with T1D in Lebanon. Social support will also moderate the mediating effect of self-care on the association between predictor variables and diabetes-related health outcomes.

## CHAPTER III

### METHODOLOGY

The aims of the study governed the selection of the philosophical view that guided the research methodology (Creswell & Poth, 2018). The purpose of this study was to describe the experience of EAs living with T1D in Lebanon and their diabetes-related health outcomes. This experience includes any changes that the EAs experienced during this developmental period, as well as their perceived challenges and support systems available to them. In addition, the study aimed to identify the sociodemographic and clinical variables that predict diabetes-related self-care and health outcomes in this population, and the role of social support in this relationship.

#### **A. Study Design**

A mixed methods concurrent triangulation study design (also referred to as convergent design) was used to answer the research questions of the study. The paradigm most often associated with mixed methods research is pragmatism, which has as its major principle “the dictatorship of the research question” (Tashakkori & Teddlie, 2003, p. 679). The ‘exploration’ and ‘verification’ nature of the mixed methods approach provides a pluralistic view of the experience of the diabetic EA within the Lebanese context. Triangulation is defined as “the combination of methodologies in the study of the same phenomenon” (Denzin, 1978, p. 291). Triangulation mixed methods designs use several methods to explore the different dimensions of a phenomenon. The different types of collected data are then compared for convergence and cross validation (Plano Clark & Creswell, 2008). Concurrent triangulation involves the simultaneous collection of qualitative and quantitative data, with equal weighting of both

components. The collected data are merged during interpretation, providing a comprehensive understanding of the findings (Creswell & Poth, 2018).

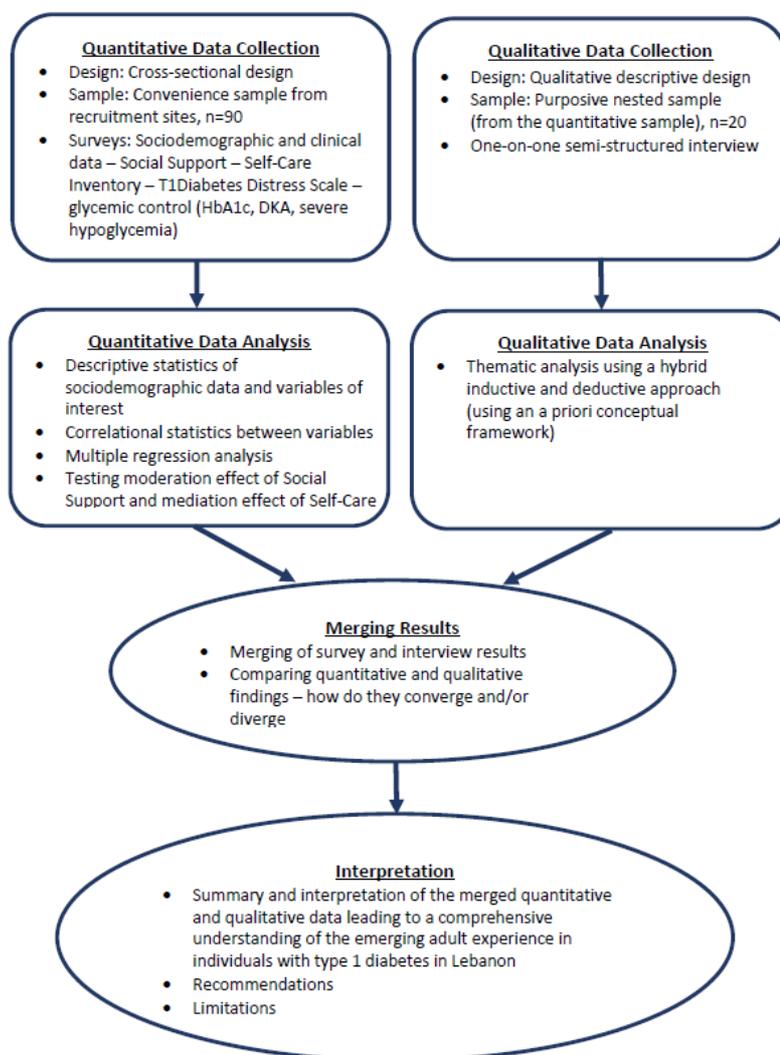
This study explored the transition experience and determinants of diabetes-related outcomes during this developmental phase from both the quantitative and qualitative perspectives. The study included individual semi-structured qualitative interviews to explore the participants' experience with diabetes during emerging adulthood, probing for any changes in self-care, challenges, and available support systems. The descriptive quantitative component allowed measuring the variables as they occur with no control or manipulation, then associations were tested using inferential statistical analyses. The qualitative component was used to explain the quantitative associations and identify aspects of the participants' experience that were not captured by the quantitative data.

The study design is cross sectional and observational mixed methods design. This design best suits the purpose of this study, which is to explore the experience of EAs with T1D in Lebanon and describe their diabetes-related health outcomes and associated factors. This design allows triangulation of the quantitative results with the qualitative data. Qualitative data collection was guided by the qualitative descriptive approach developed by Sandelowski (2000). Qualitative descriptive studies comprise a valuable methodologic approach that is widely used, especially in health sciences research, is the method of choice when descriptions of phenomena are desired, and is useful in answering questions of significance to practitioners such as the who, what, and where of events (Sandelowski, 2000). Descriptive qualitative research serves the aim of our study by allowing an in-depth understanding of transition into adulthood of EAs with T1D, providing first a literal description and then an understanding of its aspects,

achieved through the analysis and interpretation of the meaning that people attribute to their experience (Sandelowski (2000). In this study, the qualitative and quantitative components carry equal weight, and both data were collected concurrently. Thus, the design is concurrent and convergent. Figure 2 shows the skeleton of the study design.

**Figure 2**

*Mixed Methods Concurrent (Convergent) Triangulation Study Design*



## **B. Sample**

### ***1. Sampling Design***

The population of interest includes EAs with T1D. A non-probability convenience sampling design was used in this mixed methods study. Individuals from the recruitment sites who fit the inclusion criteria and were willing to participate in the study were enrolled.

A nested purposive sample from the participants of the quantitative section who agreed to sit for the semi-structured interview were recruited for the qualitative component of the study. The purposive sample was selected to include males and females, with maximum age variation.

### ***2. Sample Inclusion/Exclusion Criteria***

The sample inclusion criteria included individuals aged between 18 to 29 years with T1D and diagnosed at least one year before turning 18 years of age, in order to allow for the patient enough time to adjust to the illness and its treatment, and to allow capturing the emerging adulthood phase. Exclusion criteria included patients who are no longer residents in Lebanon, patients diagnosed with other chronic conditions that require frequent medical follow-up such as cystic fibrosis or thalassemia, and pregnant patients (based on medical records).

### ***3. Recruitment***

Originally, participant recruitment was planned to include two major diabetes clinics in the Greater Beirut area, namely the Chronic Care Center (CCC) and the

American University of Beirut-Medical Center (AUBMC) pediatric and adult diabetes clinics.

Prior to the start of the study, approval from the Institutional Review Board (IRB) at the American University of Beirut was secured. The research team also contacted the administration of the diabetes clinic at the CCC and submitted a description of the study and “letter of intent” for IRB and administration approval. The letter of intent included the research goals and purpose, the participants’ recruitment process, the data collection procedures, potential risks and benefits of participation, participant time commitment, involvement of the clinic staff, and how the data will be used. A meeting was conducted with the CCC diabetes center’s director and the study was discussed. We could not secure an IRB approval from the Chronic Care Center as the administration was not interested in the study, so no participant was directly recruited from that site.

In addition, a request to send a study invitation email to undergraduate and graduate students at the American University of Beirut, through the university’s IRB office was approved. So the emails were sent, with a brief description of the study and the contact information of the researcher to undergraduate and graduate students at the American University of Beirut (AUB). Recruitment invitations were also posted on social media platforms including Facebook, Instagram, and WhatsApp. Ninety-eight participants were approached for recruitment, eight declined to participate, which resulted in our final study sample of 90 participants. Reasons for declining to participate included being out of the country at the time of the study, being busy with exams or work, and not being interested in the study. Data collection continued until the target sample size was reached, which was over a period of five months, starting in August, 2021 and ending in December, 2021. The final distribution of the participants by

recruitment methods was as follows: 48 participants were recruited from the diabetes clinics at AUBMC, 25 via social media, and 17 by the snowballing technique. We did not receive any requests for participation from the emails sent to students at AUB.

a. Recruitment Procedure at Clinic Sites

After securing IRB and administration approvals for recruitment from the pediatric and adult diabetes clinics at AUBMC, the researcher conducted a meeting with the nurses at the clinics and discussed in details the recruitment procedure. The researcher prepared a flyer that includes the aim of the study, eligibility criteria, and her contact information (see Appendix B). The flyer was placed in the waiting areas of the diabetes clinics where it was visible to prospective participants. Due to COVID-19 related restrictions, we could not place the flyers in the physicians' and the diabetes educators' offices to be distributed to eligible participants.

Since at the time of the IRB application, IRB recommendations prohibited face-to-face contact with the participants, the following recruitment procedures were followed. In the clinic sites and during clinic hours, the physician or diabetes educator/nurse screened participants for eligibility and informed them of the study using a standard script (see script in Appendix C). The physician or diabetes educator/nurse took permission of the eligible and willing participants to share their contact information with the researcher. Then, the researcher communicated with the eligible participants and arranged for a virtual meeting either through Zoom application or through phone/ video call (according to the preference of the participant).

To ensure privacy of the participants, the researcher conducted the virtual meetings in a private room with no one present. At the beginning of the virtual

meetings, the researcher read the oral consent form to the participants and got their verbal consent (Appendix D). The researcher also sent the consent form and the survey to the participants via email or WhatsApp directly before the interview. The researcher then read the survey items together with the participants and she filled the survey as per the answers of the participants using REDCap. Participants were also invited to participate in the qualitative interviews until data saturation was reached.

Snowball sampling was also applied where the researcher asked the participants to pass the study information along with her contact information to anyone they knew who fit the inclusion criteria of the study. Those secondary participants contacted the researcher in case they decided to participate in the study, and the same data collection procedure was followed.

For the qualitative interviews, the researcher took the participants' permission to audio record the virtual meetings. The audio recordings were saved on a password-protected computer in the primary investigator's locked office at the AUB-School of Nursing.

**b. Recruitment Procedure at the University Site and Social Media**

After securing IRB and administrative approvals from the university, the investigator sent an email through the university administration to undergraduate and graduate AUB students that included an online invitation for the study with the researcher's contact information (Appendix E). The researcher also posted an online invitation to the study on her social media platforms (Facebook, Instagram, and WhatsApp platforms). The researcher arranged a virtual meeting with the participants who contacted her at a convenient time set by them for acquisition of oral consent and

survey filling. Moreover, the participants were asked if they accept to engage in a qualitative interview, and arrangements were made for those who agreed.

## **C. Data Collection**

### ***1. Quantitative Data Collection and Research Instruments***

Quantitative data were collected using a demographic tool developed by the researcher for the purpose of this study, as well as tools measuring self-care, social support, glycemic control, diabetes complications and diabetes distress. During the meeting with the participants, the researcher presented a detailed description of the study through the consent form (Appendix D). After securing the oral consent, the participant was asked the questions from the structured survey that has four sections including a demographic and clinical data section, the DCP- Social Support (DCP-SS) scale (Fitzgerald et al., 1996), the Self-Care Inventory-Revised (SCI-R) tool (Weinger et al., 2005), and the Type 1 Diabetes Distress Scale (T1-DDS) (Fisher et al., 2015) (Appendix F). The researcher answered any questions that the participants had while filling the survey. Filling the questionnaire took around 20-25 minutes. A detailed description of the selected measurement tools that were used in this study follows.

#### **a. Demographic/Socioeconomic and Clinical Data**

The demographic/socioeconomic data included characteristics such as age, gender, marital status, educational level, occupation status, crowding index, living arrangements, duration of diabetes, type of insulin treatment, presence of comorbidities, presence of medical insurance, and the number of diabetes clinic visits during the past 6 months. This section also includes a self-report on the last HbA1c level prior to the

COVID-19 pandemic, the most recent HbA1c level, and the number of DKA episodes and severe hypoglycemia events experienced during the last six months. The HbA1c levels were validated from the medical records whenever feasible. Around 41% of pre-COVID-19 and 46% of recent HbA1c levels could be verified from medical records since we did not have access to the medical record of participants who were not followed up at the AUBMC endocrinology clinics.

In addition to the above, participants were administered a battery of questionnaires that measured the variables of interest in the study. Table 1 provides a summary of the tools that were used. Following the table, the study questionnaires are described.

**Table 1***Self-Report Measurement Tools of Diabetes Distress, Diabetes Self-Care, and Social Support*

Tool	N of items & Subscales	Validity	Reliability	Scoring	Languages
<b>Diabetes Distress</b>					
Type 1 Diabetes Distress Scale (T1-DDS) (Fisher et al., 2015)	28 items, 7 subscales: powerlessness, management distress, hypoglycemia distress, negative social perceptions, eating distress, physician distress, and friends/family distress	Construct validity: 7 factor structure explaining 67.2% of variance Criterion and convergent validity: Significant correlations with: Problem Areas in Diabetes -PAID (r = .77 and .87); HbA1c (r = .17 and .26), HRQOL (r = -.46 and -.59), depressive symptoms (r = .63), fear of hypoglycemia (r = .22)	Cronbach's alpha coefficient (total scale $\alpha$ = .91, subscales $\alpha$ = .75 – .88) Test-retest Pearson correlation score: .74	Six-point Likert scale	English German Portuguese
Diabetes Distress Scale (DDS) (Polonsky et al., 2005)	17 items, 4 subscales: emotional burden, regimen distress, interpersonal distress and physician distress	Construct validity: 4 factor structure explaining 67% of variance Significant correlations with: HbA1c (r= .153 to 0.29), health-related quality of life (r = -.285 to -.52), depressive symptoms (r = .288 to .56), diabetes self-management (r = -.31)	Cronbach's alpha coefficient ( $\alpha$ = .93)	Six-point Likert scale	English Chinese Norwegian Danish Thai Portuguese Arabic
Problem Areas in Diabetes (PAID) (Welch et al., 1997)	20 items	Construct validity: Significant correlations with health-related quality of life (r = -.23), depressive symptoms (r = .56), HbA1c (r = .06), self- care (r = -.20)	Cronbach's alpha coefficient ( $\alpha$ = .93)	Five-point Likert scale	English German Chinese Turkish Norwegian Korean

Social Support					
Diabetes Care-Profile-Social Support (DCP-SS) (Fitzgerald et al., 1996)	19 items; 3 subscales: Want, Get, and Global	Construct validity: Social Provisions scale ( $r = .51$ ), Depression (CESD) scale ( $r = -.35$ ), Happiness and Satisfaction scale ( $r = .25$ )	Cronbach's alpha coefficients ( $\alpha = .69 - .93$ )	Five-point Likert scale	English Chinese Spanish Arabic
The MOS social support survey (Sherbourne & Stewart, 1991)	20 items; 4 subscales: emotional/informational, tangible, affectionate, and positive social interaction	Convergent validity: Loneliness ( $r = -.67$ ); family functioning ( $r = .53$ ); marital functioning ( $r = .56$ ), mental health ( $r = .45$ ) Structural validity: 4 factors	Cronbach's alpha coefficients ( $\alpha = .91 - .97$ )	Five-point Likert	English Chinese French Vietnamese Brazilian Arabic
The ENRICH Social Support Instrument (ESSI) (Mitchell et al., 2003)	7 items	Convergent validity: Perceived Social Support Scale (PSSS) ( $r = .62$ )	Cronbach alpha coefficient ( $\alpha = .87$ )	Five-point Likert	English German Arabic
Diabetes Self-Care					
Summary of Diabetes Self-Care Activities Revised (SDSCA) (Toobert et al., 2000)	25 items; 6 subscales: general diet, specific diet, exercise, blood-glucose testing, foot care, and smoking.	Construct validity: six factor structure explained 67.6% of the variance	Cronbach alpha coefficients: ( $\alpha = .74$ , diet) ( $\alpha = .85$ , exercise) ( $\alpha = .75$ , SMBG)	Seven-point Likert scale	English Chinese Korean Arabic Portuguese
Self-Care Inventory-Revised (SCI-R) (Weinger et al., 2005)	15 items	Concurrent validity: correlation with SDSCA ( $r = .63$ ). Construct validity: correlations with diabetes distress ( $r = -.36$ ), self-esteem ( $r = .25$ ), self-efficacy ( $r = .47$ ), depression ( $r = -.22$ ), anxiety ( $r = -.24$ ), and HbA1c ( $r = -.37$ ).	Cronbach alpha coefficient ( $\alpha = .87$ ), item-to-total correlations 0.36 to 0.67	Five-point Likert scale	Spanish Catalan Brazilian Portuguese Urdu

The Diabetes Self-Management Questionnaire (DSMQ) (Schmitt et al., 2013)	16 items; 4 subscales: Glucose Management, Dietary Control, Physical Activity, Health-Care Use	Concurrent validity: correlation with (SDSCA) ( $r = .57$ ). Construct validity: four-factor structure accounted for 61% of the variance. Confirmatory factor analysis indicated appropriate fit of the four-factor model. Convergent validity: HbA1c ( $r = -.4$ )	Cronbach alpha coefficients: (total scale $\alpha = .84$ , subscales $\alpha = .60 - .77$ )		English Thai Spanish Hungarian Urdu Arabic
Diabetes Self-Management Assessment Report Tool (D-SMART) (Peyrot et al., 2007)	49 items	-	Cronbach alpha coefficients: ( $\alpha = .65 - .80$ ) Test-retest reliability: ICC ( $\alpha = .83 - .89$ )	Five-point Likert scale	English Spanish
Diabetes Self-Care Scale (DSCS) (Lee & Fisher, 2005)	35 items	Construct validity: 3 factors structure accounted for 67.2% of the total variance	Cronbach alpha coefficients: ( $\alpha = .80 - .90$ )	Six-point Likert scale	English Turkish

*Note.* ENRICHD = Enhancing Recovery in Coronary Heart Disease; MOS = Medical Outcome Study; SMBG = Self-Monitoring of Blood Glucose

b. The Type 1 Diabetes Distress Scale (T1-DDS)

The two most commonly used diabetes distress measures include the Problem Areas in Diabetes (PAID) scale (Welch et al., 1997) and the Diabetes Distress Scale (DDS) (Polonsky et al., 2005). Both tools are widely used in T1D and T2D populations, showing good psychometric properties and generally comparable results (Schmitt et al., 2016). Later, the developers of the DDS conducted a qualitative study with 59 individuals with T1D aged  $\geq 19$  years and developed the Type 1 Diabetes Distress Scale (T1-DDS), which differs from the DDS in that it captures the sources of distress that are unique to T1D (Fisher et al., 2015). The T1-DDS tool fits our conceptual definition of diabetes distress and has similar psychometric properties to those of the PAID and DDS scales. Accordingly, the T1-DDS was used to measure diabetes-related distress in this study.

The T1-DDS (see Appendix F) is a 28-item self-report scale that includes seven factor-derived subscales that measure powerlessness (five items), management distress (four items), hypoglycemia distress (four items), negative social perceptions (four items), physician distress (four items), eating distress (three items), and family/friends distress (four items) (Fisher et al., 2015). Participants rate the degree to which each item is currently problematic for them on a six-point Likert scale (1=Not a problem, to 6=A very serious problem). The scale provides a summative score of overall diabetes-related distress with higher scores reflecting higher distress, as well as subscale scores that can help identify the specific sources of diabetes distress for adults with T1D (Fisher et al., 2015). In addition, item scores are averaged to a total score between 1 and 6, with higher values indicating greater distress. The developers reported a mean-item cut-point score of 2 or higher as reflecting clinically meaningful distress levels (moderate

distress). This cut-point score was determined by detecting significant linear associations of the T1-DDS scores with HbA1C levels (Fisher et al., 2015). Exploratory factor analysis of the original version confirmed the seven-factor structure of the tool (Fisher et al., 2015). The T1-DDS was translated and psychometrically tested in German and Portuguese (Schipfer, 2016; Silveira et al., 2017).

The original T1-DDS demonstrated good reliability with an overall Cronbach's  $\alpha$  coefficient of 0.91 and subscale scores ranging between 0.75–0.88, in addition to a 9-month test-retest reliability of a Pearson correlation coefficient of 0.74 (for the total scale) (Fisher et al., 2015). Likewise, the two translated versions of the scale showed reliability scores of the overall scale of 0.92 and 0.93, and subscale reliability scores ranging between 0.61 to 0.87 (Schipfer, 2016; Silveira et al., 2017). Moreover, test-retest reliability coefficient of the Portuguese translated version showed ICC score of 0.94 (Silveira et al., 2017).

Criterion and construct validity of the scale were demonstrated through its correlations with diabetes distress (PAID) ( $r = .77$  and  $.87$ ) (Schipfer, 2016; Silveira et al., 2017), HbA1c ( $r = .17$  and  $.26$ ), health-related quality of life ( $r = -.46$  and  $-.59$ ) (Fisher et al., 2015; Schipfer, 2016), depressive symptoms ( $r = .63$ ) (Fisher et al., 2015), and fear of hypoglycemia ( $r = .22$ ) (Fisher et al., 2015; Schipfer, 2016). There is no Arabic version of the T1-DDS.

### c. The Diabetes Care Profile - Social Support Scale (DCP-SS)

Social support in clinical populations has been measured by general and disease-specific tools. The Medical Outcomes Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991) and the ENRICHD Social Support Instrument (ESSI)

(Mitchell et al., 2003) are two widely used measures of social support with good psychometric properties. However, these tools are measures of general aspects of social support and are not disease specific. Tools that measure diabetes-specific social support include the Diabetes Social Support Questionnaire (DSSQ) (La Greca, 2002), Social Support Scale for Self-care in Middle-Aged patients with T2D (S4-MAD) (Naderimagham et al., 2012), and the Diabetes Care Profile-Social Support scale (DCP-SS) (Fitzgerald et al., 1996). The (DSSQ) and the (S4-MAD) are not suitable for this study since they target adolescents and middle-aged participants, respectively.

On the other hand, the DCP-SS is a widely used, psychometrically sound diabetes-specific measure that can be used in adult patients with T1D or T2D. The DCP consists of 14 subscales with 234 items that measure attitudes towards self-care, as well as social, and psychological factors that affect a patient's adjustment to diabetes and its treatment. The DCP includes a 19-item subscale that assesses diabetes-specific social support, with four sections. The first three sections, with six items each, represent the global social support attitude, the actual social support received (GET), and the needed social support (WANT). The fourth section includes one item that asks who provides the most support to the participant (Fitzgerald et al., 1996). The global scale asks participants to respond to items such as "my family or friends listen to me when I want to talk about my diabetes". The GET and WANT questions consist of the same items but with the difference of using the term (want) in the WANT questions and my family/friends help me... (GET). Each item of the first three sections is measured on a Likert Scale (1= Strongly Disagree, to 5= Strongly Agree). The GET and WANT scales also include a 'Does not Apply' option. Lower summative scores of the scale suggest less social support by family and friends about diabetes and its treatment. In this study,

only the GET and Global questions were included in the statistical analysis since these reflect the actual social support received and experienced by the EAs.

The internal consistency coefficient of the original Social Support scale was 0.69 in a community-based sample and 0.73 in a sample recruited from a medical center (Fitzgerald et al., 1996). The Social Support subscale continued to show good internal consistency in different studies, with reliability coefficients ranging between 0.69 and 0.93 (Fitzgerald et al., 1998; Yanover & Sacco, 2008). Construct and concurrent validity of the Social Support subscale were supported in the original study by significant correlations of the subscale with the Social Provisions scale ( $r = .51$ ), the Center of Epidemiologic Studies (CES) Depression scale ( $r = -.35$ ), and the Happiness and Satisfaction scale ( $r = .25$ ) (Fitzgerald et al., 1996).

The DCP Social Support scale was translated into several languages including Chinese and Spanish. The Chinese version showed good reliability scores for the three sections ranging between 0.61 and 0.77 (Li et al., 2015). It also demonstrated significant, albeit low correlations to HbA1c levels ( $r = -0.19$  to  $-0.26$ ), demonstrating criterion validity. Likewise, the Spanish version showed moderately good reliability coefficients of the three sections ranging between 0.54 and 0.97 (Cunningham et al., 2005). Convergent validity was demonstrated through significant correlations with the Beck Depression Inventory and the Diabetes Family Behavior Checklist (Cunningham et al., 2005).

The Social Support subscale was translated into classical Arabic and used in a study of 51 adolescents with T1D in Jordan (Al-Akour, 2003). The author reported a Cronbach's alpha coefficient of 0.65. The Arabic version was also used in a sample of 140 patients with T2D in Lebanon and showed a reliability coefficient  $\alpha = 0.88$

(Sukkarieh-Haraty & Howard, 2015). In contrast with the literature, the authors reported a significant positive correlation between social support and HbA1c levels, such that participants with higher HbA1c levels reported receiving more support from their social network. This, according to the authors, could be related to the Arab culture traits where social support increases and becomes a moral obligation as the individuals' health worsens (Sukkarieh-Haraty & Howard, 2015). The Arabic translated version of the DCP-SS was used in this study (see Appendix F).

d. The Self-Care Inventory – Revised (SCI-R)

Several tools measure self-care practices in patients with diabetes. However, some are specific to patients with T2D, while others are domain specific, such as measuring medication or diet adherence practices (see Table 4.1). Five psychometrically sound tools that measure self-care practices in patients with T1D include the Self-Care Inventory-Revised (SCI-R) (Weinger et al., 2005), the Diabetes Self-Care Scale (DSCS) (Lee & Fisher, 2005), the Diabetes Self-Management Questionnaire (DSMQ) (Schmitt et al., 2013), the Diabetes Self-management Assessment Report Tool (D-SMART) (Peyrot et al., 2007), and the Summary of Diabetes Self-Care Activities Revised (SDSCA-R) (Toobert et al., 2000). Upon careful consideration of the measurement tools, the SCI-R was selected for this study because it is a short tool with good psychometric properties and was originally developed specifically for patients with T1D. A comparison of the items of the three tools showed that the SCI-R was the most relevant to the current study since the items of the scale reflect the conceptual definition of self-care used for this study, which includes self-care practices to manage illness.

The tool was originally developed by La Greca and colleagues (1988) to assess participants' perceptions of the frequency with which children and adolescents with T1D adhere to treatment recommendations. Weinger et al. (2005) revised the SCI to reflect current diabetes practice, resulting in a global scale of self-care behaviors. The SCI-R evaluates the individuals' perceptions of how often they perform their treatment prescriptions. The scale consists of 15 items that address diet (4 items), medication (3 items), preventative/routine aspects of self-care (3 items), blood glucose testing and monitoring (2 items), hypoglycemia management (2 items), and exercise (1 item). Items are scored on a five-point Likert scale (1=Never, to 5= Always). Scores are averaged and converted to a 0- to 100-point scale, with higher scores indicating higher levels of self-care (see Appendix F).

Concurrent validity of the SCI-R was supported by a significant correlation ( $r = .63$ ) of its scores with those of the Summary of Diabetes Self-Care Activities (SDSCA). Moreover, construct and criterion validity were supported by significant correlations of the SCI-R with diabetes related emotional distress ( $r = -.36$ ), self-esteem ( $r = .25$ ), self-efficacy ( $r = .47$ ), depression ( $r = -.22$ ), anxiety ( $r = -.24$ ), and HbA1c ( $r = -.37$ ). The authors also reported discriminant validity by showing significant differences in SCI-R scores between patients with good ( $\text{HbA1c} \leq 7.0$ ) and poor ( $\text{HbA1c} \geq 9$ ) glycemic control (Weinger et al., 2005). Confirmatory factor analysis of the SCI-R showed that items loaded on one factor supporting the use of a total test score.

The SCI-R was translated into several languages including Spanish and Catalan (Jansà et al., 2013), Brazilian Portuguese (Teló et al., 2020), and Urdu (Mumtaz et al., 2016). The Spanish and the Urdu versions were tested in samples of patients with T1D, while the Brazilian Portuguese version was tested in a sample of patients with T2D.

Authors of the translated versions reported good psychometric properties of the tool, including adequate internal consistency, good concurrent and convergent validity, known-groups discriminant validity, and sensitivity to change (Jansà et al., 2013; Mumtaz et al., 2016; Teló et al., 2020). There is no Arabic version of the SCI-R.

## ***2. Pilot-test of the Questionnaire***

Since there is no Arabic version of the SCI-R and the T1-DDS scales, the scales were translated into Arabic using the back translation method, which is a well-documented process of instrument translation (Cha et al., 2007; Wild et al., 2005). The focus of the backward translation method was to examine the cross-cultural and conceptual validity of measurement tools, rather than only the linguistic/literal equivalence of the translated versions. First, forward translation was done by having the researcher and a translator, who are bilingual with Arabic as their native language, translate independently the instrument from the original version (English) to the target language (Arabic). The translation aimed at the conceptual equivalence of a word or phrase, not a word-for-word translation. The researcher and the translator considered the definition of the original term and attempted to translate it in the most relevant and clear way possible. Then, the researcher and the translator reviewed and compared the two independent forward translations and documented any discrepancies. Discrepancies and recommendations for resolutions were discussed until consensus was reached. Second, an independent bilingual professional translator, who was not familiar with the questionnaire, translated the instrument back to English. The researcher and the translator discussed the discrepancies between the back-translated and the original version, until a satisfactory Arabic version was reached.

Afterwards, a panel of experts in diabetes management and education (including one endocrinologist, one diabetes educator, one nursing faculty member, one nurse who works in adult medical surgical units, and one pediatric nurse) assessed the content validity of the translated tool by comparing the Arabic and English versions for conceptual relevance and cultural appropriateness. The experts were asked to rate the relevance and appropriateness of each item on a 4-point Likert scale (1= not relevant or appropriate at all; to 4=extremely relevant or appropriate). The item content validity index (I-CVI) was calculated by noting the proportions of experts who rated each item as 3 or 4. The overall scale content validity (S-CVI) was calculated as the proportion of items on the scale that achieve a relevance scale of 3 or 4 by all experts. A scale with excellent content validity should be composed of I-CVIs of  $\geq 0.78$  and a S-CVI of  $\geq 0.8$  (Shi et al., 2012). The experts were also asked to include any comments or recommendations for removing or modifying any of the scales' items. No changes were recommended.

*SCI-R*: For cultural relevance, the Arabic version of the SCI-R had excellent I-CVI scores (range = 0.8 – 1) and overall S-CVI score of 0.8. As for conceptual relevance, the translated scale had excellent I-CVI scores (range = 0.8 – 1) and good overall S-CVI scores of 0.73.

*T1DDS*: For cultural relevance, the Arabic version of the T1DDS had excellent I-CVI scores (range = 0.8 – 1) and overall S-CVI score of 0.89. As for conceptual relevance, the scale had a full score of 1 for both I-CVI and overall S-CVI.

The final translated versions along with the other Arabic scales and the demographic section were pilot tested with five patients who had the same characteristics as the participants in the study. These participants were recruited from

the researcher's personal contacts and the diabetes clinics and the same consent form was used before data collection. These patients were informed that the aim of the pilot study was to evaluate whether or not the questionnaire items were clear. The participants were asked whether any of the words or questions was not clear or difficult, as well as any word or expression that they found unacceptable or offensive. All participants reported that the survey items were clear and appropriate, and did not recommend any changes to be done to the piloted version. Data from the pilot study were not included in the results of the main study.

### ***3. Qualitative Data Collection***

The researcher conducted individual virtual interviews with the participants in a quiet, private, and distraction-free place. Semi-structured interviews with open-ended questions based on an interview guide were conducted and audio-recorded with only the participant and the researcher present. The researcher conducting the interview has received training in qualitative interviewing. The interviews took place following collection of the quantitative questionnaire data. Two participants requested that the interview be made at a later date, so arrangements were made to accommodate their request, and the interview was conducted within a period of three days.

The interview guide included open-ended questions incorporating key topics linked to the research aims and concepts of the transition theory, (Appendix G). This guide was used to sustain consistency of probing across the data collection process (Creswell & Poth, 2018). In seeking to understand how participants experienced living with diabetes during emerging adulthood, the interview started with a broad question on their experience living with diabetes, followed by if and how their diabetes self-care

practices changed from adolescence to the present time. Then the interview was directed into more specific topics such as what challenges they faced during this time and their views about support systems available during this period. The interview ended with a concluding question where participants were given a chance to add information that might be of significance to them and were not covered during the interview.

All the interviews were conducted by the same researcher in order to maintain uniformity in the interviewing technique. The researcher pilot tested the interview guide in a practice interview on two volunteers from the diabetes clinic to detect adequacy of content, flow and time span of the interview. The volunteers reported the adequacy of the interview guide questions and did not recommend any changes. Moreover, the guide was open for adjustment after one or two interviews with participants taking into consideration any issues that might arise during those interviews. However, no changes were needed.

Prior to the start of the interview, the researcher usually engaged the participant in a 5-minute introductory chat in order to establish rapport and help “break the ice”. All interviews were audio recorded and transcribed in a de-identified form. The researcher audio recorded the interview using the Zoom recording, or audio recorded on her phone if using a WhatsApp call. The researcher also used another backup audio recorder at the same time, in case any technical issues arose during the interview. The researcher also collected field notes during the interview that helped capture non-verbal cues such as certain behaviors and facial expressions, in addition to noting the environmental context of the interview. Field notes complement the audio recorded interviews and provide a context for the data during the analysis phase (Sutton & Austin, 2015). The field notes were stored in a secure place with the recorded data since they contained private

information about the research participants. After the interview, a “cooling down” period with the interviewee was done by asking him/her about any thoughts or feelings regarding the interview. In addition, the researcher asked for the permission of three of the participants to contact them for member checking.

#### **D. Ethical Considerations**

Prior to the conduct of the study, the research team obtained approval from the Institutional Review Board (IRB) at the American University of Beirut. The researcher also sought approval from the recruitment sites to conduct the study. All the recruitment sites and participants were provided with a copy of the consent form, which outlined the research goals and purpose, participant selection, types of data collected, collection procedures, potential risks and benefits of participation, length of the study, participant time commitment, how the data will be used, as well as the researcher’s contact information. The recruitment sites were also provided with a copy of the study questionnaire and the interview guide.

After confirming eligibility and initial participation approval, the researcher secured the participant’s consent and sent him/her the form before the scheduled interview. During the virtual meeting, the researcher read the consent form to the participants and if they agreed to participate, she took their oral consent. During that time, the researcher answered any questions or concerns the participants had regarding the study. Participants were informed through the consent form that their participation is voluntary, that they can skip answering any questions that make them uncomfortable, and that they can withdraw from the study at any time. Participants were also

guaranteed that choosing not to participate in the study will not affect the care received at the clinics.

The researcher assured the participants that their confidentiality will be maintained throughout the study and that no identifying information will be reported with the data. Participants were also notified of the risks associated with participation in this study, which in this case were no greater than minimal risk to which a person gets exposed in daily life. The main risk was the inconvenience because of the time taken for the answering the questions and engaging in the qualitative interview. There was also a possible risk of the participants finding some of the survey questions upsetting since they pertain to their diabetes. Participants received a monetary participation incentive for 60,000 Lebanese Liras. The participants who agreed to receive this monetary compensation, did so at a time and place convenient to them, and the investigator followed the recommended COVID prevention precaution measures during the delivery of the compensation money.

The research team ensured maintaining the privacy of the participants throughout the study phases and confidentiality of the collected data. During data collection, the researcher maintained privacy of the participants by choosing a private place for the interviews with minimal interruptions. In addition, names were not recorded anywhere. The researcher assigned a code number to each participant and an alias name for the participants who were interviewed for the qualitative part of the study. The code numbers and alias names were locked away in a cupboard in the office of the primary investigator at the AUB Hariri School of Nursing. Data analysis was done anonymously, as all data were de-identified and coded. As for data management, all the data were used only for the purposes specified in the study consent form. The

electronic data (study surveys and audio-recordings from the Zoom and the WhatsApp video calls) were saved on a password-protected computer in the primary investigator's locked office at the University's School of Nursing. Only the research team members had access to the study data. Transcription of the interviews was done directly after the interviews so that the audio-recordings could be promptly destroyed to protect confidentiality. All data records will be appropriately discarded after three years of completion of the study.

The research team implemented rigorous methods of data analysis and reporting in order to maintain the integrity of the data. Care was also exercised in sharing the participants' quotes so as not to allow identification of the participants. Lastly, the research team will share copies of the final report with the participants upon their request.

## **E. Data Analysis**

### ***1. Sample Size Estimation***

Sample size was calculated based on research question 3, since it requires the largest sample size. Answering this research question involves running two multiple linear regression analyses with HbA1c and Diabetes Distress as dependent variables. Acute diabetes complications (hypoglycemia and DKA episodes) were considered as a secondary outcome and so they were not included in the sample size calculations. Given the fact that we have two main outcomes, we considered a significance level of  $0.05/2 = 0.025$  in the power calculations. From previous studies that included linear regressions on those two outcomes, estimates of effect size ( $R^2$ ) were 0.24 (Law et al., 2012), 0.24 (Hendricks et al., 2013), 0.41 (Garvey et al., 2012), 0.51 (Stahl-Pehe et al., 2017), and

0.51 (Majumder et al., 2016). To be conservative, we used the smallest reported effect size (0.24). We opted to use a power of 80% instead of 90% in the study since two of the questionnaires are not yet adapted to the Arabic language, in which case a less conservative power is recommended. Therefore, for an 80% power, 0.025 significance level, 0.24 effect size and 10 predictors, the sample size needed was at least 90 subjects. Power calculation was done using GPower version 3.0.10. Considering 20% refusal rate, we decided to approach 108 patients to ensure reaching our desired sample size.

As for the qualitative component of the study, a sample of 20 participants was assumed to be needed to reach data saturation when using thematic analysis (Braun & Clarke, 2006). Data saturation is the time when no new knowledge is gained from the qualitative interviews. During the data collection period, the researcher was directly analyzing the data, and it was noted that at participant number 12, no new information or ideas surfaced during analysis. Data collection was continued with three additional participants, which confirmed data saturation. Therefore, data saturation influenced the required sample size and a decision was made by the research team to stop recruitment at that point, with a final qualitative sample size of 15 participants.

## ***2. Qualitative Data Analysis***

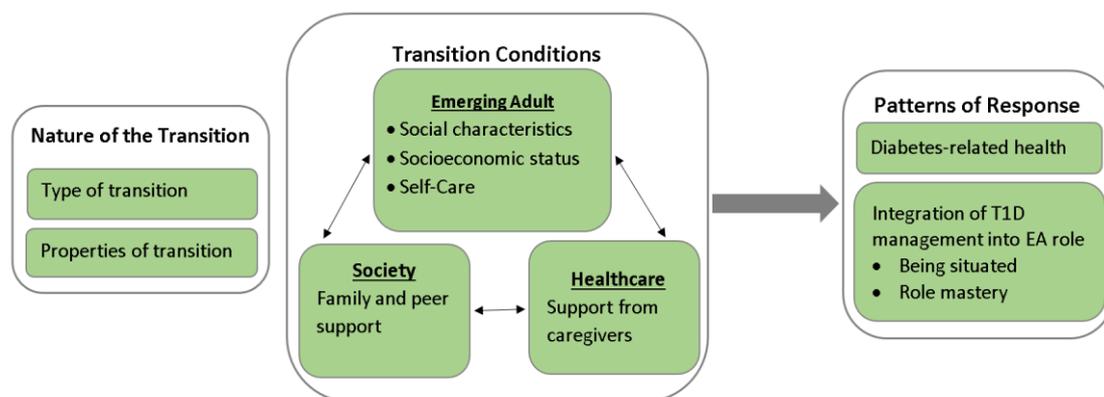
Data analysis was done by conducting a thematic analysis. Thematic analysis can be carried out using themes derived from existing theory (deductive), data (inductive), or both (hybrid). Hybrid thematic analysis facilitates the interpretation and development of identifiable themes (Braun & Clarke, 2006). By acting as an epistemological bridge between different fields, inductive and deductive thematic analysis allows for the confirmation of theories, while permitting theoretical expansion (Vaismoradi et al.,

2013). Since this study is inspired by the Transition Theory and Self-Care Theory of Chronic Illness, a hybrid thematic analysis was used. Two of the research team members: Dr. Samar Nouredine (SN), the primary investigator and a professor at the American University of Beirut-School of Nursing, with experience in conducting Mixed Methods design studies, and Ms. Amani Bayrakdar (AB), the researcher and a PhD in Nursing student, with training in conducting qualitative design research, carried out the qualitative data analysis.

To start, the researcher transcribed the recordings of the interviews verbatim. Afterwards, the researcher checked all the transcripts for accuracy by listening to the audio-records while reading the transcripts. First, the hybrid thematic analysis commenced with a deductive approach using the study's *a priori* conceptual framework derived from the Transition theory (Meleis et al., 2000) (see Figure 3). Three key concepts from the theory – nature of transition, transition conditions, and patterns of response – were initially employed as sensitizing concepts to categorize and code the data, then used to assist in the interpretative process in a more inductive way.

**Figure 3**

*Qualitative a priori Conceptual Framework Guided by the Transition Theory*



Then an inductive open coding was done to further explore the fit of the a priori coding framework and detect any additional emerging themes from the data. To ensure clarity and validity, a codebook was developed that included definitions and examples of the conceptual components to guide the analytical process (Table 2).

**Table 2**

*Coding Framework*

<b>Question</b>	<b>Code</b>	<b>Definition of Codes</b>	<b>Examples</b>
What is the experience of living with T1D?	Diabetes experience (negative – positive)	What it is like living with diabetes at this point.	Some days it [diabetes] keeps me going more because it means that I am a strong person no matter what... I would say: “you [diabetes] are making my life hard, it’s OK, because I am a strong person. You chose me because I am a strong person, so I am going to prove you right...” Other days, I feel weaker, so I let it be, I surrender to my feelings... but after that I bounce back stronger than before.
How did your diabetes self-care practices change from late adolescence until now?	Change in self-care	The changes that were noted in the way the participants cared for their diabetes from when they were adolescents.	Now, I measure my carbohydrates myself, and I take one unit for very 15 grams for example. And I don’t go out without taking juice or candy with me in case I had a hypoglycemia. And I am checking my BG levels more frequently. I didn’t use to do all that before.
Who is helping you now with your diabetes care and how? a. Probe: parents, peers, health care providers?	- Parents Role during EA - Significant other role during EA - Diabetes Peers Role (Diabuddies) - Non-diabetes Peers Role - HCP Role	The role that parents, significant others, peers with and without diabetes, and the health care professionals play at this point in the participants’ diabetes care.	I mean I still ask her [her mom] about how much insulin I should take for my meals, ... even when I am in hypo or hyper, my mom is the one who helps me the most, she rushes to get me some water and sugar and things like that...so they [her parents] are always with me in these situations, every single time. I never had a hypo or a hyper [glycemia] and they were not helping me.
What are the things that make it harder/easier for you to perform diabetes self-	Barriers to self-care Facilitators of self-care	The factors that prevent the participants from practicing adequate self-care. The factors that facilitate the	I feel like what helps are the new diabetes inventions. For example, there is this machine that tests your sugar levels and shows it to you... the Freestyle... you just put it on your hand and that’s it... you can check your sugar levels as much as you want.

care practices by yourself?		participants' practicing adequate self-care.	
How does COVID19 and the economic crisis in Lebanon affect your diabetes self-management?	COVID-19 effect Economic crisis effect	The ways that COVID-19 and the economic crisis affected diabetes self-care.	During COVID we stayed at home and I started eating like crazy, always ordering fast food and always eating unhealthy foods... COVID really affected this aspect.
How do you think your diabetes affects your life?	Effect on academic/ work life Effect on family/ social life	The ways that having diabetes affected aspects of the participants' academic, work, family, and social lives.	It [social life] boomed... I'm everything I am because of my diabetes. All the people that I know, all the things that I do... I am grateful for my diabetes because I wouldn't be Me without my diabetes...
If you could change anything about your relationships with your parents, peers, and healthcare team, what would you change?	Change Parents Change HCP Change society/ peers Effect of society	- The wishes for changes in the relationships between the participants and their parents, peers, and HCP - The demands the participants have from their parents, peers, and HCP	I think there is a kind of stigma in our society to a certain extent that people would say: "Ohh, he's diabetic, he's not going to enjoy his life or he's going to suffer a bit"... that kind of 'old regressed mentality' if you say. I wish they would change that because it's not really true ...

*Note.* HCP = Health Care Provider

The second step included testing of the coding framework to determine applicability of the codes to the raw data. This was done by two coders using the framework to independently code two interview transcripts. Results of the coding were compared and few minor modifications were done to the framework. This process allowed triangulation of analysis, which is considered an agreement on interpretations between researchers (Creswell & Poth, 2018).

The data was hand-coded, which refers to the process of searching and identifying concepts by hand and not by a computer software. This approach facilitated a deeper

immersion in the data. The six phases of thematic analysis by Braun and Clarke (2006) were followed. First, the coder read the data corpus (all available transcripts) in order to familiarize herself with the data, while noting down initial concepts and phrases that are considered interesting or significant. Second, the initial codes included in the conceptual framework (see Figure 3) were validated by coding similar aspects of the data across the data set, and organizing them in relation to each code. Open coding was done during this phase with constant comparisons within and across the three conceptual categories (nature of transition, transition conditions and patterns of response) as shown in Figure 3, in order to identify new codes that may arise inductively from the data. This iterative process was repeated in order to refine the coding framework and achieve greater clarity during the on-going data analysis. Third, subthemes were developed from the codes, and all the data relevant to each theme were grouped together. Fourth, the themes were revised and the final thematic “map” was generated, by checking if the themes of the a priori framework and the added themes from the data were compatible with the coded extracts and the entire data set.

The process was repeated for the interviews with constant comparison. Data saturation was determined when there was no additional information in terms of the concepts for the codebook and no new information was found that added to the understanding of the categories or themes. Next, the coder defined and named the themes and subthemes that emerged from the codes, in addition to the a priori framework. The final themes were then identified and excerpts from the data were extracted to provide evidence of the existence of each theme. The final analysis included the careful selection of the statements that were presented for every theme and their analysis. The PI and the researcher conducted periodic meetings to closely monitor

all the previous phases of the coding process. This included an iterative process of referring back to the data, codes, and themes.

During data analysis, caution was exercised for the possibility that some portions of raw data might not fit within the suggested transition conceptual framework. Data to support alternative justifications were sought to explain the exception patterns. A limitation that can be associated with using a hybrid thematic analysis method is the possibility of selectively omitting important themes that emerge from the data but do not fit the a priori theoretical framework of the study (Javadi & Zarea, 2016). However, the researcher's personal inferences and preconceptions related to the theoretical background and the aim of the study were acknowledged and did not affect the interpretation of the data. This was accounted for through the practice of reflexivity that took place throughout the study process.

It is important to note that the data analysis was done on the data that was transcribed verbatim in Arabic language. At the end of the analysis and for the sake of reporting and publication of the findings, only the data excerpts that were used to explain the themes were translated into the English language. The researcher and a bilingual translator back translated the selected excerpts to provide trustworthiness of the translated data.

a. Reflexivity

Reflexivity is essential throughout the stages of the study to identify possible threats to the "truth value" that are influenced by the researcher's own viewpoints or biases. Addressing the issue of reflexivity is a vital step that all researchers need to

tackle in a comprehensive and rigorous manner while conducting qualitative research (Rae & Green, 2016).

Thus, the two research team members (SN) and (AB), addressed reflexivity of the researcher (AB) prior to and throughout the whole research process by performing periodic critical reflection of her position and values with regards to the research, by explicitly acknowledging personal biases, values, and judgements in a diary that was discussed in the course of the study. There were no prior major biases identified since the researcher was not directly involved in providing care to the study participants or other EAs with T1D. The only bias was the researcher's prior knowledge of the studied phenomenon from empirical and theoretical work and from her previous clinical experience, so the researcher reflected on her preconceptions during the data collection and analysis stages. AB maintained an open-mind attitude during these phases by recognizing the context and environment of the study, and not disregarding any information that did not fit into previous findings or theoretical frameworks. These assumptions and preconceptions were shared with the researcher's advisor, and recognized in relation to their possible impact on the data analysis. The use of continuous self-evaluation and self-analysis during the stages of the study maintained the credibility of the study findings.

b. Rigor

The interpretive and subjective nature of qualitative research makes it crucial that researchers establish rigor and trustworthiness of its findings. Validity and reliability of qualitative studies can be achieved by demonstrating high levels of rigor throughout the research process (Denzin & Lincoln, 2018). First, the researcher provided a clear

description of the epistemological stance underpinning the study and justification of the methods used to answer the research question (Research Question 1). Second, she established data trustworthiness, namely credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Credibility establishes whether the research findings represent true information drawn from the participants (Lincoln & Guba, 1985). The researcher attempted to ensure credibility by providing a step-by-step description of the data analysis process, as described in the previous section, to portray transparency in the development of the final themes, which were validated by actual quotations from the raw data. Other strategies used to ensure the credibility of this study included triangulation and member checking (Lincoln & Guba, 1985). Triangulation is a way of achieving coding reliability by analyzing data from multiple perspectives, which in this study included the input of another coder who was impartial to the data. The two coders, (AB) and (SN), independently applied the codebook to analyze the same two transcripts and came up with the codes from the data. The two coders then compared and discussed the findings, and inter-rater-reliability was calculated and was > 80% for both transcripts. This procedure ensured credibility of data and validated the impartiality of the analysis. Moreover, the researcher further confirmed the rigor of the results by seeking concordance of the findings with the literature and with the theories that are guiding the study (Denzin & Lincoln, 2018). This confirmation acted as triangulation of the results through a cross verification of the findings from two or more sources (Carter et al., 2014).

Member checking, also known as respondent validation, was also performed to demonstrate the credibility of the findings (Denzin & Lincoln, 2018). Three participants

were asked to read the analysis of their data in order to check the authenticity of the findings and to evaluate whether the researcher adequately captured their perceptions of the phenomenon or experience. All three participants communicated their approval of the analysis and stated that the description accurately reflected their perspective on the issue discussed; they did not suggest any changes to be done. Their feedback served as a check of the credibility of the interpretation.

Dependability is establishing that the study findings are consistent and repeatable and can be attained by producing enough descriptive data regarding a phenomenon (Lincoln & Guba, 1985). This was achieved by having a researcher who is well-trained in qualitative interviewing conduct the interviews, thus ensuring the collection of good quality and rich data. In addition, the researcher attempted to ensure transferability, which is the ability to transfer the study findings to other situations or contexts; this was attempted by employing a purposive sample with maximum variation in age and gender, which allowed for an inclusive viewpoint of the phenomenon, supporting the transferability of findings to other contexts.

Confirmability of data collection and analysis is the consistency and predictability of the study findings through their replication by other researchers. Confirmability ensures that the findings are a reflection of the participants' viewpoints, rather than the researcher's biases (Lincoln & Guba, 1985). To verify confirmability, the researcher documented an audit trail of the decision process that took place throughout the stages of the study. The audit trail demonstrated that the analysis followed a logical path, and confirmed that the findings of the study are based on the participants' responses rather than the researcher's own preconceptions and views (Creswell & Poth, 2018).

### *3. Quantitative Data Analysis*

The quantitative data were prepared and managed for missing data because missing data decrease the accuracy of measuring the desired variables, thus reducing the power of the study (Pedersen et al., 2017). During the virtual meetings, the researcher read the survey questions to the participants and filled the survey according to their answers. This process considerably reduced the occurrence of missing quantitative data. The collected data was then coded and cleaned by checking for inaccuracies in data entry and missing values. Management of missing data was planned for missing data values of  $> 5\%$  (Schafer, 1999).

Frequencies were run for all variables to detect the percentage of missing data. No variables had a missing data of  $> 5\%$ , so missing data management was not performed. The low percentage of missing data was a result of the data collection procedure that included zoom or video call. This procedure ensured that all items of the study survey were properly filled.

#### c. Statistical Analysis

Quantitative data was entered and analyzed using Statistical Product and Service Solutions (SPSS) version 26. Statistical significance was set at a two-tailed p value of  $< 0.05$ . To answer the research questions, several statistical phases were conducted.

First, preliminary psychometric testing was performed for the three scales used in this study (DCP-Social Support scale, SCI-R, and T1-DDS). Cronbach's alpha coefficient was calculated to assess the internal consistency reliability of the scales. In addition, construct validity of the questionnaires was tested by measuring correlations

of the scores with relevant variables. No factor analysis was attempted because of the limited sample size.

Second, descriptive statistics were used to summarize the demographic and clinical characteristics of the participants. The Shapiro-Wilk test along with visual inspections of histograms and Q-Q plots were used to assess the normality of distribution of the continuous variables. In case of normality, means and standard deviations (SD) were presented for continuous variables such as age, number of years with diabetes, scale scores, etc... Otherwise, medians and inter-quartile ranges (IQR) were used to describe continuous non-normally distributed variables. Counts and percentages were used for categorical variables such as gender, level of education, socioeconomic status, etc...

Third, statistical tests were performed to answer the research questions of the quantitative section of the study as described below.

*Research Question 2:* Descriptive statistics were used to describe the diabetes-related health outcome variables (HbA1c, acute diabetes complications, Diabetes Distress) of the EAs. Diabetes distress scores were presented in two ways: 1) the mean and SD of the T1DDS scale summative score, and 2) an item-average cutoff scores indicating levels of distress (1.0 – 1.4 = little or no distress, 1.5 – 1.9 = mild distress, 2.0 – 2.9 = moderate distress, and  $\geq 3.0$  = high distress). Measuring acute diabetes complications included identifying the incidence and frequency of DKA or severe hypoglycemia during the past six months. For analysis purposes, acute diabetes complications were considered a categorical variable defined as participants either experiencing at least one acute diabetes complication during the last 6 months or not.

*Research question 3:* First, bivariate analyses were conducted to test associations between the independent variables (demographic/sociodemographic and clinical variables) and the outcome variables (HbA1c, Diabetes Distress, and acute diabetes complications). For continuous variables (HbA1c, diabetes distress, and self-care) we used parametric tests including independent sample t tests, Pearson r correlation coefficient, and ANOVA, or non-parametric tests such as Mann Whitney, Spearman Rho coefficient, and Kruskal Wallis depending on types and normality of the variables. For the categorical outcome (acute diabetes complications), we used chi-square and simple logistic regressions analysis depending on types of the variables.

Second, two multivariable regression analyses were run to determine the predictors of HbA1c and Diabetes Distress. All variables with a p value  $\leq 0.2$  at the bivariate level were entered into the multivariable linear regression model in order to allow for the inclusion of possible confounding variables. Variables were entered into the model in a simultaneous manner. Assumptions of running multivariable regression models were checked. This includes showing independence of observations, linear relationships, homoscedasticity, multicollinearity, checking for outliers and the normal distribution of residuals. The model fit, significance of the model, as well as that of each predictor were determined and reported.

Moreover, a secondary exploratory analysis of the secondary outcome (acute diabetes complications) was done by running a logistic regression analysis to determine the predictors of this outcome, based on the results of the bivariate analyses.

*Research question 4:* In order to test the mediation effect of self-care on the association between the demographic and clinical variables, and diabetes-related health outcomes, we used Hayes' simple mediation model (model 4) in the PROCESS macro

for SPSS (Hayes, 2018), for each of the two dependent variables (HbA1c and DD). The predictor variables that were significantly associated with both self-care and the outcome variable at the bivariate level of analysis were included in the moderation analysis.

*Research question 5:* In order to test if a moderation effect of social support on the association between self-care and diabetes-related health outcomes existed, we had to show that the nature of this relationship changed as the values of social support changed. The moderation analysis was conducted using PROCESS macro model number 1 for simple moderation analysis (Hayes, 2018). The significance of the model and interaction term were checked and reported.

*Moderated Mediation Analysis.* The study framework suggests the social support will moderate the mediating effect of self-care. To test this relation, we ran a moderated mediation analysis using PROCESS macro Model 14 (Hayes, 2015). This analysis allowed us to detect the changes in the indirect effect of predictor variables on the outcome variables via self-care, according to the levels of social support. We used 5000 bootstrap samples and a confidence interval of 95% to detect significance levels.

## **F. Data Integration and Presentation**

Concurrent mixed methods designs involve simultaneous quantitative and qualitative data collection and analysis, followed by an integrated interpretation of the findings. During the interpretation stage, data integration occurs through three approaches: integration through narrative, integration through data transformation, and integration through joint display (Fetters et al., 2013). The first 'integration through narrative' approach involves reporting separate discussions of qualitative and

quantitative results. The second ‘integration through data transformation’ includes the transformation of either qualitative data into quantitative data or vice versa, followed by the interpretation of the data as a whole. During the third ‘integration through joint display’, the data is presented in a visual display, such as a table, figure, or a matrix form. This display brings the data together to draw out new insights and generate new inferences beyond the information gained from the separate quantitative and qualitative results (Guetterman et al., 2015).

In this study, we used two approaches of data interpretation and reporting. First, qualitative and quantitative results were reported through the “narrative approach”, where both quantitative and qualitative results were separately presented and interpreted (Fetters et al., 2013). Then, the data was presented in a “themes-by-statistics” type of joint display, which is the most commonly used type in concurrent designs (Guetterman et al., 2015). “Themes-by-statistics” joint displays include organizing a side-by-side presentation of qualitative data (themes or quotes) and quantitative data (scores of measurement scales). This type of display can help the researchers provide a comprehensive understanding of the study findings by explaining the convergence or divergence of the quantitative and qualitative data.

## CHAPTER IV

### RESULTS

The purpose of this study was to describe the experience of EAs living with T1D in Lebanon. It also aimed to describe the diabetes-related health outcomes of these individuals, as well as what predicts and affects these outcomes. For the sake of this study, the T1DDS and SCI-R tools were translated into Arabic using the back-translation method, and the whole study survey was piloted with five participants. The qualitative interview guide was also piloted with two participants. Results are presented according to the specific aims, starting with the qualitative results, then the quantitative results, after which the integrated findings are presented. The section below shows the characteristics of the sample. A total of 98 EAs with T1D were recruited, with 90 accepting to participate in the study, for a 91.84% response rate.

#### A. Sample Characteristics

##### *1. Sociodemographic Characteristics of the Study Participants*

Demographic data of the sample are presented in Table 3.

**Table 3**

*Descriptive Statistics of Demographic Characteristics*

<b>Characteristics</b>	<b>N</b>	<b>%</b>
Age, Mdn (IQR)	21 (19–25)	
Age by Category		
18-24 years	65	72.2
25-29 years	25	27.8
Gender		
Male	35	39
Female	55	61

Social status		
Single	80	88.9
Married / Engaged	10	11.1
Living With		
Family / Spouse	85	94.4
Alone / Friends	5	5.6
LOE		
High school level or less	5	5.6
University (current/ graduate)	85	94.4
LOE, Head of Household		
High school diploma or less	46	51.1
University graduate	44	48.9
Employment Status		
Unemployed	11	12.2
Student	46	51.1
Part-time job	7	7.8
Full-time job	28	31.1
Has health Coverage	78	86.7
Health Coverage Type		
No diabetes coverage	16	17.8
Hospital admissions	62	68.9
Lab tests	61	67.8
Insulin	49	54.4
Test strips	37	41.1
Glucose Sensors	11	12.2
Insulin Pump and Supplies	6	6.7
Smoking Status		
Non-smoker	61	67.8
Cigarette	17	18.9
Hubble-bubble	12	13.3
Consumes Alcohol	18	20.0
Crowding Index, Mdn (IQR)	1 (0.75–1)	

*Note.*  $N = 90$ . LOE = level of education. Categorical variables are presented by numbers and percentages, non-normally distributed continuous variables are presented by median and IQR.

As shown in Table 3, the participants had a median age of 21 (IQR, 19–25) years, with 72.2% between 18 and 24 years old, and 27.8% between 25 and 29 years old. The majority were females (61%) and single (88.9%), with 5.6% reporting having children.

The majority were enrolled at university at the time of data collection or were university graduates (94.4%), and were living with their parents or spouses (94.4%). Regarding employment status, over half of the respondents (51.1%) were still studying, 12.2% were unemployed, and the remainder were working either part-time (7.8%) or full-time (31.1%) jobs. Health coverage was mostly for hospital admissions (68.9%), lab tests (67.8%), and insulin (54.4%). Only few had coverage for test strips (41.1%), glucose sensors (12.2%), or insulin pump and supplies (6.7%), while nearly one-fifth of respondents (17.8%) had no coverage for any diabetes-related care. One fifth (20%) of participants reported drinking alcohol, and more than one-third reported current smoking (32.2%), of which 18.9% smoked cigarettes and 13.3% used hubble-bubble. The study sample had a high crowding index of 1 (IQR, 0.75–1), and almost half (48.9%) of the head of households had university education.

## 2. *Clinical Characteristics of the Study Participants*

The clinical characteristics of the study participants are presented in Table 4.

**Table 4**

### *Descriptive Statistics of Clinical Characteristics*

<b>Clinical Characteristics</b>	<b>N</b>	<b>%</b>
Treatment site		
Adult diabetes clinic	51	56.7
Chronic Care Center	26	28.9
Pediatric Diabetes Clinic	18	20.0
Family medicine clinic	2	2.2
Follow-up with same physician since age 17	42	46.7
Two or more clinic visits during last year	65	72.2
Insulin Treatment Type		
Lantus/ Levemir/ Toujeo/ Tresiba + SAI	75	83.3

Insulin Pump Therapy	12	13.3
NPH + SAI	3	3.3
Glucose Monitoring Type		
Glucometer	57	63.3
Freestyle Libre	31	34.4
Continuous glucose monitor (CGM)	2	2.2
Has Glucagon Kit	44	48.9
Has chronic Diseases	9	10.0
Medical check-ups over the last two years		
Kidney test	77	85.6
Blood test for lipids/cholesterol	72	80.0
Blood pressure check	67	74.4
Eye exam	66	73.3
Foot exam	20	22.2
Received Diabetes Management Education	59	65.6
Diabetes Management Knowledge, Mdn (IQR)	4 (3–4)	
Fair	11	12.2
Good	28	31.3
Very Good	32	35.6
Excellent	19	21.1
Age at diagnosis in years, Mdn (IQR)	12 (9–16)	
Diabetes duration in years, $M \pm SD$	10.3 $\pm$ 4.6	

*Note.*  $N = 90$ . SAI = short acting insulin. Continuous variables are presented by mean and standard deviation ( $M \pm SD$ ) or median and intra-quartile range [Mdn (IQR)] if the distribution is not normal.

Half of the participants were diagnosed with T1D at the age of 12 years (range 9-16 years), and had a mean diabetes duration of  $10.3 \pm 4.6$  years. More than half of the participants (56.7%) were followed-up at an adult diabetes clinic, 20% still followed-up at a pediatric diabetes clinic, 28.9% were followed at the Chronic Care Center, and 2.2% followed-up at a family medicine clinic. Nearly more than half of the participants (46.7%) reported following-up with same physician since the age of 17 years. Regarding clinic attendance, 72.2% reported attending at least two clinic visits with their care provider during the past year.

Insulin treatment therapy was mostly received through multiple daily insulin injections (long-acting with short-acting insulin combination) (83.3%), with 13.3% using insulin pump therapy, and only 3.3% used an intermediate-acting (NPH) and short acting insulin (SAI) combination. Around two thirds used a glucose meter to test their home blood glucose levels (63.3%), one third used a “Freestyle Libre”, which is a type of continuous glucose monitoring device (34.4%), and only 2.2% used continuous glucose monitoring that usually complements the insulin pump.

The most frequently performed medical check-ups over the last two years were kidney tests (85.6%), followed by blood lipid tests (80%), blood pressure assessments (74.4%), and eye exams (73.3%), and the least frequent check-up was foot exam (22.2%). Other health issues were identified, with only 10% of participants reported having another chronic disease such as eye problems (3.3%), high blood lipids (2.2%), and others (5.6%) including hypothyroidism, hyperthyroidism, Grave’s disease, and Hashimoto’s disease.

Around two-thirds of participants (65.6%) reported receiving formal diabetes management education from a health care provider. When participants were asked to rate their own knowledge in managing diabetes, over half reported “excellent” or “very good” knowledge (21.1% and 35.6% respectively). Around one-third (31.3%) identified their knowledge as “good”, while only 12.2% considered it to be “fair”.

## **B. Qualitative Findings: The Experience of EAs Living with T1D**

As participants were recruited to the study, they were informed of the qualitative component and invited to a semi-structured interview. Twenty-one participants agreed to sit for the interviews, and the interviews were scheduled at a time convenient to them

through Zoom or WhatsApp calls. Choosing the participants for the interviews aimed at maximum variation sampling in terms of age and gender. Analysis was done as soon as possible following each interview. By the 12<sup>th</sup> interview, no new data was emerging, so three more interviews were made to verify data saturation, which resulted in a total of 15 qualitative interviews. Calls were made to the six participants who did not get the chance to be interviewed explaining the conclusion of the data collection phase. Table 5 presents the demographic and clinical characteristics of each participant.

**Table 5***Characteristics of the Qualitative Study Participants*

Participant	Gender	Age	Diabetes Duration in years	Treatment Site	Insulin Treatment Type	Diabetes Education	Diabetes Knowledge	Social Support Score	Self-Care Score	ADC	HbA1c	Diabetes Distress Score
Kamal	M	21	9	CCC	MDI	Yes	Very good	48	73.3	Yes	6.3	103
Faten	F	19	8	PDC	MDI	Yes	Very good	48	73.3	No	8	63
Rami	M	20	15	CCC	MDI	Yes	Good	44	66.7	Yes	6.4	82
Maya	F	19	17	ADC	MDI	Yes	Very good	60	48.3	Yes	8.6	90
Tarek	M	20	18	CCC	MDI	Yes	Excellent	40	56.7	No	11	84
Hadi	M	21	12	ADC	MDI	No	Very good	51	51.7	No	13.1	53
Sally	F	18	1	ADC	MDI	No	Good	48	63.3	Yes	7.5	83
Rola	F	19	9	CCC	MDI	Yes	Very good	46	66.7	No	5.7	49
Sara	F	25	19	CCC	MDI	Yes	Excellent	38	88.3	No	7.5	44
Layla	F	29	14	ADC	Pump	Yes	Excellent	57	70	No	9.8	80
George	M	21	15.5	ADC	MDI	Yes	Excellent	59	26.7	Yes	7.2	59
Rania	F	25	11	CCC	MDI	No	Fair	54	48.3	No	8.1	112
Mira	F	26	11	ADC	MDI	Yes	Excellent	48	63.3	Yes	7	42
Yasmeen	F	21	5	CCC	Pump	Yes	Good	56	71.7	Yes	6.2	37
Maria	F	22	15	CCC	MDI	Yes	Very good	52	38.3	Yes	6.5	86

*Note.* Pseudonyms are used instead of the participants' real names. M = male, F = female, CCC = chronic care center, PDC= pediatric diabetes clinic,

ADC = adult diabetes clinic, MDI = multiple daily injections, ADC = acute diabetes complications

The qualitative sample was reflective of the overall study sample in terms of sociodemographic and clinical characteristics. The sample included 10 females and 5 males, with ages ranging between 18 to 29 years ( $M = 21.7 \pm 3.1$ ). Participants reported age at diabetes diagnosis ranging between 2 to 17 years ( $M = 9.8 \pm 5.0$ ), with diabetes duration ranging between 1 to 18 years ( $M = 12.0 \pm 5.0$ ). Nine participants were students, and six were employed. Eight of the participants were followed-up at the Chronic Care Center, six were followed-up at an adult diabetes clinic, and only one still attended a pediatric diabetes clinic. The majority were on multiple daily insulin injection therapy ( $n=13$ ), and only two were on insulin pump therapy. Thirteen participants reported receiving formal diabetes education, and five participants rated their diabetes management knowledge as “excellent”, six participants as “very good”, three participants as “good”, and one participant considered it to be “fair”. Diabetes clinical characteristic of the qualitative sample were comparable to the overall study sample, with a mean HbA1c level of  $7.9 \pm 2.0$ , social support score of  $49.9 \pm 6.5$ , self-care score of  $60.4 \pm 15.7$ , 80 % reported experiencing at least moderate diabetes distress levels, and almost half ( $n = 8$ ) reported having experienced at least one acute diabetes complication during the last six months.

### ***1. The Thematic Map***

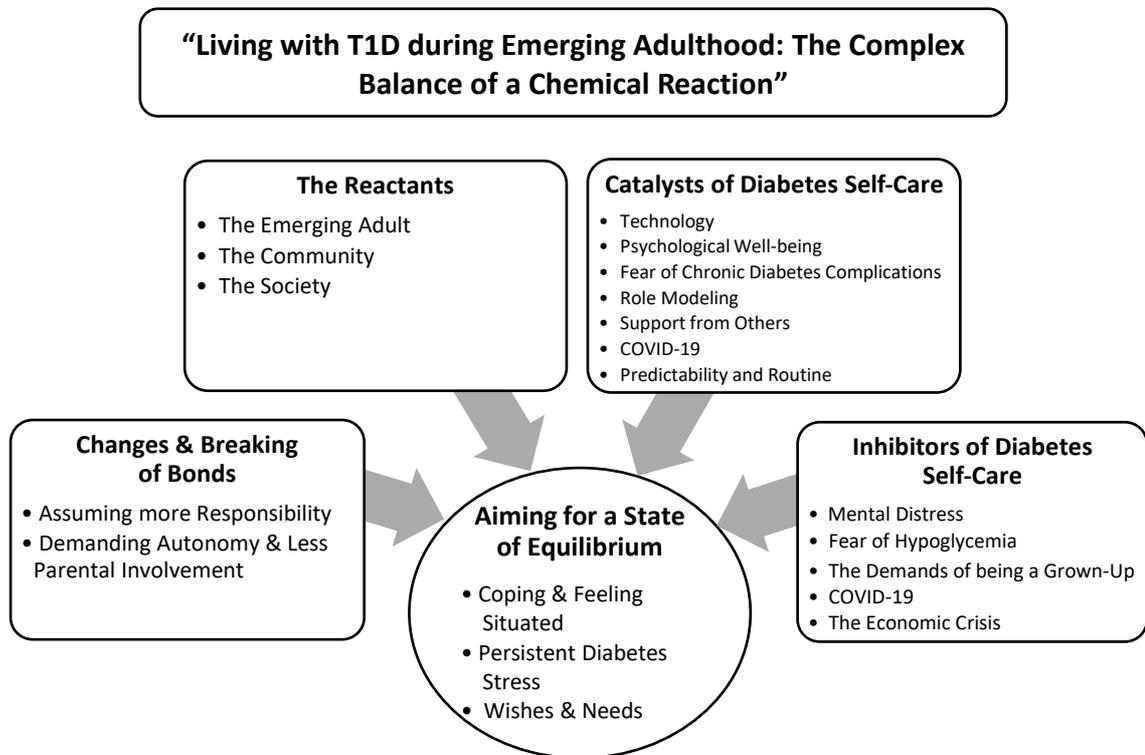
The iterative process of data analysis yielded a final “thematic map” of five themes and 20 subthemes that were best represented by the overarching theme, “Living with T1D during emerging adulthood: the complex balance of a chemical reaction”. The experience of EAs with T1D is akin to a chemical reaction, where they go through change and breaking of bonds by demanding autonomy from their parents. There is also

the involvement of different reactants with the EAs, like their community and society, with the influence of facilitators (like catalysts) and barriers (like inhibitors) to their self-care practices. Finally, the EAs attempt to reach a state of equilibrium by feeling situated and coping with diabetes, and voicing their wishes and needs from their environment.

Hence, the final five themes that were articulated in the thematic map included, “Breaking of Bonds: Changes and Taking Ownership of their Diabetes”, “The Reactants: Factors Affecting the Diabetes Experience”, “The Catalysts: Facilitators of Diabetes Self-Care”, “The Inhibitors: Barriers to Diabetes Self-Care”, and “Aiming for Equilibrium”. The EAs realized their changing role and started interacting differently with their surroundings. Although they experienced setbacks and worries, they relied on their available resources, to eventually allow them to reach their equilibrium. Figure 4 represents the thematic map with the themes and subthemes developed from the data.

**Figure 4**

*Thematic Map of the Experience of EAs Living with T1D in Lebanon*



## **2. *Breaking of Bonds: Changes and Taking Ownership of their Diabetes***

Similar to the breaking of bonds between the atoms of a substance going through a chemical reaction, the EAs reported going through changes and breaking of bonds. All participants experienced cognitive and attitudinal changes that encompassed breaking the diabetes-related ties from their parents, and were looking forward to take ownership of their disease. Two subthemes were generated that described the participants’ breaking of bonds. These subthemes included *assuming more responsibility* and *demanding autonomy and less parental involvement*.

### **a. Assuming more Responsibility**

This subtheme reflects a conscious and spontaneous shift in diabetes-related responsibilities from the parents to the EAs. Participants felt a change in their thought

process and sensed the need to take responsibility for their health. This shift was evident during the interviews when participants explained when and how this shift happened.

Now that I have grown up..., I'm a grown-up so they [his parents] have "given me the reins" as you say. I took this control and I took this ownership of having to deal with everything on my own (*George, 21 years*).

When someone gets older, their mentality changes, everything changes... when I got older, I understood the importance of taking care of my diabetes for the long-run, especially taking care of my HbA1c levels and eating healthy, it is for my own sake... (*Maria, 22 years*).

Moreover, in contrast to their experiences as teenagers with diabetes, the EAs felt a substantial desire to care for their diabetes because they "wanted to", as opposed to being "told to" by their parents, as illustrated in the below excerpts.

During adolescence, I didn't really care if I tested my blood sugar or not because I knew that my parents will tell me "check your blood sugar" or "take this many units [of insulin]". But now... now I want to do it...this responsibility is all mine now. This is the major thing that changed [from adolescence], I have more responsibility now (*Rami, 20 years*).

When you are a teenager, you are reckless about diabetes. You would say: "you only live once" so you become reckless... But when you become an adult, you start looking at the outcomes of the actions you did during your teenage years. You would see how harmful your actions were, so you start adjusting everything... what you eat, your insulin intake, your blood sugar testing, your HbA1c... (*Tarek, 20 years*).

#### b. Demanding Autonomy and Less Parental Involvement

It was evident that during this period, the EAs demanded autonomy from their parents' constant involvement in their daily diabetes routines, and shied away from parental supervision.

They [her parents] do not have any role towards me anymore... I mean, I reached an age where I am responsible for this thing [diabetes care]. This was by my request, not theirs... (*Faten, 19 years*).

I mean to protect myself from their [her parents] reaction, you know I'll be in a state I am not ready to listen to them scolding me about diabetes... I mean if I had a hypo [hypoglycemia] or two or three during the day, I will manage it and I will control it... but my mother, for example, gets scared and stuff... that's why I decided to keep my diabetes situation in my control... I'm controlling it (*Maya, 19 years*).

In addition to the participants' demands for autonomy, the changing lifestyle during this period, such as starting college or a new job, led to a compulsory decrease in direct parental involvement in their children's activities and decisions.

Now they [his parents] don't take care of me, not because they don't want to, but because they don't know what's happening with me... unless it happens when they are around (*George, 21 years*).

Anyway, I am not around my parents all day... I only see them at night, so they don't have time... And we don't have as much communication between us as we used to have... yeah... If I want to take care of myself, I just do... They don't have time to take care of me because I am not around, they don't see me all day (*Faten, 19 years*).

### **3. *The Reactants: Factors Affecting the Diabetes Experience***

This theme recognizes the three major reactants or factors that interact together in affecting the emerging adult's experience of living with diabetes. In line with the theoretical *a priori* framework, these subthemes included the *Emerging Adult*, the *Community*, and the *Society*.

#### **a. The Emerging Adult**

Developmental transformations during emerging adulthood underpinned some changes in the personal characteristics of the individual with T1D. Part of becoming an adult meant assuming responsibility for managing their diabetes and health. The main two characteristics that were noted in our sample included *changes in self-care* and *increased knowledge of diabetes management*.

##### **i. Changes in Self-Care**

The reported assumption of more responsibility and autonomy at the cognitive level in managing their life translated into changes in their diabetes self-care practices

that was evident among almost all of the participants. The majority experienced improvements in self-care practices and in managing acute diabetes complications.

Now I calculate my carbohydrates, for example, I take one unit [of insulin] for every 15 grams. I'm better at this now. Also, for example, I always have with me juice or candy when I go out in case I had a low blood sugar.... I didn't use to do that before... I'm also testing my blood sugar more than before... (*Karim, 21 years*).

This thing [diabetes self-care] changed a lot between my teenage years and now... Now, I am controlling it mainly... I mean now I am dealing with the hypers [hyperglycemia] and hypos [hypoglycemia], and I am adjusting my insulin doses and all of that... (*Maya, 19 years*).

The improvement in self-care was coupled with an emphasis on autonomy in performing these practices. Through sound decision-making, the EAs were able to prove their ability to manage their diabetes with minimal or no help from their parents.

Now, after I turned 18, I felt the need to take care of everything... I started testing my blood sugar, take my insulin shot according to my meal needs and my blood sugar test. I became responsible for everything related to my diabetes. Also, now, I go to my clinic appointments by myself. I do everything by myself... (*Rami, 20 years*).

Diabetes management is my job alone. No one else has a role in how I manage my diabetes or how I care for my diabetes. My parents used to have a role in meal planning, not anymore. Now I do the meal planning (*Layla, 29 years*).

Contrariwise, one of the participants reported experiencing worsening of self-care practices and the emergence of reckless behavior related to diabetes that was not present during his adolescent years. He accredited this change to the decreased parental involvement in diabetes-related management during emerging adulthood.

Now that I'm basically like my "own man" as they say, I started becoming more reckless. I started going out more with my friends... To be honest, I feel like I am going backwards... OK, so I don't test [his blood sugar], I take insulin randomly... so even if I my blood sugar is 50 or 100, sometimes I take up to 30 units of Humalog. I mean this is recklessness without testing. I had multiple incidences like that and had severe hypoglycemia events (*George, 21 years*).

ii. Increased Knowledge of Diabetes Management

The development of diabetes self-care skills involves a process of learning about the characteristics of the disease and its management. During emerging adulthood, the need for autonomy acted as a drive for the individuals to seek new information in order to increase their knowledge about how to manage diabetes and develop appropriate coping strategies, as reflected in the below excerpts.

Around 3 to 4 years ago... I started to read more about diabetes. I started to read about different insulin types, impact of food, glycemic index, protein, carbs, all those things... So I started to have a better understanding of how food impacts my glucose (*Sara, 25 years*).

I started to read more and I started to understand more how food affects my glucose, to a point where I even requested from my doctor to change my insulin type. I used to be on a pre-mixed insulin, now I am on a basal bolus insulin (*Hadi, 21 years*).

It is worth mentioning that few participants would sometimes seek diabetes information from the internet and social media instead of turning to the health care professionals.

I used to go to the clinic at (--) and they were awesome, but it was just... I mean I tried to dig more for information. So I googled and I started reading articles and stuff... Then I said to myself, maybe there is like an influencer for type 1 diabetes on Instagram, or I can find more information on social media (*Maya, 19 years*).

#### b. The Community

The community factor was reflected through the support that EAs received from their parents, family members, partners, friends, and their health care providers. Therefore, this subtheme included four categories: the parents/ family, the peers (those with and without diabetes), health care providers, and social media. Community support that came from different key people fulfilled the two primary needs of the emerging adult with T1D, one related to managing their disease and the other concerning emotional support.

i. The Parents/ Family Members

As per the norm in collectivist cultures, all participants were living with family members; with 14 participants still living with their parents, and one living with her spouse. Even though the diminished need for support in managing the disease from parents was evident, the parents were still reluctant to give up the reins and were always there in the background, mainly providing tangible support for their children. The participants often did not need this support from their parents, but accepted it nonetheless since it was important to their parents to be involved in their diabetes care.

Honestly, my parents would always say, “even if you are one hundred years old, we will still go with you to the doctor’s visit”, they always say this... (*Rami, 20 years*).

My mom sometimes changes my insulin pen needle. She would say, “Did you change the needles? Let me change them for you”. That kind of help... Some days if I was very low [blood sugar], she would make me juice or something. Even though I have a stock of juice boxes, so I would just grab one and drink it, so I do not really need the help...that’s all... (*Sara, 25 years*).

The majority of participants reported that the most pronounced presence of parental support was during the occurrences of acute complications. In addition, eight participants reported that they would turn to their parents for support during these complications.

Sometimes I go to my Mom and tell her that the issue is so and so [talking about her blood sugar levels] and I would ask her what should I do... and she would tell me what to do (*Maya, 19 years*).

When I am in hypo [hypoglycemia] for example, my mom helps me the most, she rushes to bring me some sugar or stuff... They are always with me during these kind of things... always always... I mean not once did I go through a hypo or a hyper and they were not helping me (*Rami, 20 years*).

Few participants communicated the emotional support they received from their parents or significant others. Being able to share the burden of diabetes with their

family members made the participants feel supported and encouraged them to manage their disease.

They [his parents] would always tell me: “why would you allow a disease to defeat you... you have the upper hand?”... They help me by being supportive... they are very caring towards me, they don't neglect me (*George, 21 years*). It's mostly psychological support. I thank God that I'm very lucky to have a very loving and caring spouse who wants to be part of my diabetes (*Layla, 29 years*).

Another role that some participants reported their parents to play during this period included continuing to provide financial support to their children.

Right now, they [her parents] are only responsible for securing my diabetes supplies (*Yasmeen, 21 years*).

Overall, only few participants reported no role for their parents during this period, while others reported the need for help from theirs to manage their diabetes.

They [her parents] do not have any role towards me (*Faten, 19 years*). Everyone has needs from his family... If one has diabetes, she needs more care in my opinion... I mean I can depend on myself and I manage my diabetes by myself, but sometimes I need their [her parents] support (*Rola, 19 years*).

## ii. The Peers

Support from peers was clearly articulated during this period. When talking about their peers, participants discussed friends who did not have diabetes and friends who did. Some of the participants' peers who did not have diabetes had a positive effect on the EAs in terms of diabetes care and psychological support, which in some cases promoted a sense of acceptance of the disease amongst the EAs, as described below.

...Their support made me believe that this disease is nothing to be ashamed about... Everyone accepts me with my diabetes, so it [diabetes] is not a problem for me (*Sally, 18 years*).

They [her friends] sometimes used to give me my insulin injections... They are all very supportive to be honest... If I had a low blood sugar at university, someone would rush to bring me some sugar... They all have a positive effect on me (*Maria, 22 years*).

My friends would mostly give me emotional support if I was having a bad day with diabetes (*Hadi, 21 years*).

On the other hand, other participants reported no role for their peers in terms of their diabetes, and felt the need to separate their diabetes condition from their social life.

In general, no [his peers do not have a role in his diabetes management]. This is my personal life... I mean it is nobody's business... nobody's... (*Tarek, 20 years*).

I mean I honestly feel that they [his peers] do not have big role in my life with regards to diabetes, like managing or helping or anything like that. I mean having diabetes was never "a thing" for me to have them support me or not (*Rami, 20 years*).

A very pronounced source of this support for the participants was their peers who had diabetes. These peers are referred to as "DiaBuddies", which is a new terminology meaning friends with diabetes. Some participants were introduced to their DiaBuddies through participating in the social activities at their diabetes clinic, while others connected through social media, such as through WhatsApp groups or Instagram pages. By connecting with other DiaBuddies who shared a common course, the participants had the feeling of not being alone, being listened to and understood, and having their experiences validated and shared. In addition, these friends provided a source of knowledge and diabetes self-care support that had the advantage of being readily available and accessible whenever needed.

Well, my doctor does not have diabetes. Now she understands and knows how to manage my sugar levels, but she will not understand my feelings and what I am going through... so that is why knowing that someone else knows what you are feeling can help you. It is so good for my mental health (*Rola, 19 years*). First, it is sharing knowledge... And even at any hour of the day, I would talk with someone, ask about anything. For example, we have this WhatsApp group, and if anyone has a problem and don't know how to manage, they would ask on the group and we would give advice and tell him/her what to do. This type of knowledge that they share, I always take them into consideration. So I try to become better because of this knowledge that I am getting from other people with diabetes (*Rami, 20 years*).

iii. The Health Care Providers

Eight of the participants were treated at the CCC, where a multidisciplinary team of physicians, diabetes educators, and allied professionals provides the care. The rest were seen in the endocrinologist clinic, where they had access to a diabetes educator only upon need. Seven participants were followed-up by the same physician since age 17 years. Participants highlighted the key roles that their health care providers played during this period. The majority considered their health care providers as a major support system that was readily available to provide guidance during this critical period.

It is like they [the health care team] are my fort, they protect me as I walk through. I mean the clinic visit that I take every three months, it sets the path that I need to take for the next three months, you know... (*Sara, 25 years*). They [health care team] have been very helpful before... Even outside the office hours, I am grateful for her [diabetes educator]. I have been able to meet with her without prior appointment, that's very very helpful (*Hadi, 21 years*).

Health care providers were also a source of information and provided diabetes self-care education and skills that facilitated independent self-management.

That stage where I started to become responsible, the medical team played a major role because every time I needed anything, I was referring back to them [the diabetes educators] and asking them and taking information from them... so during this transition, they played a very big role (*Rami, 20 years*). There is some information that I needed to know, you could say that they gave me all the information that I need to know. So now, I am ready to be alone in managing these issues (*Yasmeen, 21 years*).

Several participants reported receiving psychological support from their health care providers, signifying a therapeutic communication between them.

You can say that my doctor helps me psychologically more than through insulin and injections. He supports me psychologically a lot... he would talk with me about how to accept diabetes.... He supports me...He is someone I can talk with about anything, and he always gives me hope that I can control this disease (*Faten, 19 years*).

Some participants reported a stronger connection with their diabetes educators/nurses as opposed to other members of the health care team.

I mean I think the physician's role is to confirm what we are doing... but the major work is with the nurses, they had a much bigger role than the physicians (*Sally, 18 years*).

They [the nurses] help me a lot... I mean I have this nurse, she is so good, like she is my nurse from childhood until adulthood... she is the best one for me (*Rola, 19 years*).

As with the case of their parents, some participants stated a significant decrease in the role of health care providers in their diabetes management due to their feelings of increased confidence and competence in self-managing their disease, as they grew older. They believed that they understood themselves and their condition better than the health care team did.

After a while, the diabetes patient starts managing himself medically... For example, I take 2 [units of insulin] for a portion [of carbohydrates]... If I felt that the 2 units are too much, I would experiment with the doses. Unless I wouldn't know how to manage, then the doctor would help... Because really, with time, the diabetes patient would take control of all these things with only some supervision from the doctor... so I consider my doctor as someone who just gives me some advice (*Mira, 26 years*).

Now, I would say that my medical team has very minimal role, I don't consult much with them... I reached a point where I am fully aware of my case, my condition, and I can manage myself because I've been living with it [diabetes] for too many years (*George, 21 years*).

#### iv. Social Media

Diabetes social media platforms are gaining wide interest among the EAs with T1D since they provide the option for dynamic interactions with others who share their topic of interest. The participants reported turning to social media because they felt a sense of belonging and got to connect with other people with T1D. Some of these platforms are nationally based, which include people with T1D living in Lebanon, while others include international communities of people living with T1D. Participants reported knowing of these groups by word of mouth or by actively searching for them on social media platforms.

We have this support group that has around 60 people from all around the world. They ask questions... they share stories, they share things that happened with them. They ask for tips. We even do Zoom support group sessions... you know, like every Friday there is a session. We talk... and I feel supported... just like that... And I know I have the knowledge, so I give them tips. I also have experience, so I give them tips, I give them care... (*Layla, 29 years*).  
At first, I felt like I am suffering, like I am weird... Then I knew that it's not only me... there are like millions of people around the world with diabetes. So when I know that there is someone else feeling what I am feeling, it makes me feel better. I mean there are millions who have diabetes, not only in Lebanon, but outside as well. So I felt... Oh if I need anything I can ask for help or I can watch YouTube videos... how they manage this or that... (*Rola, 19 years*).

Despite the positive impact of social media, sometimes it acted as a source of frustration when the participant could not replicate the success stories shared on social media by others living with diabetes. One participant reported this negative experience:

Sometimes it [social media] makes me a bit disappointed because I can't reach her [a diabetes influencer on social media] goals (*Maya, 19 years*).

### c. The Society

The third factor that affected the experience of the EAs with T1D in Lebanon was the views of their society. Society can act as a facilitator or an inhibitor for a healthy transition by either providing or withholding a supportive environment. The main feelings towards the society shared by the participants included feeling stigmatized against due to their disease. Stigma was perceived at varying levels ranging from low, like feelings of pity and lack of awareness about T1D, to high levels expressed by discrimination against them in the workplace.

They [people] always, always, every single person mixes between type 1 and type 2 diabetes, it's very frustrating. On our first date, my boyfriend was like: "why do you always inject things in your body, you shouldn't do that you should just do pills"... so I was like No, No, No, No, wait, wait... (*Maya, 19 years*).

When I was young, I used to get scared from the stories they [people] would tell [about diabetes]. They would say that when a person has diabetes, he would need kidney dialysis, or he would lose his toes, or his eyes... One time we were visiting someone who was doing kidney dialysis, I asked him if he had diabetes,

he said: “No, No, if I had diabetes I would have died at age 40”... Moments like these... I would never forget them in my life... they bother me a lot (*Faten, 19 years*).

I lost my job internship because of my diabetes... I was at an internship, and one day I woke up and I had a hypo... I told my supervisor that I am going to arrive late because of my hypo... she was rude to me and she was like “we don’t babysit here, please if you’re sick another time you have a hypoglycemia, we don’t babysit here, we don’t need you to come here”... (*Maya, 19 years*).

#### **4. *The Catalysts: Facilitators of Diabetes Self-Care***

The participants were asked about what promoted good diabetes self-care practices, and seven subthemes were identified from the interviews, which included: *technology and treatment advancements, psychological well-being, role modeling, fear of chronic complications of diabetes, support from others, predictability and routine, and COVID-19.*

##### **a. Technology and Treatment Advancements**

Participants reported that technological assistance, such as the use of continuous monitoring devices and diabetes mobile apps, facilitated blood glucose checking, reduced anxieties, and alleviated the burden of disease management.

I felt that the sensor is something that really made it easier for me, especially when they had that app on the phone... This thing made it [diabetes self-care] easier. I mean, I used to test around 5, 6, 7, 10 times an hour. Unconsciously I scan my phone, I mean you unconsciously do it. (*Mira, 26 years*).

Currently, I have the sensor that comes with the pump, and sometimes I use the Freestyle Libre alone... Honestly, the pump and the sensor played a very big role in my life... At first, I was really against wearing them. I was very scared of the idea of something attached to my body at all times ... I didn’t know that the pump is that easy to use, and that it doesn’t bother you, on the contrary, you control it... (*Yasmeen, 21 years*).

##### **b. Psychological Well-Being**

Participants pointed out a connection between their psychological well-being and diabetes management in the sense that improving one's psychological status leads to a renewed vigor in facing the challenges of living with diabetes.

[When asked about what would facilitate better self-care] A peaceful life I guess... Like when you are mentally at ease, everything around you becomes easy, whether managing your sugar levels or managing your life (*Rola, 19 years*).

It [his poor self-care practices] was mainly due to my poor psychological state and low morale. So maybe, if I change my psychological state I can... for example, when I stayed in the mountains for a month in the summer, it was very nice and calm there, better than the hassle of the city and all that... So when I am mentally better I can improve my situation (*Tarek, 20 years*).

#### c. Role Modeling

Some participants were involved in activities within their diabetes society that involved interacting with other individuals with T1D. The participants reported that acting as role models drove them to practice good diabetes self-care in the hope of setting a good example to others.

I mean because of them [other children with T1D] I would want to make myself better... Because when this little boy looked up to me, and he thought of me as a role model... I would be a good example for him... (*Sara, 25 years*).

I support a lot of people with diabetes, I guide other people struggling with diabetes through my support group... and this drives me to be better (*Layla, 29 years*).

#### d. Fear of Chronic Complications of Diabetes

Participants reported that during emerging adulthood, they felt an increased sense of responsibility regarding their health choices. The fear of developing any long-term complication of uncontrolled diabetes induced a positive change in their self-care practices.

I started realizing the harmful effect of diabetes on the long run, and if I don't take care now how much it will affect my life at age 40 and beyond... I have this thing [diabetes] that I need to live with and I need to know how to take care

of myself... So, I had to adjust my lifestyle, start eating healthy, do more follow-ups, work on my HbA1c... and this is where I am at right now (Maria, 22 years).

I saw some pictures of diabetes complications and it hit me. I mean I started handling diabetes with more care and being more responsible... more responsible than when I was a teenager (Maya, 19 years).

e. Support from Others

Despite the increase in autonomy that participants reported as defining their emerging adulthood phase, they still welcomed support in managing their diabetes from others. The support received from the parents, peers, and health care professionals during this period translated into increased competence and ability to practice diabetes self-care.

One time I mistakenly injected myself two times with Apidra [short acting insulin]. Usually, when something like this happens, I ask someone else with diabetes for help... But now, I am becoming more responsible, so I called my nurse and he told me what to do... whenever these things happen, I directly ask the nurses to know what to do (Rami, 20 years).

The main thing that helps is the support I get from my family and friends... Really, their support makes me take better care of my health. When I see how they take care of me, it makes me feel motivated to take care of myself and do proper management of my diabetes (Sally, 18 years).

f. Predictability and Routine

The participants stated that having predictability and routine in day to day activities decreases the mental effort of deciding diabetes management activities, leading to improved self-care. Diabetes self-care also became a routine over the years.

When my days are somewhat similar, when I am in a familiar situation, familiar place, eating food that I am used to eating... it would be more easy for me to carb count. Seeing familiar people, having a regular schedule... I would be mentally at ease... I would be relaxed, I know my environment, it [diabetes self-care] would be easier (Layla, 29 years).

At first, it [managing diabetes] was hard, then I got used to it. It became a habit, a daily routine... it's nothing hard anymore, just something I am living with (Maria, 22 years).

g. COVID-19

When talking about living with T1D during the COVID-19 pandemic, participants pointed out to several contradictory ways in which COVID-19 affected their diabetes management and glycemic levels. A surprising finding was that COVID-19 promoted better self-care practices. In this context, participants reported that the positive effect of the COVID-19 pandemic was a consequence of two factors: having enough time during the lockdown to focus on their diabetes and their overall health, and the fear of the negative effect of COVID-19 on their health if they had poor glycemic levels.

It [COVID-19] had a very positive effect on my diabetes. Staying home during the lockdown made it easier for me to manage my diabetes... My diabetes before COVID was much different than after COVID... because during this period, I invested in myself to learn more about diabetes, about how to manage by myself... I turned to social media, I connected with others and learned from them, and I got involved with [diabetes] communities... (*Rami, 20 years*).

Like at the beginning of COVID, I used to get scared and wanted my sugar levels to remain stable in case I am infected, it should not be high. I should not have a fever, because it [blood sugar] increases with fever. So I used to always keep it stable and within the normal range (*Rola, 19 years*).

Being confined at home was very positive for me. I had time to sit by myself, I reflected a lot. One part was related to diabetes, my numbers were better. I was not so busy with work so much so I had time to focus on my diabetes... (*Sara, 25 years*).

##### **5. *The Inhibitors: Barriers to Diabetes Self-Care***

Despite the noted enthusiasm of the participants to engage in activities that promoted good control of their diabetes, some factors hindered achievement of their goals. When asked about what were the different barriers to adequate diabetes self-care, five sub-themes were articulated by the participants: *mental distress, fear of hypoglycemia, the demands of being a grown-up, COVID-19, and the economic crisis.*

a. Mental Distress

The participants reported poor mental distress as the main barrier to diabetes self-care. General life stressors affected the participants' motivation to care for their diabetes. Poor psychological state often resulted in the participants neglecting some aspects of their diabetes care such as measuring their blood glucose, taking insulin injections, and practicing healthy eating.

Anger and sadness... I feel that these are out of control and that they make it difficult for me to manage my diabetes... sometimes when I am upset, I would not take my insulin... I would say that now I am very upset and I don't want to bother with insulin right now (*Sally, 18 years*).

When I am upset, I would eat anything... anything at all... I eat a lot of sweets. I become blind sighted, I would just want to keep eating (*Rania, 25 years*).

Sometimes, the experienced anxiety or stress were diabetes-related, as participants reported feeling burned-out from the incessant demands of diabetes management, and about to give up on maintaining their health.

Sometimes, I feel burned-out from it. I'm done with it, I'm fed up, I don't want to take care of myself anymore or I like take random units and doses... (*George, 21 years*).

b. Fear of Hypoglycemia

Although participants reported fear of chronic diabetes complications as a motivator for better self-care practices, fear of hypoglycemia acted as a barrier to diabetes self-care when it was disproportionate to the actual risk of hypoglycemia. One participant reported extreme anxiety and fear of hypoglycemia, which caused her blood glucose levels to be consistently high.

Whenever I am under a lot of emotional stress, it takes over me. My irrational mind takes over... I wouldn't be a rational person who is capable of taking the right decisions. I become irrational and act based on my fear... I am afraid of insulin, of hypos [hypoglycemia]... I am afraid of writing the right carb count [in the pump] because I am afraid of having a hypo. Even if I take the right amount of insulin, I would be in a state of panic for three hours because I would

be scared of having a hypo... so that's what goes on in my head (*Layla, 29 years*).

c. The Demands of Being a Grown-Up

Some participants were starting careers or family, thus experiencing the demands of being an adult. The participants reported that the overwhelming responsibilities of their career, securing their finances, and managing a household, made them put their diabetes in the backseat and neglected

Sometimes I would feel very tired, and I would not get a chance to have my breakfast on time at work, so I would have a hypo [hypoglycemia], then I rest a bit... Sometimes I feel that if you are not careful, you tend to neglect yourself when you are tired and overwhelmed at work (*Mira, 26 years*).

Now, things are more hectic. Depending if I am spending the day inside or outside the office. Whether I am eating fast food or home cooked meals... Will I have time to eat or not...? So really, all these details on top of the daily stressors... when you are married, like in my case, you have a million jobs. So sometimes, you literally forget to eat. Also sometimes, I would be backed-up in meetings, so my focus shifts from diabetes... so like I take bad or harmful diabetes decisions (*Layla, 29 years*).

d. COVID-19

Despite promoting diabetes self-care with some participants, others reported a contrary effect of the COVID-19 pandemic. The forced lockdown went hand in hand with deteriorating psychological status, poor eating habits, and significant decrease in physical exercise. It also promoted a lax attitude towards blood glucose measurements and insulin intake.

It [COVID] affected my psychological status, staying home and not getting to see other people or go out... This annoyed me, which made my blood sugar levels get higher. I even couldn't go outside to exercise to decrease my blood sugar levels so I had to take high doses of insulin (*Sally, 18 years*).

During COVID, we stayed at home and I started eating like crazy. We had food deliveries [from restaurants] all the time, and all the time eating fast foods and unhealthy foods. I mean COVID really affected this aspect (*Maya, 19 years*).

I can say that the lockdown ruined everybody's routine... There was also a bit of unhealthy eating, and it changed my whole routine. I also did not pay attention

to my blood sugar tests as I used to, and the timings and doses [of insulin] and stuff... (*Hadi, 21 years*).

e. The Economic Crisis

The exacerbating economic crisis in Lebanon had major effect on the self-care practices of the EAs. High prices and shortage of insulin and diabetes supplies sometimes compelled the participants to decrease their blood glucose measurements, and even to sometimes ration their insulin intake.

Honestly, I was thinking that I need to eat less, so that I won't have to take insulin as much, so that my insulin will last me longer... I was thinking I need to check my sugar levels less so that I use fewer needles and strips, because you know that now the price is very high, so it might last me longer... what's happening is very bad... (*Rania, 25 years*).

We reached a stage in Lebanon where even if you do have the money, there is a shortage of supplies... the pump supplies, the insulin... everybody is affected by the insulin shortage. I am ordering my pump supplies from abroad. I am scared that one day I won't be able to secure the pump supplies, I would have to remove the pump... (*Yasmeen, 21 years*).

Suddenly you find yourself out of supplies... this is a huge hit for us. Imagine I used to test [blood sugar level] around 10 times an hour [with the sensor]... now I do only 4 times a day... You are not having 24 hours monitoring, you don't feel reassured about your health anymore (*Mira, 26 years*).

In addition, the increased prices of healthy food options also exacerbated the predicament, making it difficult for the participants to maintain healthy food choices.

Even the food... I mean when I first had diabetes, I used to eat very healthy foods. But now, there are many things that I cannot afford to buy anymore to improve my diet... you know... (*Sally, 18 years*).

## **6. *Aiming for Equilibrium***

The path to equilibrium for these EAs is akin to a roller coaster track, filled with ups and downs, depending on the interplay between the reactants, catalysts and inhibitors to self-care. The participants are breaking their teenage bonds, trying to navigate the roads of diabetes management, and striving to fit into the role of an adult

with diabetes. The participants attempted to find a way to reach their equilibrium by normalizing the disease, integrating it at the identity level, and making requests from their communities. Three categories comprised this theme: *Coping and Feeling Situated*, *Persistent Diabetes Stress*, and *Wishes and Needs*.

a. Coping and Feeling Situated

Coping with diabetes necessitated a process of changing the perception of the disease in a way that normalizes it as a constant in the individual's daily life. This process involved accepting diabetes with all its aspects that previously used to evoke feelings of shame. Feeling situated, on the other hand, reflected the participants' locating themselves within their environment as people with diabetes and how this affected the different aspects of their lives. Three categories that exhibited this theme included "normalizing diabetes", "diabetes impact on personal and professional life" and "Strength and resilience".

i. Normalizing Diabetes

The majority of the participants articulated accepting diabetes as part of their identity and described living with it as just "a unique lifestyle". They reported that the key to coping with diabetes was by considering it as a friend not a foe, and that fighting diabetes will always be a losing battle.

Diabetes is not easy to handle, but if you befriend it, you can live with it... Right now, I am very much at ease and I am coping with it... I mean, you have to think of diabetes as a person... if you don't consider him a friend, you cannot continue your trip together, he will defeat you. So I consider it as a friendship, I don't make him sad so he doesn't make me sad (*Yasmeen, 21 years*).  
Currently, it is something normal for me. I don't stress about it. It is something like any other thing in my daily living... I don't think much of taking my insulin or testing my blood sugar, you just do it. You check, you eat, and you take your

insulin... yeah... it's a lifestyle, you get used to it and it doesn't bother you anymore (*Mira, 26 years*).

ii. Diabetes Impact on Personal and Professional Life

Diabetes played different roles in the lives of the participants. Sometimes, it was the facilitator of new exciting opportunities, while at other times it weighed down on the participants and acted as a burden in their daily living. Some participants reported that diabetes improved their personal lives in terms of boosting their social network like through social media and receiving more support from their community, as illustrated below.

When I tell people I have diabetes, I feel they start caring for me more (*Kamal, 21 years*).

Regarding my social circle, diabetes plays an “ice breaking” role. When meeting new people, I would talk about my diabetes, and I manage to make it be nice (*Maya, 19 years*).

It [social life] boomed... I wouldn't know one percent of the people I know if it weren't for my diabetes. And the more I get into it [diabetes], the more I know people from around the world. I have a huge circle of friends because of it. It made me connect with a lot of people... So I am very grateful for my diabetes... (*Layla, 29 years*).

Alternatively, some participants reported that diabetes increased the strain on their parental and marital relationships, and interfered with their social life.

It [diabetes] sometimes puts a strain on your relationship with your parents and that annoys me... I mean they [his parents] would keep nagging me and saying: “test your sugar, take your injection, take care of yourself, take juice with you”.... things like that... (*Kamal, 21 years*).

[Talking about her parents] I mean it is nice to care for your kids, but you shouldn't show them how scared you are for them. This makes me lose faith in myself, not believe that I can do anything. This kind of “over-rated scary”... it annoys me... mentally (*Rola, 19 years*).

Diabetes puts stress on your relationship with your spouse. It is a huge part of a marriage, because it goes with you everywhere... it's a burden...and it depends on how much your spouse is willing take part of that burden. It is nothing you can do alone... (*Layla, 29 years*).

I can't go out to places where they do lots of activities, as I used to, anymore... because I am afraid for the pump... Like hiking for example, or things like that.

I can't take the risk of anything happening to me up there ... (*Yasmeen, 21 years*).

As opposed to their personal lives, almost half of the participants did not report any negative impact of diabetes on their professional lives, which they attributed to having an understanding environment in the workplace. However, one participant reported losing a work internship because of her diabetes complications.

It [diabetes] didn't cause me any trouble because where I worked, they knew that I have diabetes... so if one day I was teaching and my blood sugar got low, I would just say that I am not concentrating well because of my low blood sugar, it is not a big deal (*Maria, 22 years*).

Diabetes affected it [work life] a lot. I was at an internship, and one day I woke up and I had a hypo... I told my supervisor that I am going to arrive late because of my hypo... she was rude to me and she was like "we don't babysit here, please if you're sick another time you have a hypoglycemia, we don't babysit here, we don't need you to come here" (*Maya, 19 years*).

The main reported negative effect of diabetes on work or academic life was a disruption in concentration as a consequence of experiencing blood glucose fluctuations. This sometimes affected academic achievements for some of the participants.

If I am having high blood sugar levels, it is hard for me to go into class and participate and understand... Sometimes, I would be too tired from having high blood sugar levels all night, to wake up early, feeling energized and do well at university.... It is hard... other times, during classes, I would have a hypo [hypoglycemia], so I would have to leave class to have something to eat or drink (*Yasmeen, 21 years*).

On the other hand, another participant reported the positive effect of having diabetes on her career. She viewed having diabetes as something that boosted her confidence in the workplace, and gave her resilience to achieve her goals. When asked about how diabetes affected her work/career life, she said:

... if anything, it [diabetes] makes me more confident, and more hard-headed about many things... You become... confidence-wise... you discover that you have a strong will, that you are strong enough to multi-task... I mean you can

manage your diabetes while you are doing a million other things, like it's nothing... So you discover that you can do whatever you want, and that you have qualities you didn't even know you had... (*Sara, 25 years*).

iii. Strength and Resilience

The participants reported that living with diabetes was sometimes very rewarding. It helped shape them, and gave them motivation, confidence, and perseverance.

Sometimes it [diabetes] keeps me going... I am a strong person no matter what. So I become persistent... You [diabetes] are making my life hard? It's OK, I am a strong person. You [diabetes] even chose me because I am a strong person, so I am going to prove you right, I try harder... (*Maya, 19 years*).

It is wonderful when you see a 6-year-old girl, like I was when I was diagnosed, looking up to you and say: "oh so you have a job?" You have the chance to remove the misconceptions that a person with diabetes can't have a normal life. They would look up to you and see how you can have a normal, independent life... that you are self-sufficient, you have your work, you friends... So it makes you feel like you can help them, as if you are helping yourself when you were their age. But you are doing it for someone else... The feeling is amazing, I cannot describe it... (*Sara, 25 years*).

I feel more capable than anyone else. I am even better because I have diabetes... because I am capable of keeping myself alive (*Layla, 29 years*).

b. Persistent Diabetes Stress

As participants grew more adjusted to living with diabetes, they continued experiencing related stress that evoked a wide array of emotions and responses ranging from anger and frustration due to perceived diabetes stigmatization, fear for their future, to feeling burned-out from managing diabetes.

i. Anger and Frustration from Perceived Diabetes Stigmatization

The majority of participants reported feelings of anger and frustration due to perceived diabetes stigmatization from the society. These feelings of stigma and stereotyping tended to interfere in the process of healthy coping with their illness.

Some people when they know I have diabetes they would say: “Are you diabetic? Ohhh, it’s OK dear, don’t be sad”... it makes me mad. (*Maya, 19 years*).

People shouldn’t say, “Oh poor so and so” for having diabetes because diabetes is not shameful and is not pitiful. This thing [diabetes] makes me special and unique in the society. Some people when they see me doing my injection... it really bothers me when they look at me with pity, they make me feel like I am different... No, I am not... I am just like you... (*Maria, 22 years*).

How society looks at me annoys me a lot. It bothers me that they make you feel like you are sick... This annoys me a lot... even at times, I would get too worked-up that it would make my blood sugar levels get high (*Sally, 18 years*).

One participant, who was fired from a work internship because of a negative interaction with her supervisor related to diabetes complication, reported that this experience caused her to perceive diabetes as something that decreases her self-worth, and consider it a limitation to her ability to achieve her life goals.

I am always dealing with everything as if I am not good enough and I am not complete... I relate this to my diabetes... Always thinking, what if diabetes ruins it...relationships, jobs, university, everything... And there is always this feeling that what if anything happens and I lose what I achieved or I lose even this whole life because of this disease... that’s always at the back of my mind (*Maya, 19 years*).

#### ii. Fear for the Future

Other participants reported feeling afraid of the effect of diabetes long-term complications on their health, and its effects on their ability to have an easy pregnancy and a healthy baby.

I am afraid when they say that high levels [blood sugar] damages some body organs. That is the most thing I am afraid of on the long-run (*Kamal, 21 years*). There is something that scares me on the long-run, when I get married and get pregnant... I am afraid that I won’t be able to control my diabetes while I am pregnant... they say any hypo [hypoglycemia], you can lose the baby or something... I get scared of getting to that point... (*Mira, 26 years*).

#### iii. Diabetes Burnout

Even though participants wanted autonomy in disease management, they found that it was not always as easy as they imagined it would be. The unremitting demands of diabetes and its complications often led to feelings of burnout affecting their mental health.

Honestly, it has been a lot of hard work. It increases your mental load... and the funny part is, I support a lot of people with diabetes, I know what I should do. I guide other people but I can't do it myself, which is also a lot of pressure... So it's really... it makes you feel bad about yourself because you feel you're like a "false hero" in a sense (*Layla, 29 years*).

It is a love-hate relationship... sometimes, I feel burned-out from it... from the events [hypoglycemia] that I have, so it affects me negatively (*George, 21 years*).

c. Wishes and Needs

Participants reported several wishes and needs for change from their parents, society, health care professionals, and the government. These wishes reflected the missing factors that will facilitate reaching a state of equilibrium and promote good physical and mental health.

i. Wishes and Needs from Parents

It was evident from the interviews that participants have not yet received total autonomy of their disease management from their parents. Parents were still hesitant to relinquish control to their kids for fear of complications. This often led to conflicts arising between the participants and their parents, which were most pronounced during periods of acute complications. Thus, the majority of the participants reported wishing for their parents to ease back on them, worry less, and show more trust in their abilities to manage their diabetes as noted in the below examples.

I would definitely have my parents worry less about me... I mean if it is not a big deal for me, don't make it for you. I would have them worry much less, because now they worry all the time, and this stresses me out... (*Rami, 20 years*). They saw me as someone less capable, that I can't do much because of this [diabetes]... I always was trying to prove them wrong... So maybe I would ask them to like stop being overprotective and just support me... to see me as someone who is capable of doing everything (*Layla, 29 years*). I want to be more independent. I want them to trust me more... not to be constantly asked about it [diabetes]... (*Hadi, 21 years*).

Participants also requested a less reproaching behavior from their parents when they experience acute complications.

When I have a low blood sugar event, they would start reprimanding me saying: "why did you this or that, why did you take too much insulin, why didn't you eat well, and things like that"... I would be really tired and they would scold me on top of everything... that bothers me a lot. I just wish they would know how I feel... (*Sally, 18 years*).

One participant reported mixed feelings about her relationship with her parents in the sense that she still needs their attention but not the worry.

The feelings I have for my mother... like I don't want to hurt you and I don't want to make you worry... but at the same time, I really like to feel her support and I like her involvement (*Maya, 19 years*).

On the other hand, other participants reported a good relationship with their parents with no wishes for any change.

## ii. Wishes and Needs from Society

The most prominent changes that the participants requested from society revolved around stigmatization and lack of awareness of T1D.

I wish they would do some awareness about diabetes for people, parents, schools, friends... That we are human too. As I said before, sometimes one wrong word affects you. You feel bad about yourself sometimes when you feel like you are not like everyone else... But I am, I have something more, which makes me special (*Rola, 19 years*).

There is a stigma to a certain extent in our society. People would say: “Oh, he is diabetic, he’s not going to enjoy his life or he’s going to suffer”. This old regressed mentality... I wish they would change that. What they say is not true. I’ve been diabetic since I was 9 years old and here I am in college almost graduating (*Hadi, 21 years*).

iii. Wishes and Needs from HCP

In terms of the relationship with health care professionals, the majority of participants reported a good relationship with their health care providers. However, in some cases there was room for improvement. For instance, some participants wished for better access to the health care team and allocating more time for clinic visits.

I would say that the visit times are a bit short, 10-15 minutes, that’s it. Sometimes, you would have an incident that you would like to discuss it a bit with the doctor... the current pace it feels a bit rushed... I think the visits should be a bit longer (*Hadi, 21 years*).

Endocrinologists are not only for people with T1D. So they can’t give us as much time as they wish. I wish we had more, like the US or Europe, more conversations and events with diabetics where the health care team and the patients come together and exchange information... (*Layla, 29 years*).

Some participants reported limited attention to their psychological health and needs since the main focus was on their medical management.

There is a topic that is always brushed aside, while in fact it is very important. You should always take care of your mental health along with your diabetes because this chronic condition affects you in a way that you wouldn’t expect (*Sara, 25 years*).

I would ask to view the person coming to your clinic as a human being with feelings and needs, he is not just a patient. When you just tell him to adjust his doses, and you don’t truly understand what they’re going through, you’re not really helping them. Maybe this person is going through a psychological condition that is affecting his numbers... it’s not only about the medications (*Layla, 29 years*).

Other participants stated lack of education about proper diabetes management and requested access to better diabetes management education from the health care providers.

I feel they [health care team] should give me more information about diabetes, because till now, I feel that I am lacking information that I need to know... like in case anything happens to me to know what to do... (*Sally, 18 years*). They [health care team] need to assess if the patients have enough education... Because I know a lot of people with diabetes who don't know to carb count, a lot of people who don't know what to do in case of emergencies... you know, the things that the health care professionals should teach (*Layla, 29 years*).

These needs reflected lack of proper communication with the health care professionals, which some participants voiced during the interviews.

I ask that the people in the healthcare field in general to talk more with people with diabetes, sit with them, listen to their concerns, get in their heads... (*Layla, 29 years*).

#### iv. Wishes and Needs from the Government

The current economic crisis that the Lebanese people are going through affected the people living with diabetes negatively in terms of decreased access to health care, insulin treatments, and diabetes care supplies. This situation led the participants to experience consistently a lot of stress where they constantly feared running out of insulin and diabetes supplies.

The economic situation is scary. Everywhere people are telling me to store insulin because it will not be available anymore... one person, told me that he is not finding insulin in the pharmacies anymore and if he did, it was very expensive. What should I do? I get scared... what should I do if I can't get it anymore, I would die... I get scared (*Rola, 19 years*).

I am not being able to afford or to manage living. After all, as a diabetic you need insulin to live, if you don't have money or the means to buy it, how you're going to afford living. It's sad... it's very sad (*George, 21 years*).

There was a time where I couldn't get the sensors for the Freestyle. I had anxiety so I can't be without a sensor, I passed through times where I couldn't function... it was very hard. And then we had to pay for them in dollars... so it was very very emotionally nerve wrecking (*Layla, 29 years*).

The economic crisis exacerbated the forgoing poor governmental healthcare services provided for people with diabetes, and prompted the participants to demand better health coverage for diabetes medications, supplies, and health care services.

We need better access to medications, better access to hospitalization, better healthcare system... These are the basic needs a human can ask for... and we don't have them so this is what I ask (*George, 21 years*).

As the ministry of health, they should at least provide us with the basic life needs that a patient with diabetes should have... if not free of charge, then for something affordable. .... They should provide us with diabetes treatment, we need diabetes supplies... I wish we can reach a stage where we won't be in need of anything, because managing diabetes costs a lot (*Mira, 26 years*).

## 7. Summary

The overarching theme “Living with T1D during emerging adulthood: the complex balance of a chemical reaction” sets the theme to the study, in which the changes that the EAs experience during this period, the facilitators and barriers of performing adequate self-care, and their ability to reach equilibrium are described. The themes, subthemes, and categories are supported by excerpts from the participants.

The participants explained the changes in their autonomy levels and their need to assume more responsibility in managing their diabetes, thus seeking more diabetes knowledge and changing their self-care practices. The participants also described how their relationship with their community and society resulted at times in feeling supported, while at other times it was a source of discouragement and frustration. Technology, psychological well-being, fear of chronic diabetes complications, role modeling, predictability and routine, and COVID-19 were the main facilitators of self-care in our sample. However, despite their improved self-care practices, the participants experienced some challenges that hindered adequate self-care, which revolved around mental distress, fear of hypoglycemia, the demands of being a grown-up, COVID-19, and the current economic crisis. The participants reported negative feelings of frustration and anger from diabetes stigmatization, as well as burnout from the unrelenting demands of managing diabetes. However, the participants were able to

utilize the support they received from their community in order to normalize diabetes and situate themselves within their community as people with diabetes. Finally, the participants communicated their needs from the community and the society at large, to help promote their physical and mental health and reach their aspired state of equilibrium. Table 6 below elaborates the themes, subthemes, and categories, noting the number of participants who exemplified each category.

**Table 6**

*The Themes, Subthemes, and Categories*

Themes	Subthemes and Categories	Description
1. Breaking of Bonds: Changes and Taking Ownership	1.1. Assuming More Responsibility (N = 13)	1.1 The conscious and spontaneous shift in diabetes-related responsibilities from the parents to the EAs
	1.2. Demanding Autonomy & Less Parental Involvement (N = 6)	1.2 Demanding autonomy and less involvement of parents in the daily activities of diabetes management and care.
2. The Reactants: Factors Affecting the Diabetes Experience	2.1. The Emerging Adult	2.1 The personal characteristics of the individual with T1D during emerging adulthood
	2.1.1. Changing Self-Care (N = 13)	
	2.1.2. Increased Knowledge of Diabetes Management (N = 6)	2.2 The support received from parents, family members, friends, and the health care providers.
	2.2. The Community	
	2.2.1. The parents/ family members (N = 15)	2.3 The society's role in providing or withholding a supportive environment.
	2.2.2. Peers and DiaBuddies (N = 15)	
	2.2.3. Health Care Providers (N = 15)	
2.2.4. Social media (N = 6)		
2.3. The Society (N = 4)		
3. The Catalysts: Facilitators of Diabetes Self-Care	3.1 Technology and Treatment Advancements (N = 7)	3.1 Technology alleviating the burden of diabetes
	3.2 Psychological Well-being (N = 5)	3.2 Good psychological status promotes self-care
	3.3 Role Modeling (N = 3)	3.3 Practicing good self-care to set a good role model to others with T1D
		3.4 Fear of developing long-term complication promoted self-care
		3.5 Support from the parents, peers, and health care professionals

	3.4 Fear of Chronic Complications of Diabetes (N = 4)	translated into increased competence
	3.5 Support from Others (N = 15)	3.6 Maintenance of daily routine decrease the mental effort of related to diabetes management activities
	3.6 Predictability and Routine (N = 3)	3.7 Improved self-care by having more time during quarantine to focus on diabetes, and fearing COVID-19 complications
	3.7 COVID-19 (N = 6)	
4. The Inhibitors: Barriers to Diabetes Self-Care	4.1 Mental Distress (N = 13)	4.1 Mental Distress decreased the motivation to care for diabetes and promoted negligence.
	4.2 Fear of Hypoglycemia (N = 1)	4.2 Extreme anxiety and fear of hypoglycemia leading to keeping consistently high blood glucose levels.
	4.3 The Demands of being a Grown-Up (N = 5)	4.3 The overwhelming competing responsibilities of adulthood shifts priorities away from diabetes.
	4.4 COVID-19 (N = 4)	4.4 COVID-19 negatively affecting psychological status and lifestyle habits with poor eating practices.
	4.5 The Economic Crisis (N = 3)	4.5 Crisis effect on shortage of insulin, supplies, and the ability to live a healthy lifestyle.
5. Aiming for Equilibrium	5.1 Coping & Feeling Situated	5.1 Coping through normalizing diabetes as a constant in their daily lives, and identifying as people with diabetes within their community.
	5.1.1 Normalizing Diabetes (N = 9)	
	5.1.2 Diabetes Impact on Personal and Professional Life (N = 15)	
	5.1.3 Strength and Resilience (N = 5)	
	5.2 Persistent Diabetes Stress	5.2 The psychological responses of EAs living with T1D.
	5.2.1 Anger and Frustration (N = 8)	
	5.2.2 Fear for the Future (N = 3)	
	5.2.3 Diabetes Burnout (N = 5)	
	5.3 Wishes & Needs	5.3 The wishes and needs that reflect the missing factors that will facilitate reaching a state of equilibrium and promote good physical and mental health. Examples include wishing parents would let go, government provides supplies and increase public awareness about diabetes
	5.3.1 From Parents/ Family (N = 15)	
	5.3.2 From Society (N = 11)	
	5.3.3 From Health Care Professionals (N = 15)	
	5.3.4 From the Government (N = 3)	

## C. Quantitative Results

The quantitative analysis includes the following, 1) preliminary psychometric analysis of the study instruments; 2) descriptive analysis of the study variables; and 3) hypothesis testing to determine the predictors of diabetes-related outcomes through multiple linear regression, with moderation and mediation testing.

### 1. Psychometric Testing of the Study Instruments (DCP-SS, SCI-R, and T1DDS)

Psychometric testing was performed for the DCP-Social Support scale, SCI-R, and the T1DDS. Cronbach's alpha coefficients to assess the internal consistency reliability of the scales are presented in Table 7.

**Table 7**

*Reliability Analyses of the DCP-SS, SCI-R, and T1DDS*

<b>Scales</b>	<b>Cronbach's <math>\alpha</math></b>
DCP-SS (18 items)	.72
SCI-R (15 items)	.77
T1DDS	
Total Distress (28 items)	.92
Powerlessness (5 items)	.76
Management Distress (4 items)	.70
Hypoglycemia Distress (4 items)	.81
Negative Social Perceptions (4 items)	.73
Eating Distress (3 items)	.76
Physician Distress (4 items)	.83
Friend/Family Distress (4 items)	.82

*Note.* N=90.

#### a. The Diabetes Care Profile – Social Support (DCP-SS) Scale.

The DCP-SS scale had a Cronbach's alpha coefficient of .72. Construct validity was tested by determining the correlation between social support and the two main

outcomes, HbA1c and diabetes distress. There was no significant correlation between the DCP-SS scale and the outcome variables. However, secondary analysis showed a positive correlation of DCP-SS with the family/friends distress subscale of the T1DDS,  $r_s(88) = .22, p = .034$ .

b. The Self-Care Inventory - Revised Scale (SCI-R).

The SCI-R scale had Cronbach's alpha coefficient of .77. Construct validity of the translated scale was tested by measuring the correlations of the scale with HbA1c and diabetes distress. As expected, the SCI-R negatively correlated with both HbA1c,  $r_s(88) = -.29, p = .005$ , and diabetes distress  $r(88) = -.30, p = .005$ .

c. The Type 1 Diabetes Distress Scale (T1DDS)

The T1DDS had an excellent internal consistency reliability with a Cronbach's alpha coefficient of .92. Internal consistency reliability of the seven subscales ranged between .73 and .83, as shown in Table 5.5. The scores are comparable to the original tool results with an overall scale score of  $\alpha = .91$  and subscales scores of  $\alpha = .75 - .88$  (Fisher et al., 2015). Construct validity of the T1DDS was supported by a positive correlation of T1DDS with HbA1c,  $r_s(88) = .24, p = .023$ .

Overall, the three instruments showed acceptable to high reliability scores and acceptable validity results, indicating the appropriateness of their use in this study.

## 2. Descriptive Analysis of the Diabetes-Related Outcomes

The second aim of the study was to provide information on the current diabetes-related health status of the EAs with T1D in Lebanon, namely HbA1C, diabetes distress, and acute complications. Results are shown in Table 8.

**Table 8**

*Descriptive Statistics of Diabetes-Related Outcomes*

<b>Diabetes Clinical Characteristics</b>	<b>Minimum</b>	<b>Maximum</b>	<b><i>M</i> ± <i>SD</i> or Mdn (IQR)</b>	<b>Frequency (%)</b>
HbA1c Level	5.2	13.1	7.7 (6.6–8.4)	
Pre-COVID-19 HbA1c Level	5.4	14.5	8 (7–8.9)	
Diabetes Distress Score	32	140	80.4 ± 25.6	
Diabetes Distress Categories				
No / Mild Distress				17 (18.9)
Moderate Distress				31 (34.4)
High Distress				42 (46.7)
HbA1c Level ≥ 7 mg/dl				63 (70.0)
Diabetes Acute Complications, during the last 6months				
DKA				4 (4.4)
Severe Hypoglycemia				42 (46.6)
Self-Care Score	26.6	96.67	69 ± 13.4	
Social Support Score	33	60	48 (41–53.3)	
Want Subscale	6	30	15 (11.7–20)	
Get Subscale	6	30	22 (17.7–26)	
Global Attitude Subscale	12	30	27 (25.7–30)	

*Note.* *N* = 90. DKA = diabetic ketoacidosis. Continuous variables are presented by mean and standard deviation (*M* ± *SD*) or median and intra-quartile range [Mdn (IQR)] according to normality.

Normality checks of the variables have shown that HbA1c and social support were not normally distributed, whereas diabetes distress and self-care scores were. Both

HbA1c and social support scores had a significant Shapiro-Wilk's test ( $p < 0.05$ ), and a visual exam of their histogram, Q-Q plots, and box plots showed that their values were not normally distributed. HbA1c had skewness value of 0.848 (SE = 0.254) and a kurtosis of 1.863 (SE = 0.503), indicating a positive skewness to the right and thick tails with distribution of some values around the tails. Social support had skewness value of  $-0.218$  (SE = 0.254) and a kurtosis of  $-0.973$  (SE = 0.503), indicating a negative skewness to the left with heavy tails.

The study participants had a median HbA1c level of 7.7 (IQR, 6.6–8.4) with over two thirds (70 %) of the participants having HbA1c levels of  $\geq 7\%$ , which is above the ADA recommended HbA1c target for adults with diabetes. The mean diabetes-related distress score was high ( $80.4 \pm 25.6$ ), with the majority of the participants (81.1%) experiencing at least moderate distress levels. Further breakdown of distress categories showed that 34.4% had moderate distress levels, and 46.7% experienced high distress levels related to diabetes.

Regarding diabetes-related complications, half of the participants reported at least one acute diabetes complication during the past six months. Participants mainly reported experiencing severe hypoglycemia (46.6%) with a median number of 3 events (range 2-5), and only 4.4% experienced one DKA event during the past six months.

In general, the participants demonstrated good levels of self-care practices, with a mean self-care score of  $69 \pm 13.4$  out of a 100. As for social support, the score was relatively high signifying high social support received by the participants. The total received support and general support attitude sub-scores had a median of 48 (IQR, 41–53.3) out of 60.

a. HbA1c Levels Changes Before and During the Pandemic.

To assess the effect of the COVID-19 pandemic on the glycemic status, we collected self-reported HbA1c levels prior to COVID-19 (prior to February 2020) and compared them with the participants' current HbA1c levels. Non-parametric Wilcoxon Signed Rank test showed a significant difference between HbA1c levels during and prior to the pandemic,  $Z = -.35$ ,  $p = .001$ . As shown in Table 3b, participants had lower HbA1c levels during the pandemic with a median of 7.7 (IQR, 6.7–8.5), than before the pandemic,  $Mdn = 8$  (IQR, 7–8.9).

**3. *Predictors of Diabetes-Related Health Outcomes***

The third aim of this study was to determine the association between demographic and clinical variables (age, gender, level of education, living arrangements, social status, presence of medical insurance, age at diagnosis, duration of diabetes, co-morbidities, diabetes education, and perceived diabetes knowledge) and diabetes-related health, and to identify the predictors of these outcomes among the EAs in Lebanon.

a. Associations between Demographic/ Clinical Variables and Diabetes-Related Health Outcomes

The first step in answering aim 3 included conducting bivariate analyses between the demographic and clinical variables with diabetes-related variables. For ease of analysis, employment status was recoded into two variables, unemployed/ student and employed. In addition, there were only three participants on NPH + SAI insulin treatment, so we combined the NPH + SAI group and the Lantus/ Levemir/ Tresiba +SAI group, and recoded the insulin treatment variable into two groups, patients on

insulin through multiple daily injections and those on insulin pump therapy. We also regrouped “the blood glucose measurement” groups into two groups, one included measuring blood glucose through a glucometer, and the other combining the “FreeStyle Libre” group with the continuous glucose monitoring group. Finally, the treatment site variable was grouped into 3 categories: adult diabetes clinic, chronic care center, and pediatric/family medicine. Table 9 shows bivariate analyses of HbA1C and diabetes distress with select variables.

**Table 9**

*Associations of HbA1c and Diabetes Distress with Select Variables*

	<b>HbA1c</b>		<b>Diabetes Distress</b>	
	Mdn (IQR) / correlation ( $r_s$ )	$p$	$M \pm SD$ / Mdn (IQR) / correlation ( $r$ )	$p$
Gender		.349		.095
Male	7.8 (7–8.3)		74.8 $\pm$ 24.1	
Female	7.5 (6.4–8.5)		84 $\pm$ 25.8	
Social Status		.200		.658
Single	7.8 (6.6–8.5)		80.8 $\pm$ 25.1	
Married/engaged	7.1 (6.1–7.5)		77 $\pm$ 29.3	
Living With		.275		.681
Family/ Spouse	7.8 (6.6–8.5)		80.6 $\pm$ 25.5	
Alone/ Friends	7 (6.3–7.5)		75.8 $\pm$ 26.9	
LOE		.951		.306
High school or less	7.8 (6.4–8.8)		69 $\pm$ 30.3	
University (current/ graduate)	7.6 (6.6–8.4)		81.1 $\pm$ 25.2	
LOE, Head of Household		.213		.564
High school diploma or less	8 (6.4–8.8)		81.9 $\pm$ 26.3	
University graduate	7.3 (6.6–8.1)		78.8 $\pm$ 24.7	
Employment Status		.552		.640
Student/ Unemployed	7.8 (6.6 – 8.6)		81.4 $\pm$ 23.6	
Employed (Full-/ Part-time)	7.5 (6.9 – 8.1)		78.7 $\pm$ 28.6	
Treatment Site		.237		.587
Adult diabetes clinic	7.9 (6.8–8.5)		79.5 $\pm$ 25.5	
Pediatric diabetes clinic/ Family medicine clinic	8.0 (6.8–8.8)		87.2 $\pm$ 23.6	

	<b>HbA1c</b>		<b>Diabetes Distress</b>	
Chronic Care Center	7.1 (6.4–7.9)		78.3 ± 26.6	
Clinic Visits in Last Year		.220		.240
< 2 visits	8 (7.1–8.4)		82 (69.5–97.5)	
≥ 2 visits	7.5 (6.5–8.4)		80 (53.5–100)	
Health Coverage		.673		.57
No	7.65 (6.6–8.0)		71.5 (65.0–84.8)	
Yes	7.7 (6.6–8.5)		82.5 (63.0–100.3)	
BG Monitoring Type		.057		<b>.026</b>
Glucometer	7.9 (7.0–8.5)		84.9 ± 25.1	
Continuous Monitoring	7.0 (6.2–8.3)		72.6 ± 24.5	
Insulin Treatment Type		<b>.024</b>		0.597
Multiple Daily Injections	7.9 (7.0–8.5)		80.9 ± 25.5	
Insulin pump therapy	6.7 (6.2–7.6)		76.8 ± 26.1	
Chronic Diseases		.973		.995
No	7.8 (6.5–8.5)		80.4 ± 25.4	
Yes	7.5 (6.7–8.1)		80.4 ± 27.4	
Diabetes Management Education		.249		<b>.030</b>
No	8 (6.8–8.5)		88.3 ± 23.0	
Yes	7.5 (6.6–8.1)		76.2 ± 25.8	
Age by Category		.479		.531
18-24 years	7.8 (6.5–8.7)		79.3 ± 23.3	
25-29 years	7.5 (7.0–8.0)		83.1 ± 30.7	
Age	-.03	.776	.13	.207
Crowding Index	.09	.402	.31**	<b>.003</b>
Age at Diagnosis	-.29**	<b>.006</b>	.08	.485
Diabetes Duration	.24*	<b>.022</b>	-.03	.815
Diabetes Management Knowledge	-.13	.226	-.29**	<b>.005</b>
Self-Care Score	-.29**	<b>.005</b>	-.29**	<b>.005</b>
Social Support Score	.09	.415	.14	.171

Note.  $N = 90$ . LOE = level of education, BG = blood glucose. \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

i. HbA1c

Only insulin treatment type, age at diagnosis, diabetes duration, and self-care scores demonstrated a statistically significant association with HbA1c levels. A Mann-Whitney Test revealed that HbA1c levels were significantly higher in the multiple daily injections group ( $Mdn = 78.5$ ,  $n = 78$ ), compared to the insulin pump therapy group

( $Mdn = 6.65$ ,  $n = 12$ ),  $U = 278.0$ ,  $z = -2.26$ ,  $p = .024$ . In addition, being diagnosed with T1D at an older age was significantly correlated with lower levels of HbA1c. Moreover, and as expected, diabetes duration was significantly associated with HbA1c levels,  $r_s(88) = 0.24$ ,  $p = .022$ . This finding indicates that having diabetes for longer periods is related to worsening glycemic levels. Finally, higher self-care score was associated with a lower HbA1c.

ii. Diabetes Distress

Only blood glucose monitoring type, diabetes management education, crowding index, diabetes management knowledge, and self-care scores demonstrated a statistically significant relationship with Diabetes Distress scores. Participants who were using continuous glucose monitoring methods had lower mean diabetes distress scores than those using a glucometer (72.6 versus 84.9). Moreover, participants who reported receiving formal diabetes management education reported experiencing less diabetes-related distress, than people who did not receive a formal education (76.2 versus 88.3). In addition, higher crowding index score was associated with higher diabetes distress scores. Moreover, there was a significant correlation between the reported perceived knowledge of diabetes management and diabetes distress scores,  $r_s(88) = -.29$ ,  $p = .005$  such that as diabetes management knowledge increased, levels of diabetes distress decreased. Finally, higher self-care was associated with lower diabetes distress.

iii. Acute Diabetes Complications

Tables 10 shows the results of bivariate analyses with the acute diabetes complications variable (hypoglycemia and DKA). The only variable significantly

associated with the presence of acute complications was the level of education of the head of household and acute diabetes complications,  $\chi^2 (1) = 6.46, p = .011$ . Acute complications were more likely to be reported when the head of the household had high school education or less.

**Table 10**

*Associations of Acute Diabetes Complications with Select Variables*

	No (n=47)	Yes (n=43)	$\chi^2(1)$	<i>p</i>	OR	95% CI
	Frequency (%) / <i>M</i> ± <i>SD</i> / <i>Mdn</i> (IQR)					
Gender			0.10	.755		
Male	19 (40.4)	16 (37.2)				
Female	28 (59.6)	27 (62.8)				
Social Status			1.43	.320		
Single	40 (85.1)	40 (93)				
Married	7 (14.9)	3 (7)				
Living With			0.13	1.000		
Family/ Spouse	44 (93.6)	41 (95.3)				
Alone/ Friends	3 (6.4)	2 (4.7)				
LOE			2.20	.189		
High school or less	1 (2.1)	4 (9.3)				
University (current/ graduate)	46(97.9)	39 (90.7)				
LOE, Head of Household			6.46*	<b>.011</b>		
High school diploma or less	18 (38.3)	28 (65.1)				
University graduate	29 (61.7)	15 (34.9)				
Employment Status			1.47	.226		
Student/ Unemployed	27 (57.4)	30 (69.7)				
Employed (Full-/ part-time)	20 (42.6)	13 (30.3)				
Treatment Site			0.438	.803		
Adult diabetes clinic	25 (53.2)	25 (58.1)				
Pediatric diabetes clinic/ Family medicine	7 (14.9)	7 (16.3)				
Chronic Care Center	15 (31.9)	11 (25.6)				
Clinic Visits in Last Year			2.07	.150		
< 2 visits	10 (21.3)	15 (34.9)				
≥ 2 visits	37 (78.7)	28 (65.1)				

BG Monitoring Type			1.47	.226
Glucometer	27 (57.4)	30 (69.7)		
Continuous Monitoring	20 (42.6)	13 (30.3)		
Insulin Treatment Type			0.62	0.54
Multiple Daily Injections	42 (89.3)	36 (83.7)		
Insulin pump therapy	5 (10.7)	7 (16.3)		
Chronic Diseases			0.84	.489
No	41 (87.2)	40 (93)		
Yes	6 (12.8)	3 (7)		
Diabetes Management Education			0.65	.421
No	18 (38.3)	13 (30.2)		
Yes	29 (61.7)	59 (69.8)		
Age by Category			1.92	.239
18 – 24 years	31 (66.0)	34 (79.1)		
25 – 29 years	16 (34.0)	9 (20.9)		
Age	22 (19–25)	21 (19–23)	0.91	[0.79-1.04]
Crowding Index	0.8 (0.7–1)	1 (0.8–1)	1.82	[0.53-6.24]
Age At Diagnosis	12 (9–16)	12 (7–16)	0.98	[0.89-1.08]
Diabetes Duration	10.6 ± 4.8	10.0 ± 4.5	0.97	[0.89-1.07]
Diabetes Management Knowledge	4 (3–4)	3 (3–4)	0.73	[0.47-1.14]
Social Support Score	48 (40–54)	48 (43–53)	1.02	[0.97-1.09]
Self-Care Score	58.4 ± 13.9	55.6 ± 12.8	0.98	[0.95-1.02]

Note.  $N = 90$ . OR = odds ratio; CI = confidence interval; LOE = level of education, BG = blood

glucose. Analysis is presented as follows:  $\chi^2$  statistic for categorical predictor variables, and odds ratio for continuous predictor variables. \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$

#### iv. Diabetes Self-Care

Prior to running the mediation analysis of self-care, a bivariate analysis was conducted to determine the association between self-care and the predictor variables, and the results are shown in Table 11.

**Table 11***Association of Self-Care Scores with Select Variables*

	<i>M</i> ± <i>SD</i> / <i>Mdn</i> (IQR) / correlation ( <i>r</i> )	<i>p</i>
Gender		.582
Male	68.7 (60.3–75.3)	
Female	68.7 (60.3–75.3)	
Social Status		.215
Single	68.4 ± 13.6	
Married	74 ± 11.1	
Living With		.604
Family/ Spouse	69.2 ± 13.5	
Alone/ Friends	66 ± 11.8	
LOE		.574
High school level or less	72.3 ± 15.6	
University - current or graduate	68.8 ± 13.3	
LOE, Head of Household		.372
High school diploma or less	67.8 ± 14.1	
University graduate	70.3 ± 12.6	
Employment Status		.943
Student/ Unemployed	69.0 ± 12.5	
Employed (Full-/ Part-time)	69.2 ± 15.1	
Treatment Site		.069
Adult diabetes clinic	70.2 ± 13.1	
Pediatric diabetes clinic/ Family medicine	69.2 ± 13.0	
Chronic Care Center	77.2 ± 13.2	
Clinic Visits During Last Year		<b>.041</b>
< 2 visits	64.4 ± 12.2	
≥ 2 visits	70.8 ± 13.5	
BG Monitoring Type		.104
Glucometer	67.3 ± 12.0	
Continuous Monitoring	72.1 ± 15.2	
Insulin Treatment Type		.692
Multiple Daily Injections	68.8 ± 13.3	
Insulin pump therapy	70.5 ± 14.2	
Chronic Diseases		.339
No	68.6 ± 12.8	
Yes	73.1 ± 18.1	
Diabetes Management Education		<b>.018</b>
No	64.5 ± 10.5	
Yes	71.4 ± 14.2	
Age by Category		.632
18 – 24 years	71.6 ± 13.7	
25 – 29 years	73.1 ± 12.8	

Age	.00	.997
Crowding Index	-.057	.596
Age at Diagnosis	.196	.065
Diabetes Duration	-.143	.179
Diabetes Management Knowledge	.26*	<b>.013</b>
Social Support Score	-.075	.481

Note. N=90. LOE = level of education. \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$

Only the frequency of clinic visits, diabetes management education, and perceived diabetes management knowledge were associated with self-care scores. Participants who had less than two visits during the last year reported significantly lower self-care scores than participants who had two or more visits (64.4 vs. 70.8). Moreover, participants who received a formal diabetes education had higher self-care scores than patients who did not receive a formal diabetes education. Likewise, as diabetes management knowledge increased, self-care scores increased.

b. Regression Analysis to Predict Diabetes-Related Health Outcomes

The second step in answering aim 3 included running two multiple linear regression analyses to determine the predictors of HbA1c and Diabetes Distress. Independent variables were included in the regression models if they had a p-value of  $\leq .2$  on the bivariate level in order to allow for the inclusion of possible confounding variables. Variables were entered simultaneously. Before employing the multiple regression analysis, the data were examined for meeting the assumptions of multiple regression, including the presence of normality, linearity and homoscedasticity, and the absence of multicollinearity. The model fit, significance of the model, as well as that of each predictor are determined and reported.

i. Predictors of HbA1c

Assumptions of linear regression analysis were checked in the regression model for HbA1c. Visual inspection of the histogram and Q-Q plots determined the normality of the of the model residuals. Linearity and homoscedasticity was examined by plotting the residual against the predicted values. All plots did not show any clear pattern, which indicates that those assumptions were met. Variance Inflation Factors (VIF) were less than 5 indicating absence of multicollinearity (James et al., 2013).

Five variables were identified with a p-value  $\leq .2$  at the bivariate analysis level with HbA1c including: age at diagnosis, diabetes duration, blood glucose monitoring type, insulin treatment type, and self-care; they were entered simultaneously into the regression model.

While checking the assumptions of regression analysis, standardized residuals analysis revealed the presence of two outliers with a standardized r score  $> 2$ . After careful inspection of the data, a decision was made to remove the two outliers from the analysis. All other assumptions of regression were reassessed and met after the removal of the outliers. The model explained 20.7% (adjusted  $R^2$ ) of the variability of HbA1c, the model fit was significant with an  $F(5, 82) = 5.551, p < .001$ . In this model, insulin treatment type, age at diagnosis, and self-care were significant predictors of HbA1c. Table 12 shows the results of the regression analysis for HbA1c.

**Table 12***Regression Models of Main Predictors on HbA1c*

Variables	<i>B</i>	<i>SEB</i>	<i>t</i>	<i>p</i>	95% CI
<b>Model 1<sup>a</sup></b>					
(Constant)	11.46***	1.09	10.51	<.001	[9.29, 13.63]
Insulin Treatment Type <sup>c</sup>	-1.02**	0.37	-2.78	.007	[-1.76, -0.29]
Age at Diagnosis	-0.10*	0.04	-2.50	.014	[-0.19, -0.02]
BG Monitoring <sup>d</sup>	-0.31	0.04	-1.20	.233	[-0.82, 0.20]
Diabetes Duration	-0.02	0.04	-0.50	.618	[-0.10, 0.06]
Self-Care	-0.02	0.01	-2.02	.046	[-0.04, 0.00]
<b>Model 2<sup>b</sup></b>					
(Constant)	10.87***	0.69	15.69	<.001	[9.49, 12.25]
Insulin Treatment Type <sup>c</sup>	-1.14**	0.35	-3.25	.002	[-1.84, -0.44]
Age at Diagnosis	-0.09**	0.03	-3.30	.001	[-0.14, -0.04]
Self-Care	-0.02	0.01	-2.01	.047	[-0.04, 0.00]

*Note.* *N* = 88. CI = confidence interval.

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

<sup>a</sup> = In model 1 all variables with correlations are entered into the regression model. Model fit:

Adjusted  $R^2 = 0.21$ ,  $F(5, 82) = 5.551$ ,  $p < .001$ .

<sup>b</sup> = In model 2, only significant predictors were retained in the final model. Model fit: Adjusted

$R^2 = 0.21$ ,  $F(5, 82) = 5.42$ ,  $p < .001$ .

<sup>c</sup> = Insulin Treatment Type: 1 = multiple daily injections, 2 = insulin pump therapy. <sup>d</sup> = BG

monitoring: 1 = glucometer, 2 = continuous BG monitoring.

Before removing diabetes duration and blood glucose monitoring type from the model, testing for interaction and confounding effects was done. Interaction was tested by computing interaction terms for these two variables with all the other variables, and including these terms separately in the regression analysis. None of the interaction terms was significant. Confounding was tested by running the regression with and

without diabetes duration and blood glucose monitoring type, and then the crude and adjusted coefficients and the significance of the other variables were compared. There was no change in either magnitude or significance of the model variables, indicating absence of confounding effect. Therefore, diabetes duration and blood glucose monitoring type were dropped from the model.

The final model included insulin treatment type, age at diagnosis, and self-care, as significant predictors of HbA1c. The model (model 2) explained 21.1% (adjusted  $R^2$ ) of the variability of HbA1c, and had a significant model fit with an  $F(3, 84) = 8.76, p < 0.001$ . After controlling for age at diagnosis and self-care, insulin treatment by insulin pump therapy predicted around one point decrease in HbA1c levels as compared to individuals on multiple daily injections,  $B = -1.14, p = .002, 95\% \text{ CI } [-1.84, -0.44]$ . Age at diagnosis, also predicted HbA1c after controlling for insulin treatment type and self-care, with around 0.1 decrease in HbA1c levels with every one year increase in age of diagnosis,  $B = -0.09, p = .001, 95\% \text{ CI } [-0.14, -0.04]$ , such that being diagnosed at an older age predicted lower HbA1c levels in our sample. Finally, after controlling for insulin treatment type and age at diagnosis, self-care predicted around 0.02 decrease in HbA1c levels with every one-point increase in self-care score,  $B = -0.02, p = .047, 95\% \text{ CI } [-0.04, 0.00]$ , implying that better self-care practices predicted lower glucose levels in our sample.

## ii. Predictors of Diabetes Distress

Similar to the previous regression analysis, assumptions of linear regression analysis were checked in the regression model with diabetes distress as the outcome variable. Visual inspection of the histogram and Q-Q plots determined the normality of

the of the model residuals. Residual plots did not show any clear pattern, which indicates that those assumptions of linearity and homoscedasticity were met. Variance Inflation Factors (VIF) were less than 5 indicating absence of multicollinearity.

Seven variables were identified with a p-value  $\leq .2$  at the bivariate analysis level with diabetes distress: gender, blood glucose monitoring type, diabetes education, perceived diabetes management knowledge, crowding index, social support, and self-care. All the variables were entered simultaneously into the regression model. Analysis of the standardized residuals was done, which revealed no outliers present. Results of the regression analysis for diabetes distress are shown in Table 13.

**Table 13**

*Regression Models of Main Predictors on Diabetes Distress*

Variables	<i>B</i>	<i>SEB</i>	<i>t</i>	<i>p</i>	95% CI
<b>Model 1<sup>a</sup></b>					
(Constant)	98.77	24.22	4.08	<.001	[50.61, 146.94]
Diabetes Knowledge	-6.30*	2.95	-2.13	.036	[-12.18, -0.42]
Diabetes Education	-3.50	5.91	-.06	.953	[-16.02, 7.17]
Crowding Index	12.10	6.97	1.74	.086	[-1.77, 25.97]
Gender <sup>c</sup>	13.07*	5.05	2.59	.011	[3.03, 23.11]
BG Monitoring <sup>d</sup>	-13.02*	5.38	-2.42	.018	[-23.73, -2.32]
Self-care (SC)	-0.41*	0.19	-2.13	.036	[-0.78, -0.027]
Social Support (SS)	0.23	0.34	0.67	.506	[-0.45, 0.90]
<b>Model 2<sup>b</sup></b>					
(Constant)	312.62***	69.90	4.47	<.001	[173.63, 451.60]
Diabetes Knowledge	-5.94*	2.66	-2.23	.028	[-11.23, -0.65]
BG Monitoring <sup>d</sup>	-10.33*	5.04	-2.05	.044	[-20.36, -0.30]
Self-Care (SC)	-3.74**	1.23	-3.04	.003	[-6.18, -1.29]
Social Support (SS)	-3.63*	1.43	-2.54	.013	[-6.48, -0.79]
Interaction term SC*SS	0.07*	0.03	2.01	.007	[0.02, 0.12]

*Note:* *N* = 90. CI = confidence interval; SC = self-care; SS = social support; BG = blood

glucose.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

<sup>a</sup> = In model 1 all variables with correlations  $p < .2$  are entered into the regression model. Model fit: Adjusted  $R^2 = 0.22$ ,  $F(7, 82) = 4.526$ ,  $p < .001$ .

<sup>b</sup> = In model 2, only the final predictors were retained in the model. Model fit: Adjusted  $R^2 = 0.21$ ,  $F(5, 84) = 5.701$ ,  $p < .001$ .

<sup>c</sup> = Gender: 1 = male, 2 = female. <sup>d</sup> = BG monitoring: 1 = glucometer, 2 = continuous BG monitoring.

The first model explained 22% (adjusted  $R^2$ ) of the variability of Diabetes Distress, the model fit was significant with an  $F(7, 82) = 4.526$ ,  $p < .001$ . Before removing the non-significant predictor variables from the model, we tested for interaction and confounding effects. One interaction term (social support and self-care) was significant, with  $p = .019$ . Confounding was also tested by running the regression with and without all other non-significant variables and then the crude and adjusted coefficients and the significance of the other variables were compared. There was no change in either magnitude or significance of the model variables, indicating absence of confounding effect. Therefore, these variables were dropped from the model.

In the final model, diabetes distress was predicted by diabetes knowledge, blood glucose monitoring type, self-care, and social support. The final model explained 20.9% (adjusted  $R^2$ ) of the variability of Diabetes Distress, and the model fit was significant with an  $F(5, 84) = 5.701$ ,  $p < .001$ . After controlling for blood glucose monitoring type, self-care, and social support, a one point increase in perceived knowledge of diabetes management predicted around six points decrease in diabetes distress scores,  $B = -5.94$ ,  $p = .028$ , 95% CI  $[-11.23, -0.65]$ . Also after controlling for diabetes knowledge, self-care, and social support, using continuous blood glucose monitoring predicted around

10 points decrease in diabetes distress scores than participants using a glucometer,  $B = -10.33$ ,  $p = .044$ , 95% CI  $[-20.36, -0.30]$ . After controlling for diabetes knowledge, blood glucose monitoring type, and social support, one point increase in self-care scores predicted four points decrease in diabetes distress scores,  $B = -3.74$ ,  $p = .003$ , 95% CI  $[-6.18, -1.29]$ . Similarly, after controlling for diabetes knowledge, blood glucose monitoring type, and self-care, one point increase in social support score predicted around four points decrease in the diabetes distress scores in our sample  $B = -3.63$ ,  $p = .013$ , 95% CI  $[-6.48, -0.79]$ .

Having a significant interaction term of self-care with social support on predicting diabetes distress indicates that a moderation effect is present. Therefore, we ran two regression models according to social support levels, high versus low, with the median as cut off. The model of the low social support group was statistically significant  $F = 6.142$ ,  $p = 0.002$ , and accounted for 28.9% (Adjusted  $R^2$ ) of the variance in Diabetes Distress. In this model only self-care predicted diabetes distress ( $B = -0.85$ ,  $p = 0.006$  and 95% CI from  $-1.43$  to  $-0.26$ ). In the high social support group, the model was not significant.

### iii. Predictors of Acute Diabetes Complications

Assumptions of multiple logistic regression analysis were checked in the regression model for acute diabetes complications. This outcome variable was measured on a dichotomous scale (Yes/No). The linear relationship between continuous predictor variables and the logit of the outcome was checked by visually inspecting the scatter plots between each predictor and its logit values. Box-Tidwell test was also performed to check for linearity between the predictors and the logit. All plots did not show any

clear pattern and the aforementioned test showed non significance concerning the linearity of the logit in the model, which indicates that the assumption was met. Variance Inflation Factors (VIF) were less than 5, indicating absence of multicollinearity.

Five variables were identified with a p-value  $\leq .2$  at the bivariate analysis level with acute diabetes complications including: age, level of education, number of clinic visits during the past year, perceived diabetes management knowledge, and the head of household level of education. All the variables were entered simultaneously into the regression model. Table 14 shows results of the logistic regression for predicting acute complications.

**Table 14**

*Logistic Regression for Acute Diabetes Complications*

Variables	<i>B</i>	<i>SE</i>	Wald	<i>p</i>	Odds ratio	95% CI
(Constant)	5.18*	2.22	5.45	.020	177.58	
Age in Years	-0.06	0.08	0.62	.432	0.94	[0.813–1.092]
Level of Education	-2.05	1.24	2.73	.098	0.13	[0.01–1.46]
Clinic Visits	-0.68	0.52	1.71	.191	0.51	[0.18–1.4]
LOE, Head of House Hold <sup>a</sup>	-1.04*	0.46	5.0	.025	0.35	[0.14–0.88]
Diabetes Management Knowledge	-0.28	0.25	1.26	.262	0.76	[0.46–1.23]

*Note.* *N* = 90. Outcome variable = Acute diabetes complications. CI = confidence interval. <sup>a</sup> 1 = high school diploma or less, 2 = university graduate. Model fit:  $\chi^2(5) = 13.52, p = .019$ . \**p* < .05.

The logistic regression model was statistically significant,  $\chi^2(5) = 13.52, p = .019$ . The model explained 18.6% (Nagelkerke  $R^2$ ) of the variation in acute diabetes complications and correctly classified 68.9% of cases. The goodness-of-fit test is the

Hosmer–Lemeshow test that yielded a  $\chi^2(8)$  of 2.674 and was not significant  $p > .05$ , suggesting that the model was a good fit to the data. The final model retained only one predictor of acute complications, which was the head of household’s educational level. Testing for interaction and confounding effects was done, and none of the variables had an interaction or a confounding effect.

In the final model, age, level of education, number of clinic visits during the past year, and perceived diabetes management knowledge did not add significantly to the overall model. However, the odds of acute diabetes complications in EAs with T1D were 0.35 times lower if the head of household had a higher level of education (university graduate) as compared to lower levels (high school diploma or less).

#### iv. Predictors of Diabetes Self-Care

Assumptions of linear regression analysis were checked in the regression model for self-care. Visual inspection of the histogram and Q-Q plots determined the normality of the of the model residuals. Plotting the residual against the predicted values did not show any clear pattern, which indicates that the linearity and homoscedasticity assumptions were met. Variance Inflation Factors (VIF) were less than 5, indicating absence of multicollinearity.

Seven variables were identified with a p-value  $\leq .2$  at the bivariate analysis level with self-care including: age at diagnosis, diabetes duration, blood glucose monitoring type, diabetes knowledge, treatment site, number of clinic visits, and receiving formal diabetes education. Treatment site had three categories, so dummy variables were computed and follow-up at pediatric diabetes clinic or family medicine clinic, and at the chronic care center were included in the model to be compared to the reference – follow

up at an adult diabetes clinic. All the variables were entered simultaneously into the regression model. Table 14 shows the results of the regression analysis for self-care.

**Table 15**

*Regression Models of Main Predictors on Self-Care*

Variables	<i>B</i>	<i>SEB</i>	<i>t</i>	<i>p</i>	95% CI
<b>Model 1<sup>a</sup></b>					
(Constant)	37.26*	10.75	3.47	.001	[15.86, 58.66]
F/U, Pediatric/ Family medicine	-1.64	2.97	-0.55	.582	[-7.56, 4.28]
F/U, Chronic Care Center	7.04*	2.91	2.42	.018	[1.26, 12.82]
Age at Diagnosis	0.96*	0.42	2.28	.025	[0.12, 1.79]
Diabetes Duration	-0.36	0.41	-0.88	.384	[-1.19, 0.46]
Diabetes Education <sup>c</sup>	0.31	2.99	0.10	.919	[-5.65, 6.27]
Diabetes Knowledge	5.53**	1.53	3.61	.001	[2.48, 8.58]
BG Monitoring <sup>d</sup>	0.76	2.53	0.30	.764	[-4.27, 5.80]
Clinic Visits <sup>e</sup>	1.98	2.64	0.75	.457	[-3.28, 7.23]
<b>Model 2<sup>b</sup></b>					
(Constant)	34.37***	6.68	5.15	<.001	[21.09, 47.66]
F/U, Chronic Care Center	8.24**	2.58	3.20	.002	[3.12, 13.36]
Age at Diagnosis	1.26***	0.28	4.53	<.001	[0.71, 1.82]
Diabetes Knowledge	5.39***	1.27	4.25	<.001	[2.87, 7.91]

*Note.* *N* = 88. CI = confidence interval.

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

<sup>a</sup> = In model 1 all variables with correlations are entered into the regression model. Model fit:

Adjusted  $R^2 = 0.25$ ,  $F(8, 79) = 4.626$ ,  $p < .001$ .

<sup>b</sup> = In model 2, only significant predictors were retained in the final model. Model fit: Adjusted

$R^2 = 0.28$ ,  $F(3, 84) = 12.229$ ,  $p < .001$ .

<sup>c</sup> = Diabetes Education: 0 = did not receive a formal diabetes management education, 1 =

received a formal diabetes management education. <sup>d</sup> = BG monitoring: 1 = glucometer, 2 =

continuous BG monitoring. <sup>e</sup> = Clinic visits: 1 = less than two clinic visits within the last year, 2

= two or more clinic visits within the last year. For treatment site, the reference is adult diabetes clinic

While checking the assumptions of regression analysis, standardized residuals analysis revealed the presence of two outliers with a standardized  $r$  score  $> 2$ . After careful inspection of the data, a decision was made to remove the two outliers from the analysis. All other assumptions of regression were reassessed and met after the removal of the outliers. The model explained, 24.9% (adjusted  $R^2$ ) of the variability of self-care, the model fit was significant with an  $F(9, 78) = 4.203, p < .001$ . In this model, age at diagnosis, treatment site, and diabetes knowledge were significant predictors of self-care. Before removing the non-significant variables from the model, testing for interaction and confounding effects was done. There was no evidence of interaction or confounding effect. Therefore, the non-significant variables were dropped from the model.

The final model (model 2) included age at diagnosis, follow-up treatment at the chronic care center, and diabetes knowledge, as significant predictors of self-care. The model explained 27.9% (adjusted  $R^2$ ) of the variability of self-care, and had a significant model fit with an  $F(3, 84) = 12.229, p < .001$ . Age at diagnosis, predicted self-care after controlling for treatment site and diabetes knowledge, with around 1.3 points increase in self-care scores with every one year increase in age of diagnosis,  $B = 1.26, p < .001, 95\% \text{ CI } [0.71, 1.82]$ , meaning that being diagnosed at an older age predicted higher self-care levels in our sample. Similarly, after controlling for age at diagnosis and diabetes knowledge, being followed-up at the chronic care center predicted around 8.2 points increase in the self-care score as compared to individuals following up at an adult diabetes clinic,  $B = 8.24, p = .002, 95\% \text{ CI } [3.12,$

13.36]. Finally, after controlling for age at diagnosis and treatment site, one point increase in diabetes knowledge rating predicted around 5.4 points increase in self-care score,  $B = 5.39$ ,  $p < .001$ , 95% CI [2.87, 7.91], implying that better diabetes knowledge predicted higher self-care practices in our sample.

#### ***4. Mediation Analysis of Self-Care on the Association between Predictors and Diabetes-Related Health Outcomes***

The fourth aim of this study was to assess the effect of diabetes self-care on the association between the identified predictors and glucose levels (HbA1c) and psychological adjustment (diabetes distress). Hypothesis: Diabetes self-care mediates the relationship between sociodemographic and clinical predictor variables and diabetes-related health outcomes among EAs with T1D in Lebanon.

Mediation analysis is a statistical method used to test hypotheses about how a causal variable X transmits its effect on a variable Y through a single intervening variable M. In a simple mediation model, the variable X affects the variable Y in two ways. The first is a direct causal relationship with Y or the direct effect of X on Y. The other route passes through M, where X has a causal relationship with M, which in turn has one with Y. This is known as an indirect effect of X on Y through variable M (Hayes, 2018).

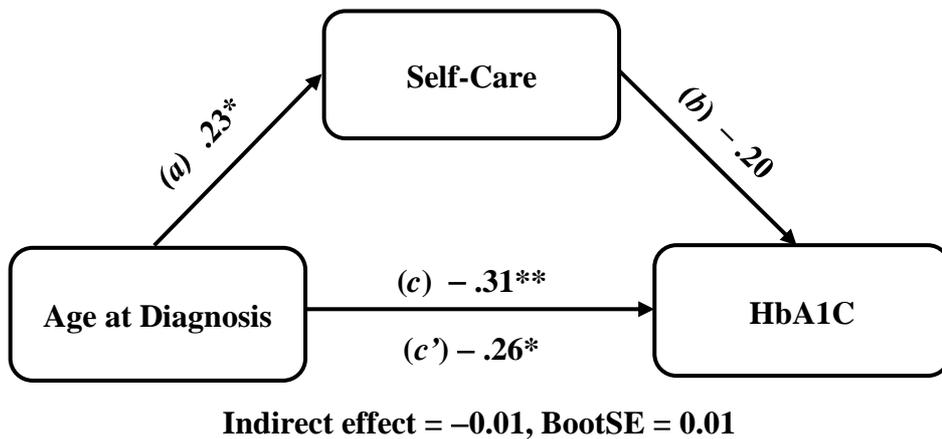
In order to test the mediation effect of self-care on the association between predictor and outcome variables, we ran a simple mediation test using PROCESS macro for SPSS (Hayes, 2017) for each of the two dependent variables (HbA1c and diabetes distress). The variables that predicted both the outcome variables (HbA1C and diabetes -distress) and self-care were included in the mediation analysis (Baron & Kenny, 1986).

a. Mediation Analysis of Self-Care on the Association between Age at Diagnosis and HbA1c

Age at diagnosis predicted both HbA1c levels and self-care scores. In this mediation model, we examined the impact of age at diagnosis (X) on HbA1c (Y) as mediated by self-care (M). This mediation model with the standardized path coefficients ( $\beta$ ) are presented in Figure 5.

**Figure 5**

*Mediation Model of Self-Care on the Age at Diagnosis – HbA1c Association*



*Notes.*  $N = 88$ . The figure shows the standardized path coefficients ( $\beta$ ) results.

\* $p < .05$ . \*\* $p < .01$ .

Age at diagnosis positively affects self-care (a)  $B = 0.65$ ,  $SE = 0.29$ ,  $p = .030$ , but self-care neared significance in affecting HbA1c (b)  $B = -0.02$ ,  $SE = 0.01$ ,  $p = .06$ , in the model. Age at diagnosis negatively affected HbA1c (c)  $B = -0.09$ ,  $SE = 0.03$ ,  $p = .003$ . Reviewing the effect of age at diagnosis on HbA1c after accounting for the mediating role of self-care suggested that there was no change in the significance or

direction of the effect ( $c'$ )  $B = -0.08$ ,  $SE = 0.03$ ,  $p = .013$ . Analyzing the indirect effect (mediation) of self-care on the association between age at diagnosis and HbA1c revealed that self-care did not mediate this relationship. Indirect Effect =  $-0.01$ ,  $BootSE = 0.01$ , bootstrap 95% CI [ $-0.03$ ,  $0.001$ ]. Hence, there was no mediating effect of self-care on the model with HbA1c as an outcome.

b. Mediation of Self-Care on the Association between Diabetes Knowledge and Diabetes Distress

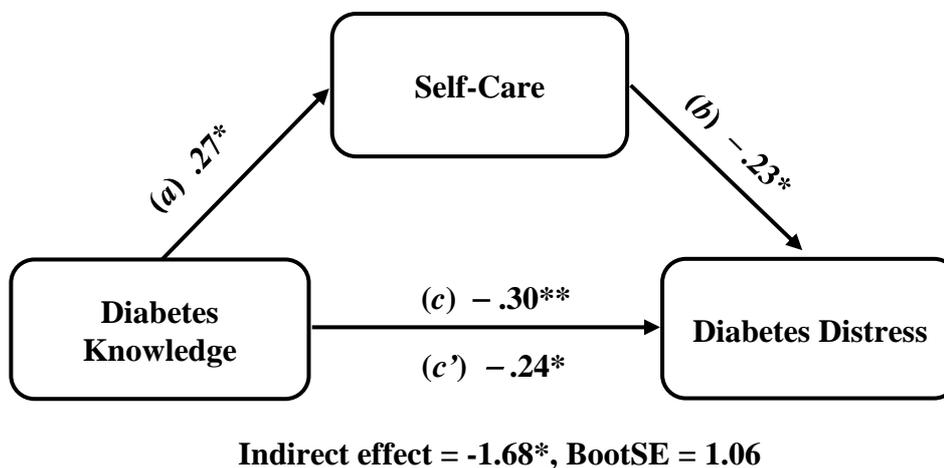
We ran the analysis to examine the impact of diabetes knowledge (X) on diabetes distress (Y) as mediated by self-care (M). This mediation model with the standardized path coefficients ( $\beta$ ) are presented in Figure 6.

Analyzing the direct paths in this model showed that diabetes knowledge positively affects self-care (a)  $B = 3.77$ ,  $SE = 1.45$ ,  $p = .01$ , and self-care in turn negatively affects diabetes distress (b)  $B = -0.44$ ,  $SE = 0.20$ ,  $p = .026$ . The results also show that diabetes knowledge negatively affects diabetes distress (c)  $B = -8.01$ ,  $SE = 2.72$ ,  $p = .004$ . Analyzing the indirect effect of self-care on the association between diabetes knowledge and diabetes distress revealed that self-care significantly mediated this relationship. Indirect Effect =  $-1.68$ ,  $BootSE = 0.19$ , Bootstrap 95% CI [ $-4.03$ ,  $-0.008$ ]. Nevertheless, the results also suggest that even after accounting for the mediating role of self-care, diabetes knowledge still significantly affects diabetes distress ( $c'$ )  $B = -6.33$ ,  $SE = 2.76$ ,  $p = .024$ . This means that the mediation is partial. In order to detect the percentage of the effect of diabetes knowledge on diabetes distress that is due to the mediating effect of self-care, we divided the indirect effect ( $-1.68$ ) by the total effect ( $-8.01$ ) giving us a result of 20.9%, meaning that self-care accounts for

around 21 % of the total effect of diabetes knowledge on diabetes distress. Thus, individuals with high levels of diabetes self-care are more likely to experience low levels of diabetes distress. Nevertheless, having good diabetes management knowledge still contribute to low feelings of diabetes distress beyond what is accounted for by self-care.

**Figure 6**

*Mediation Model of Self-Care on the Diabetes Knowledge - Diabetes Distress Association*



Note.  $N = 90$ . The figure shows the standardized path coefficients ( $\beta$ ).

\* $p < .05$ . \*\* $p < .01$ .

### **5. Moderation Effect of Social Support on the Association between Diabetes Self-Care and Diabetes Outcomes**

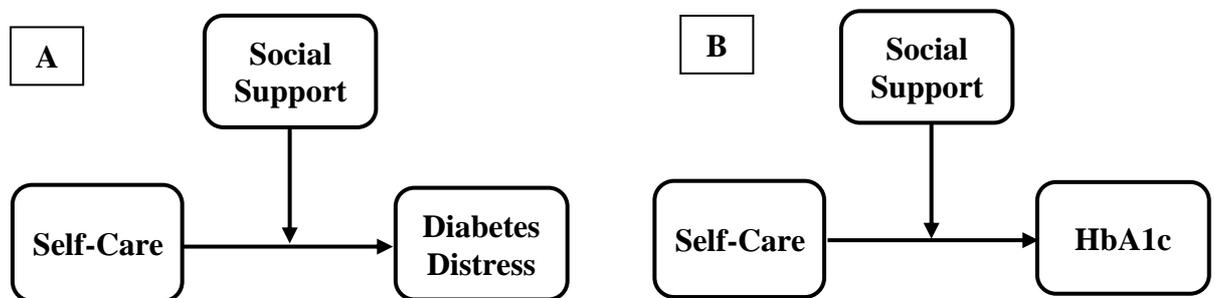
The fifth aim of this study was to assess the effect of diabetes social support on the association between diabetes self-care and diabetes-related health outcomes (HbA1c and diabetes distress). Hypothesis: Social support will moderate the association between self-care and diabetes-related health outcomes among EAs with T1D in Lebanon. Social

support will also moderate the mediation effect of self-care on the association between predictor and outcome variables.

Moderation analysis determines whether the relationship between a predictor and an outcome is affected by a third variable. It implies an interaction effect, where introducing a moderator variable affects the significance or magnitude of the predictor effect on the outcome. In other words, a variable (W) is said to moderate the effect of a predictor variable (X) on an outcome (Y) if the effect of X on Y depends on W (Hayes & Montoya, 2017). Moderation analysis was conducted for HbA1c and Diabetes Distress using Process model number 1 for simple moderation analysis. This moderation model is represented in Figure 7.

**Figure 7**

*Moderation Model of Social Support on the Association between Self-Care with Diabetes Distress (A), And HbA1c (B)*



a. Moderation analysis on HbA1c

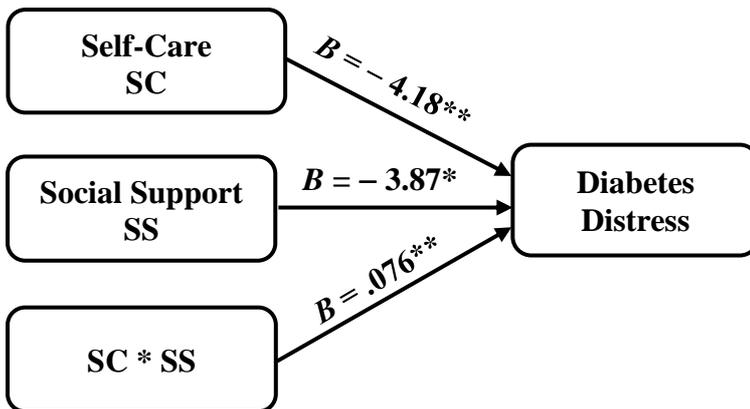
In assessing for the moderating effect of social support on the association between self-care and HbA1c, the analysis showed no significant effect of the regression model,  $R^2 = .05$ ,  $F(3, 86) = 1.68$ ,  $p = .177$ . Therefore, social support did not moderate the association between self-care and HbA1c levels.

b. Moderation analysis on Diabetes Distress

The hypothesized moderating effect of social support on self-care and diabetes distress was previously confirmed by determining a significant interaction term with self-care in the linear regression analysis. To analyze further this moderating effect we ran the analysis using PROCESS model 1. The analysis suggested a significant interaction effect of social support with self-care on diabetes distress where the model explained around 18% of the variance in diabetes distress,  $R^2 = .18$ ,  $F(3, 86) = 6.14$ ,  $p = .0008$ . The coefficients of the variables in the model are displayed in the statistical model of the moderation in Figure 8. The interaction term between social support and self-care accounted for a significant proportion of the variance in diabetes distress  $\Delta R^2 = 0.08$ ,  $\Delta F(1, 86) = 8.40$ ,  $p = .004$ .

**Figure 8**

*A Statistical Model of the Moderation Effect of Social Support on the Association between Self-Care and Diabetes Distress*



Notes.  $N = 90$ . The figure shows the unstandardized path coefficients.

\* $p < .05$ . \*\* $p < .01$ .

Further examination of the moderation analysis suggested that as social support increases, the effect of self-care on diabetes distress decreases. This is presented in Table 15, which shows that low and median levels of social support have higher effect coefficients than high levels of social support, where its moderating effect loses significance. Furthermore, Johnson-Neyman significance test showed that beyond a social support score of 50, the effect of self-care on diabetes distress becomes insignificant.

**Table 16**

*Conditional Effects of Self-Care on Diabetes Distress at Values of Social Support*

<b>Social Support</b> <sup>a</sup>	<b>Effect</b>	<b>SE</b>	<b>t</b>	<b>p</b>	<b>95% CI</b>
40	-1.16***	0.28	-4.13	.0001	[-1.71, -0.60]
48	-0.55**	0.19	-2.94	.004	[-0.92, -0.18]
56	0.06	0.28	0.20	.843	[-0.50, 0.61]

*Note.* CI = confidence interval

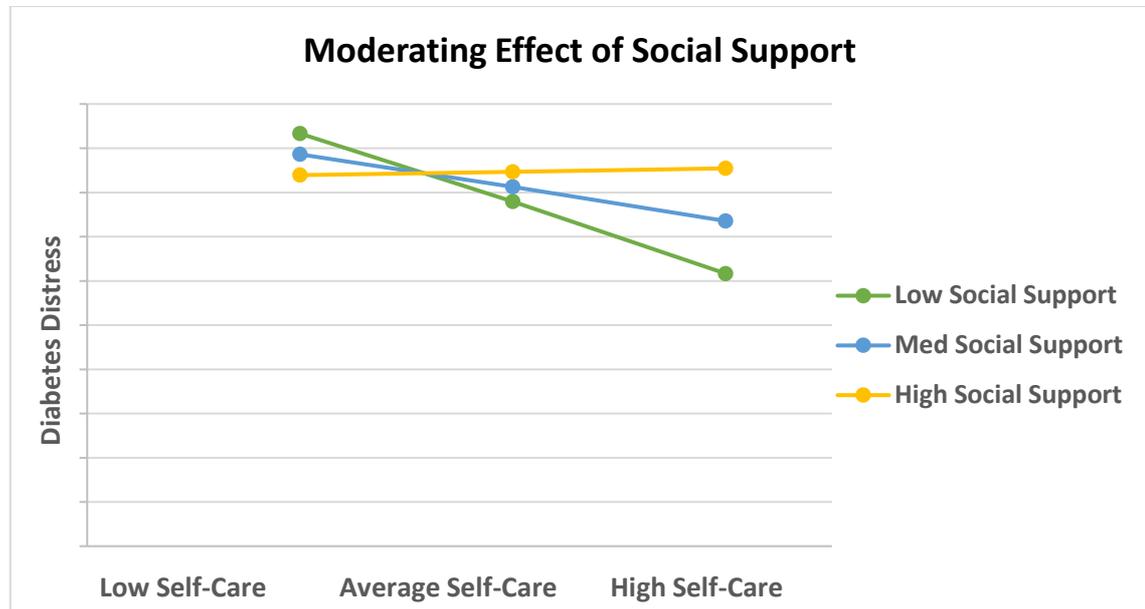
<sup>a</sup> Social Support scores at the 16<sup>th</sup>, 50<sup>th</sup>, and 84<sup>th</sup> percentiles

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Examination of the interaction plot in Figure 9 further demonstrates that at high levels of social support, self-care loses its effect on diabetes distress. At medium levels of social support, diabetes distress starts decreasing as self-care increases. However, the decrease in diabetes distress was the most prominent when individuals with high self-care practices had low social support levels.

**Figure 9**

*The Interaction between Social Support and Self-Care on Diabetes Distress Scores*



### **6. The Moderated Mediation Model**

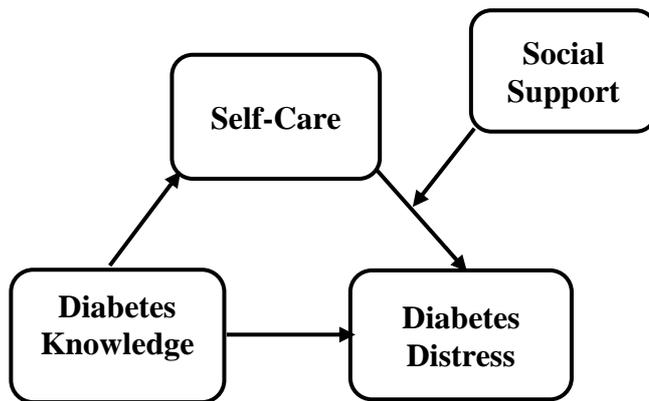
Moderated mediation is explained as “...moderated mediation occurs when the strength of an indirect effect depends on the level of some variable, or in other words, when mediation relations are contingent on the level of a moderator” (Preacher et al., 2007, p. 193). In other words, moderated mediation happens when the indirect effect of X on Y through a variable M, varies according to the levels of variable W.

In the study framework, we hypothesized that diabetes self-care will mediate the relationship between the predictors and health outcome, and that this mediation is moderated by the level of social support present during this time. Testing for the moderated mediation effect in the model was done using the moderated mediation analysis PROCESS model 14 (Hayes, 2015). This analysis investigates the moderating effect of social support on the mediation of self-care on the association between the predictor and outcome variables. Since we could not determine a mediating effect of

self-care on HbA1c, the test was run only on Diabetes Distress as the outcome variable and diabetes knowledge as the predictor variable. A visual presentation of this association is presented in Figure 10.

**Figure 10**

*Moderated Mediation Models of the Indirect Effect of Diabetes Knowledge on Diabetes Distress through Self-Care, Moderated by Social Support*



The analysis supported the hypothesized moderated mediation effect of the study model. In the model, the bootstrap 95% CI for the index of moderated mediation was from 0.024 to 0.569, which did not contain zero. This result confirms that the indirect effect of diabetes knowledge on diabetes distress via self-care differed according to the levels of social support.

Table 17 shows that the indirect effect of diabetes knowledge on diabetes distress through self-care was significant only in individuals with low to middle levels of social support. The moderated mediation effect was not detected at high levels of social support.

**Table 17***Indirect Effect According to Social Support Levels*

	<b>Social Support<sup>a</sup></b>	<b>Effect</b>	<b>BootSE</b>	<b>BootLLCI</b>	<b>BootULCI</b>
Diabetes Knowledge →	40	-3.87*	1.71	-7.73	-0.93
Self-Care → Diabetes	48	-1.69*	1.01	-4.05	-.15
Distress	56	0.49	1.29	-2.29	3.12

*Note.* LLCI = lower level confidence interval; ULCI = upper level confidence interval

<sup>a</sup> Social Support scores at the 16<sup>th</sup>, 50<sup>th</sup>, and 84<sup>th</sup> percentiles

\*Result significant at a 95% confidence interval level

## 7. Summary

This research attempted to identify the predictors of self-care and diabetes outcomes, namely, HbA1c, diabetes distress, and acute diabetes complications. The results showed that HbA1c was predicted by insulin treatment type, age at diagnosis, and self-care. Diabetes distress was predicted by diabetes knowledge, blood glucose monitoring type, self-care, and social support. In addition, acute diabetes complications were predicted by and the level of education of the head of the household. Finally, self-care was predicted by treatment site, age at diagnosis, and diabetes knowledge.

The results of the moderated mediation model indicated that (1) social support moderated the association between self-care and diabetes distress, (2) self-care had a partial mediating role on the association between perceived diabetes knowledge and diabetes distress, (3) and social support moderated the indirect link between diabetes knowledge and diabetes distress via self-care, but only in individuals with low to middle levels of social support. The greatest effect of this moderation was among individuals with lower levels of social support and decreased as social support increased reaching non-significant mediation at high levels of social support.

#### **D. Mixed Methods Results: Data Integration**

The final aspect of the analysis in mixed methods studies involves an integrated interpretation of the findings and presenting a meta-inference of the results. According to Teddlie and Tashakkori (2009, p. 152), “a meta-inference is a conclusion generated through an integration of the inferences obtained from the results of the qualitative and quantitative strands of a mixed method study.” The quantitative and qualitative data were integrated using the “themes-by-statistics joint display” technique, which is a visual display that brings the qualitative and quantitative findings together to provide a comprehensive understanding of the study findings and highlights the convergence or divergence of the data. Table 18 presents a comprehensive ‘statistics-by-themes’ joint display, where the findings related to each outcome, mediator and moderator variable are juxtaposed against relevant themes, subthemes and categories extracted with representative excerpts, with the final column interpreting the extent to which the qualitative and quantitative findings are consistent with each other.

**Table 18**

*Joint Display of the Quantitative and Qualitative Findings with Meta-Inferences*

Quantitative Results	Quantitative Results	Meta-Inferences	
	Themes, Subthemes, and Categories	Excerpts	Mixed Methods Interpretation
<b>Diabetes Distress</b>			
Diabetes Distress total score: 80.4 ± 25.6 (range 32–140), 34.4% of participants had moderate distress levels, 46.7% had high distress levels	<i>Aiming for a State of Equilibrium</i> Persistent diabetes stress	I am always dealing with everything as if I am not good enough and I am not complete... I relate this to my diabetes... Always thinking, what if diabetes ruins it...relationships, jobs, university, everything... And there is always this feeling that what if anything happens and I lose what I achieved or I lose even this whole life because of this disease... ( <i>Maya, 19 years</i> ).	<i>Convergence</i> The subtheme “Persistent Diabetes Stress” of diabetes suggested that diabetes negatively affected the psychological status of the participants. This finding validates the high overall diabetes distress scores, where 81.1% of the participants reported experiencing at least moderate distress levels.
Family/ Friends Distress subscale score: 11.0 ± 5.2 (range 4–24). Social Support score showed a positive correlation with the family/friends distress subscale, $r(88) = .22, p = .034$ . Want Social Support score 15.5 ± 0.6 (Range, 6-30)	<i>Aiming for a State of Equilibrium</i> Coping and Feeling Situated: Diabetes Impact on Personal and Professional Life  <i>The Catalysts - Facilitators of Self-Care:</i> Support from Others	Diabetes sometimes puts a strain on your relationship with your parents and that annoys me... I mean they [his parents] would keep nagging and saying: “test your sugar, take your injection, take care of yourself, take juice with you”.... things like that... ( <i>Kamal, 21 years</i> ).  I have a family that is very understanding of my condition and they provide me with everything I need to be able to take care of myself. They provide me with everything... everything I might need to feel comfortable. ( <i>Faten, 19 years</i> ).	<i>Convergence</i> The “Diabetes Impact on Personal and Professional Life” subtheme addressed how the diabetes-related interaction with family/ friends negatively affected the psychological coping of the participants. The moderately high Family/ Friends distress subscale score was confirmed by the comments of the participants when they requested more autonomy and trust from their parents. This was further reflected by the significant positive correlation between the total social support score and the Family/ Friends distress subscale score, and the low “Want” social support scores, indicating that the participants did not welcome

			high levels of involvement from their families and friends in their diabetes management. However, this negative effect was buffered by the family and peer support that the participants reported they received in the “Catalysts - Facilitators of Self-Care” theme.
Management Distress subscale score: 11.4 ± 4.7 (range 4–24)	<i>Aiming for a State of Equilibrium</i> Persistent Diabetes Stress: Diabetes Burnout	Honestly, it has been a lot of hard work. It increases your mental load... and the funny part is, I guide other people but I can’t do it myself, which is also a lot of pressure... So it’s really... it makes you feel bad about yourself because you feel you’re like a “false hero” in a sense (Layla, 29 years).	<i>Convergence</i> The “Diabetes Burnout” subtheme represented how the participants were affected by the strenuous demands of managing diabetes. The high “diabetes management distress” subscale score reflected this finding quantitatively.
Hypoglycemia Distress subscale score: 13.1 ± 5.5 (range 4–24)	<i>The Inhibitors - Barriers to Self-Care</i> Fear of Hypoglycemia	I become irrational and act based on my fear... I am afraid of insulin, of hypos... I am afraid of writing the right carb count [in the pump] because I am afraid of having a hypo. Even if I take the right amount of insulin, I would be in a state of panic for three hours because I would be scared of having a hypo... (Layla, 29 years).	<i>Convergence</i> The participants reported fear of hypoglycemia as a cause of anxiety and a barrier to practicing adequate self-care in the “Fear of Hypoglycemia” subtheme, which was consistent with the high hypoglycemia distress subscale score in our sample.
Negative Social Perception subscale score: 8.7 ± 4.6 (range 4–24)	<i>Aiming for a State of Equilibrium</i> Anger and frustration from diabetes stigmatization  Coping and Feeling Situated:	People shouldn’t say, “Oh poor so and so” for having diabetes because diabetes is not shameful and is not pitiful. This thing [diabetes] makes me special and unique in the society. Some people when they see me doing my injection, it really bothers me when they look at me with pity, they make me feel like I am different... No, I am not... I am just like you... (Maria, 22 years).	<i>Divergence</i> Eight of the participants reported feelings of anger and frustration from diabetes stigmatization, which reflected their distress from the society’s negative views towards people with T1D. However, this was not evident in the quantitative data since the negative social perception subscale score was relatively low. This can be attributed to the high levels of social support that the participants received from their community.

	Diabetes Impact on Personal and Professional Life	When I tell people I have diabetes, I feel they start caring for me more. ( <i>Kamal, 21 years</i> ).	
Physician Distress subscale score: $8.5 \pm 5.0$ (range 4–24). Follow-up with same physician since age 17: 46.7%	<i>The Reactants - Factors Affecting the Diabetes Experience</i> The Community: Health Care Providers  <i>Aiming for a State of Equilibrium</i> Wishes & Needs From health care professionals	It is like they [the health care team] are my fort, they protect me as I walk through. I mean the clinic visit that I take every three months, it sets the path that I need to take for the next three months, you know... ( <i>Sara, 25 years</i> )  I would ask to view the person coming to your clinic as a human with feelings and needs, he is not just a patient... Try to understand the psychological effect of living with this condition. Maybe this person is going through a psychological condition that is affecting his numbers... it's not only about the medications. ( <i>Layla, 29 years</i> ).	<i>Convergence</i> The quantitative findings showed that almost half the participants still followed-up with the same physician since age 17 years, which might explain the low scores of the physician distress subscale reported in the study. These results were reflected in the “Reactants -Factors Affecting the Diabetes Experience” theme, where the participants communicated a good relationship with their health care providers, and that the providers often acted as a support system during this period. Nevertheless, this did not negate the gap in care that some participants reported in the “Wishes & Needs From Health Care Professionals” subtheme, which involved a request for better communication with their health care providers and more attention from health care providers for their mental health needs.
Diabetes distress was correlated with technology Regression analysis: diabetes distress predicted by use of continuous blood glucose monitoring ( $B = -10.33, p = .044$ )	<i>The Catalysts: Facilitators of Self-Care</i> Technology and Treatment Advancements  <i>The Inhibitors – Barriers to Self-Care</i> The Economic Crisis	I felt that the sensor is something that really made it easier for me, especially when they had that app on the phone... This thing made it easier, not only on me, but for everyone with diabetes. I mean, I used to test around 5, 6, 7, 10 times an hour. Unconsciously I scan my phone, I mean it comes naturally and you unconsciously do it ( <i>Mira, 26 years</i> ).  We reached a stage in Lebanon where even if you do have the money, there is a shortage of supplies... the pump supplies, the insulin...	<i>Convergence</i> In the “Catalysts: Facilitators of Self-Care” theme, participants reported that technological assistance facilitated blood glucose checking, reduced anxieties, and alleviated the burden of diabetes management. In addition, in the “Economic Crisis” subtheme, the participants communicated their distress when they were unable to have access to these supplies. These findings validate the quantitative finding when the use of technology was found to predict lower diabetes distress levels within our sample.

everybody is affected by the insulin shortage. I am ordering my pump supplies from abroad. I am scared that one day I won't be able to secure the pump supplies, I would have to remove the pump... (Yasmeen, 21 years).

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**Diabetes Self-Care**

Diabetes Self-care scores  
69 ± 13.4  
(range 26 -96)

*The Reactants:  
Factors Affecting the  
Diabetes Experience*  
The Emerging Adult:  
Changes in self care

Now I calculate my carbohydrates, for example, I take one unit [of insulin] for every 15 grams. I'm better at this now... I always have with me juice or candy when I go out in case I had a low blood sugar... I didn't use to do that before... I'm also testing my blood sugar more than before... (Karim, 21 years).

*Convergence*  
In the "Change in Self-Care" subtheme, the participants explained how their self-care skills and abilities improved during this period. This validates the high mean scores of the measured diabetes self-care.

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Significant positive association between self-care scores with clinic visits, and receiving formal diabetes education ( $p = .041$  and  $.018$  respectively).  
Regression analysis: better self-care was predicted by treatment at the CCC ( $B = 8.24, p = .002$ )

*The Reactants -  
Factors Affecting the  
Diabetes Experience*  
The Community:  
Health Care  
Providers

There is some information that I needed to know, you could say that they gave me all the information that I need to know. So now, I am ready to be alone in managing these issues. (Yasmeen, 21 years).  
  
So if I forget anything about carb counting, they [diabetes educators] would remind me... if I forget how to do corrections [for her blood sugar levels], what to take before I sleep, whether or not to take a snack before I sleep... these kind of things and details. I mean we revise and go over everything, and we double-check our doses, my doses. (Sara, 25 years).

*Convergence*  
Self-care was correlated with attending two or more clinic visits during the last year; and self-care scores were higher when the participants were followed-up at the CCC, which has a team of diabetes educators who provide structured diabetes education to their patients. These relationships were explained qualitatively in the "Reactants -Factors Affecting the Diabetes Experience" theme where the participants reported how their diabetes educators provided them with the knowledge and support they needed to improve their diabetes self-care practices.

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Regression analysis: self-care was predicted by diabetes

*The Reactants:  
Factors Affecting the  
Diabetes Experience*

Around 3 to 4 years ago, I started taking better care of myself, I started to read more about diabetes. I started to read about different

*Convergence*  
The "Increased Knowledge of Diabetes Management" and "Changes in Self-Care"

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knowledge ( $B = 5.45$ , $p < .001$ )	<p>The Emerging Adult: Increased Knowledge of Diabetes Management</p> <p>The Emerging Adult: Changes in Self-Care</p>	<p>insulin types, impact of food, glycemic index, protein, carbs, all those things... So I started to have a better understanding of how food impacts my glucose. (Sara, 25 years).</p> <p>It [diabetes self-care] is different now, because now I am more aware of what to do... I understand my doctor's way of adjusting my sugar levels, so I am taking better care of myself, I am more attentive to what I eat, I play sports, things like that... (Rola, 19 years).</p>	<p>subthemes explain how during emerging adulthood the participants were motivated to learn more about diabetes and its management, which in turn resulted in improved self-care practices. This went in line with the quantitative findings of higher knowledge predicting better self-care.</p>
No significant association was detected between self-care and technology	<p><i>The Catalysts: Facilitators of Self-Care</i></p> <p>Technology and Treatment Advancements</p>	<p>Honestly, the pump and the sensor played a very big role in my life... At first, I was really against wearing them... I didn't know that the pump is that easy to use, and that it doesn't bother you, on the contrary, you control it... (Yasmeen, 21 years).</p>	<p><i>Divergence</i></p> <p>The "Technology and Treatment Advancements" subtheme was not consistent with the quantitative data since there was no significant association between insulin treatment method or blood glucose monitoring type and self-care. However, the technology effect was reflected through other quantitative findings where insulin pump therapy predicted better HbA1c levels, and the use of continuous blood glucose monitoring predicted lower diabetes distress scores. The small number of participants who had the pump could partially explain these findings</p>
<b>HbA1c</b>			
<p>Recent HbA1c: <math>7.7 \pm 1.4</math></p> <p>Pre-COVID-19 HbA1c: <math>8.3 \pm 1.5</math></p>	<p><i>The Catalysts: Facilitators of Self-Care</i></p> <p>COVID-19</p>	<p>Yes, for me it [COVID] had a very positive effect on my diabetes. Staying home during quarantine played a very big role and made it easier for me to manage my diabetes... My diabetes before COVID was much different than after COVID... because during this</p>	<p><i>Convergence</i></p> <p>In the qualitative interviews, participants pointed several contradictory ways that COVID-19 affected their diabetes management and glycemic levels. Some stated that they were able to achieve better glucose levels during the pandemic and</p>

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<p>Wilcoxon Signed Rank test: <math>Z = -.35</math>, <math>p = .001</math></p>	<p><i>The Inhibitors – Barriers to Self-Care COVID-19</i></p>	<p>period, I invested in myself to learn more about diabetes, about how to manage by myself... (Rami, 20 years).</p> <p>During COVID, we stayed at home and I started eating like crazy. We had food deliveries [from restaurants] all the time, and all the time eating fast foods and unhealthy foods. I mean I am not a very healthy person in general, but COVID really affected this aspect. (Maya, 19 years).</p>	<p>considered it as a facilitator to better self-care, while others considered it as a barrier. The quantitative results came in favor of the facilitating role of COVID-19 by showing that the participants had better HbA1c levels during the pandemic than they had before COVID-19.</p>
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**Social Support**

<p>Social support subscale scores: Get score <math>21.0 \pm 0.6</math>, (Range, 6-30) Want score <math>15.5 \pm 0.6</math> (Range, 6-30)</p>	<p><i>The Reactants: Factors Affecting the Diabetes Experience</i> The Community: The Parents/ Family Members</p> <p><i>Aiming for a State of Equilibrium</i> Wishes &amp; Needs From Parents</p>	<p>The maximum help my mom gives me is that she sometimes changes my insulin pen needle. She would say, “Did you change the needles? Let me change them for you”. That kind of help... Some days if I was very low [blood sugar], she would make me juice or something. Even though I have a stock of juice boxes, so I would just grab one and drink it, so I do not really need the help... (Sara, 25 years).</p> <p>I would definitely have my parents worry less about me... I mean if it is not a big deal for me, don’t make it for you. I would have them worry much less, because now they worry all the time... and this stresses me out... (Rami, 20 years).</p>	<p><i>Convergence</i></p> <p>The “Reactants: Factors Affecting the Diabetes Experience” theme stated how parents were reluctant to relinquish control and were still involved in the diabetes management of their children. This support was evident by the high scores of the received social support (GET subscale scores) reported in the quantitative findings. On the other hand, in the “Wishes and Needs from Parents” subthemes, the participants reported a need for more autonomy and wished less involvement and more trust from their parents. This was also reflected by the relatively low WANT scores of the social support scale, which reflects lower levels of wanting or needing support from family or friends.</p>
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## ***1. Summary of the Integrated Findings***

For the most part, the qualitative findings concurred with the quantitative results, with few exceptions. Results of the integrated analyses are discussed below.

### **a. Diabetes Distress**

The quantitative data indicated a negative psychological effect of diabetes, with high diabetes distress scores among the majority of the participants. This was supported by the qualitative interviews when the participants identified that diabetes burnout, parents' over-involvement in their diabetes management, fear of hypoglycemia, diabetes stigmatization, and fear for their future were causes of psychological distress during this period.

In addition, despite reporting some needs from the health care providers like a need for mental health assessment and better communication, participants overall expressed high levels of support from their providers, which was consistent with the low physician distress sub-scale scores. Moreover, the quantitative findings showed the benefits of technology use in lowering diabetes distress levels and in predicting improvements in glucose levels. The participants also communicated this positive effect in the qualitative interviews where they stated that technology use promoted better self-care practices and helped relieve the burden of diabetes management.

### **b. Diabetes Self-Care**

In the qualitative interviews, the participants reported a change in their self-care practices and abilities, which they attributed to assuming responsibility of their diabetes care and acquiring more knowledge about diabetes management during this period. The

participants also considered their health care providers as a major source of knowledge and referred back to them when they had any questions or concerns. The quantitative results reflected this improved self-care status through the high reported diabetes self-care scores. In addition, self-care was correlated with attending two or more clinic visits during the last year; and the regression analysis showed that self-care was better when participants had higher knowledge of diabetes management and when they were followed-up at the CCC. Having access to diabetes education through regular follow-up at the diabetes clinics and the support of diabetes educators showed a positive effect on the level of knowledge, consequently improving self-care practices.

One qualitative finding that was not supported by the quantitative results was the positive effect of technology on diabetes self-care stated by the participants. There was no significant association between insulin treatment type or blood glucose monitoring type and self-care; it is worth noting that only two participants (13%) in the qualitative arm of the study used the insulin pump, similar to the percent in the whole sample (12 out of 90). Nevertheless, the technology effect was reflected through other quantitative findings where insulin pump therapy predicted better HbA1c levels, and the use of continuous blood glucose monitoring predicted lower diabetes distress scores.

### c. HbA1c and COVID-19

In the qualitative interviews, the participants described the negative and positive effects of COVID-19 on their diabetes management and glucose levels. The negative effects included poor psychological adjustment and self-care practices, while the positive effects included more time to manage diabetes and better self-care practices. Quantitative results indicated that the positive effects of COVID-19 outweighed its

negative ones, since participants had better HbA1c levels during the pandemic compared to what they had before COVID-19.

d. Social Support

Social support was a complex factor that had a wide range of influence on the participants and their diabetes. The need for autonomy caused the participants to view social support mostly from parents as a cause of stress, which validated the positive correlation between social support and the family/friends distress subscale. In addition, the participants reported the reluctance of their parents to relinquish control of diabetes management, which was evident by the high received social support scores reported in the quantitative findings. Likewise, the participants wanted more autonomy in managing their diabetes, which was reflected by the low scores of the 'WANT' social support sub-scale.

The merged analysis facilitated our understanding of the experience of the EAs and helped us to develop our key insights, which we present in the following discussion section.

## CHAPTER V

### DISCUSSION AND CONCLUSION

This chapter includes a discussion of the study qualitative, quantitative and integrated findings in light of the study aims, theory and the empirical literature, the study limitations, the implications for practice and recommendations for future research. The chapter ends with a conclusion.

#### **A. Discussion**

##### ***1. Demographic Characteristics of the Participants***

There is no official diabetes registry for the prevalence or incidence of T1D in Lebanon. Therefore, we could not compare the demographic characteristics of the study sample to those of the T1D population in Lebanon. The study participants had a mean age of  $22 \pm 3.2$  years, with the majority (89 %) being single. This goes in line with the demographic characteristics of the Lebanese population in general, where the mean age of marriage for men to be 32.3 and for women 28.3 years, respectively (United Nations, 2017). Moreover, the vast majority (94.4%) of the participants lived with their parents/spouses, which reflected the collectivist characteristic of the Lebanese society of children continuing to live with their parents until marriage.

Despite the higher rate of the male to female population for people aged 0-24 years in Lebanon (104.95 males per 100 females), almost two thirds of our sample were females (Lebanon - Male to female ratio, n.d.). This percentage was consistent among the three treatment sites. Globally, there is no clear pattern of gender distribution in the prevalence of T1D, since on average girls and boys are equally diagnosed with T1D in young populations (Maahs et al., 2010). However, a higher prevalence of T1D in males

was noted in regions with high incidence of T1D, whereas a higher prevalence of T1D in females was noted in regions with a low incidence (Maahs et al., 2010).

Our sample had high levels of education, with around 95% being university students or graduates. This result was higher than the reported percentage of enrolment in tertiary education in Lebanon of 59.59 % in 2019 (Lebanon - Percentage of Enrolment in Tertiary Education, n.d.). In addition, around half of the head of households in the sample had university education. Moreover, the crowding index reported by the participants was relatively high (Mdn = 1). These findings might indicate a bias in our convenience sample of being on the upper end of the socioeconomic level. On the other hand, despite that the majority of the sample (86.7%) reported having health coverage, 17.8% of those stated that it did not include diabetes-related health coverage. This indicates that around 30% of the participants did not have health coverage for their diabetes. This high percentage is worrisome, especially in light of the increasing cost of healthcare in Lebanon due to the current economic crisis.

Forty percent of the participants reported smoking cigarettes or Hubble Bubble, and 20% reported drinking alcohol. The age range of the time they started smoking was between 14 and 23 years, while for alcohol it was between 16 and 20 years. These age ranges reflect the increased health-risk behaviors of the EAs in general (Arnett, 2000; Bachman et al., 1996), and within those living with T1D (Lee Tracy et al., 2019; Palladino et al., 2013). It also represents the age at initiation of these risky behaviors in the Lebanese population (Abdo et al., 2016; Salameh et al., 2014). These findings suggest the need for raising awareness about the detrimental effects of these risky behaviors in this vulnerable population.

## ***2. Clinical Characteristics and Health Outcomes of the Participants***

Even though the majority of the participants (56.7%) were followed-up at an adult diabetes clinic, 20% still attended pediatric diabetes clinics. This finding might indicate a reluctance of some participants to move to adult clinics, since they become more comfortable with the physician over the years. In addition, many physicians left the country in the past three years because of the economic crisis, leaving patients with few options to change their physicians; this is supported by 46% reporting keeping the same physician after age 17. This reluctance in healthcare transition from pediatric to adult clinics was reported in previous studies (Agarwal et al., 2017), and is worth investigating in future work. It is important to note the reduced cost of care (until age 21 years) and care delivery method provided at the Chronic Care Center. Usually, the participants at the Center follow up with an adult endocrinologist after turning 18 years; however, aside from the physician, the same multidisciplinary health team care for all patients of all age groups. As for clinic attendance, around 30% of the participants had less than the recommended two clinic visits per year. This suboptimal finding was similar to other findings revealing a decrease in the number of clinic attendance during emerging adulthood (Peters & Laffel, 2011; Pyatak et al., 2017).

Technological advancements in terms of insulin treatment type was minimal in our sample, with only 13.3% of the participants on insulin pump therapy. Contrariwise, technology use was more prominent in blood glucose monitoring, with 36.6% of the participants using continuous glucose monitoring devices. We have no diabetes registry of the number of people with T1D on insulin pump therapy, nor on those using continuous glucose monitoring devices. Hence, we cannot determine how the use of technology in our sample diverged from that of the T1D population in Lebanon.

Around one-third of the participants (34.4%) reported that they did not receive formal diabetes management education from a health care worker. This result was supported by the suboptimal perceived knowledge level of diabetes management of the participants, since only 44% of the participants reported to have “good” or “fair” levels of diabetes knowledge. This finding is alarming within the context of T1D in emerging adulthood, since self-management education and the individual’s knowledge of disease management are key components of improved diabetes-related health outcomes (Agarwal et al., 2017; O'Hara et al., 2017).

### ***3. The Experience of EAs Living with T1D in Lebanon***

This study aimed to explore the experience of EAs with T1D living in Lebanon. The findings indicate that the life experiences of the EAs are like going through a chemical reaction where they go through change and breaking parental bonds. The EAs connect with other reactants, like their community and society, with the influence of catalysts and inhibitors of adequate self-care practices. Eventually, the EAs try to find equilibrium by feeling situated and coping with diabetes, and voicing their wishes and needs from their environment

Participants experienced cognitive and attitudinal changes, which prompted them to break their parental bonds by demanding autonomy from their parents and shying away from parental supervision. The decreased parental involvement in their children’s diabetes management was reported in two qualitative studies (Chiang et al., 2020; Johansen, Rothmann, et al., 2020), and conformed with the developmental changes of needing autonomy and breaking of ties described in the emerging adulthood theory (Arnett, 2000). In parallel with demanding autonomy, the participants reported that they

felt a need to assume responsibility for their own health. Similar to other findings (Chiang et al., 2020; Johansen, Rothmann, et al., 2020), the participants no longer asked for assistance from their parents, but took control of managing their diabetes.

The experience of the participants was affected by three main factors including, the EAs, the community, and the society as a whole. The participants experienced changes in their self-care practices and sought diabetes knowledge, a finding previously reported by Majumder et al. (2016). However, the improvement in self-care in our sample was contrary to the reported worsening of self-care behaviors during emerging adulthood reported in two studies conducted in the USA (Hendricks et al., 2013; Ramchandani et al., 2019). Even though studies reported that self-care practices increased during emerging adulthood, there was no indication of an improvement in the quality of those practices (Abdoli et al., 2017; Ramchandani et al., 2019). This signifies that increased sense of responsibility does not always lead to better self-care. However, our participants' improved self-care might be further explained by their reported increased diabetes knowledge during this period, which contributes to self-care (Riegel et al., 2012). Our findings conformed to the postulations of the Transition theory, where awareness of the changing roles, coupled with preparation and increased knowledge, are assumed to result in improved well-being.

The interaction with the community included the relationships with family, peers, social media, and health care professionals. Parental involvement in the daily care of their children greatly decreased during this period. However, some participants still needed support from their parents and reported improved mental well-being when they could share the burden of their diabetes with their family members. A scoping review of 16 qualitative and 10 quantitative studies documented similar positive effects of

parental support, which included reduction of feelings of stress, anxiety, diabetes burnout, depression, and promotion of coping with the disease (Johansen, Rothmann, et al., 2020). In addition, the participants sometimes turned to their parents for information about self-care practices and requested assistance during acute complications, a finding reported in other quantitative studies (Pyatak et al., 2017; Visagie et al., 2018).

Moreover, in congruence with other research (Hanna, Weaver, Stump, et al., 2014; Johansen, Rothmann, et al., 2020; Montali et al., 2022), the EAs still received tangible aid from their parents, such as keeping track of supplies, making appointments, and paying for diabetes treatment. These findings reflect the residual need for parental support during this period, as these EAs are still navigating the path to adulthood.

Alternatively, some parents insisted on giving unsolicited assistance to their children with their diabetes care. This involvement reflects the difficulty the parents face while they transition from being almost completely involved in their children's diabetes practical care to no involvement at all (Johansen, Rothmann, et al., 2020). However, consistent with another study (Hanna, 2012), participants reported that over-involvement of parents in their care hindered their successful mastery of adult roles, and often led to conflict, which added a strain on their relationship. In collectivist cultures, this parental conflict might pose a bigger problem since EAs in Lebanon get more involvement from parents than in individualistic cultures. This consequently amplified the negative effect of parental involvement in our sample and led to increased distress levels. The role of parents is part of the community component in the Transition Theory. These findings delineate the intricacies in the effect of parental involvement on EAs with T1D.

Our findings indicated a clear distinction between peers who did not have diabetes and peers with diabetes. Similar to recent findings (Johansen, Pouwer, et al., 2020; Ng et al., 2021), peers without diabetes had a marginal effect in terms of diabetes care and psychological support as compared to those with diabetes. This finding was attributed to the participants' reluctance to involve their peers in their diabetes due to the common lack of awareness of T1D within the society. However, when participants experienced a supportive relationship with their peers, they reported that it prompted them to accept their diabetes and facilitated their diabetes management, a finding that was reported in other studies (Kelly et al., 2018; Pihlaskari et al., 2018; Wiebe et al., 2018). On the other hand, consistent with previous findings (Habenicht et al., 2018; Helgeson et al., 2014), negative peer and public interaction was reflected through the appearance of a clear pattern of daily diabetes management distress, feeling alone and unsupported in one's diabetes care, and fear of negative social perceptions of the disease within the participants.

Interactions with peers with diabetes or "DiaBuddies" helped reduce feelings of isolation by sharing experiences, and promoted a sense of acceptance and coping with diabetes in this study and others (Montali et al., 2022; Ng et al., 2021). In addition, the DiaBuddies provided a readily accessible source of knowledge and diabetes self-care support. In line with our findings, the positive effect of the supportive role of peers with diabetes on the physical and psychological well-being of the EAs has been widely recognized in recent work (Abdoli et al., 2017; Montali et al., 2022; Ng et al., 2021; Pihlaskari et al., 2018; Saylor et al., 2018). Sometimes, participants had face-to-face interactions with other people with T1D through diabetes-related recreational or educational activities. During these interactions, acting as a role model for others with

T1D was reported as a motivation for the participants to take better care of their health, as noted in a recent study by Johansen, Pouwer, et al. (2020). In that study, the authors did a qualitative analysis of blogs shared by patients with T1D. At other times, social media platforms, which are becoming a popular venue for interaction with other people with T1D (Johansen, Pouwer, et al., 2020), provided a more accessible meeting space for the participants to connect and share experiences with their DiaBuddies.

As for health care providers, our findings diverged from previous studies (Ng et al., 2021; Ramchandani et al., 2019), since participants mainly reported a good relationship with their health care providers. In addition to knowledge transfer and medical management, the health care providers offered emotional support, especially from diabetes educators. This support was the most pronounced when a multidisciplinary team provided the care, highlighting the significance of this approach, as reported by Joly (2015). The support received from the community facilitated the performance of diabetes self-care behaviors by providing the participants with the knowledge and confidence they needed during this period.

At the social level, stigma was the main experience reported by the participants. Consistent with previous findings (Browne et al., 2014; Chiang et al., 2020; Montali et al., 2022), stigma was perceived at varying levels ranging from low, like showing feelings of pity and lack of awareness about T1D and confusing it with T2D, to high levels expressed by discrimination against them in the workplace. The participants reported the interpersonal difficulties caused by stigmatization, which affected their perception of having diabetes, and led to increased diabetes stress, a finding similarly reported in a recent integrative review (Wentzell et al., 2020). Therefore, parental and

social interactions contributed to the persistent stress experienced by the participants, subsequently challenging their attempt to reach equilibrium.

Another factor that the participants alluded to in relation to their self-care was the use of technology. Even though other studies reported that technology had a double role as a facilitator and a barrier to self-care (Los et al., 2016; Maiorino et al., 2013; Montali et al., 2022), our participants reported that technology facilitated their self-care by reducing the burden of their diabetes management and providing flexibility. It is possible that the advantages of using CGM and insulin pumps outweighed their disadvantages in our sample because it helped decrease the mental effort needed to manage diabetes, and provided them with a sense of safety and confidence to manage their diabetes.

Participants reported that the burden of managing diabetes was amplified during emerging adulthood due to losing the predictability of the daily routines they had when they were younger, as previously reported by Montali et al. (2022). In addition, participants reported that diabetes burnout and the demands of being a grown-up often interfered with their diabetes management and negatively affected their mental well-being, a finding that was also noted in previous research (Hanna, Weaver, Slaven, et al., 2014).

Fear of diabetes complications acted as a facilitator of self-care when participants feared the effects of long-term complications of diabetes on their health and future. However, fear of acute complications, such as fear of hypoglycemia, resulted in poor self-care practices and poor glycemic control, as noted in other studies (Abdoli et al., 2017; Martyn-Nemeth et al., 2017). The mental distress experienced due to the fear of complications, the daily burden of managing diabetes, and the diabetes-related negative

interpersonal interactions, often led to the participants neglecting their diabetes and taking harmful diabetes decisions. Alternatively, psychological well-being was an important factor that facilitated good self-care practices, a finding that was reported in a qualitative study that analyzed web blogs by EAs with T1D (Johansen, Pouwer, et al., 2020).

It is also important to mention the grave consequences of the economic crisis in Lebanon on the physical and mental health of the participants. Difficulty to access insulin and diabetes supplies was a continuous source of stress, and sometimes compelled the participants to employ harming measures, like rationing their insulin and using insulin past its expiry date, to maximize their supplies. Insulin insecurity is a concept that was addressed in a study by Willner et al. (2020), which indicates difficulty in accessing insulin with the fear of a future loss of access. Experiencing insulin insecurity results in high levels of anxiety and distress, and places EAs at high-risk of developing short- and long-term complications of diabetes (Willner et al., 2020). This finding is unique to this study and significant as it affected not only the poor and uninsured, but also everyone due to the economic crisis in the country.

Another original finding related to the COVID-19 pandemic, which had a contradictory relationship with diabetes. It acted as a facilitator to diabetes self-care when participants feared the complications of poor control and kept a tight control on their blood glucose levels, so that they avoid hospitalization and exposure to COVID-19. Participants also had more time to focus on their disease self-management, which contributed to their improved diabetes health. Similar findings were reported in another study where an improvement in glycemic control was noted during the lockdown, which was attributed to a routine lifestyle and reduced work-related distress (Aragona et

al., 2020). On the other hand, in line with other research (Joensen et al., 2020; Tejera-Perez et al., 2021), COVID-19 acted as a barrier to self-care as some participants engaged in poor health behaviors such as poor diet, and experienced anxiety and distress due to the disruptions to their lives.

Ultimately, the participants attempted to find a way to reach their equilibrium by normalizing the disease and integrating it at the identity level. These themes were similar to other findings, where normalizing diabetes led to a better acceptance of T1D and promoted diabetes self-care (Johansen, Pouwer, et al., 2020; Montali et al., 2022). In addition, by identifying with their diabetes and realizing their high levels of resilience, the participants felt more empowered to face the daily challenges of living with T1D (Abdoli et al., 2017; Johansen, Pouwer, et al., 2020).

Being situated and acquiring confidence was reported in the Transition theory as an indication of successful transition into a new role (Meleis et al., 2000). The participants voiced that they still did not reach their equilibrium, as reflected in the persistent stress of diabetes that they reported because of the social stigma, burnout and fear for the future. They reported a need for more trust and independence from their parents in managing their diabetes. Consistent with a recent review on parental support for EAs with T1D (Johansen, Rothmann, et al., 2020), participants did not want to be dependent on their parents; however, they wanted them to be available when needed.

Regarding the health care providers, the findings suggested the presence of some gaps in the patient-health care provider relationship. Participants highlighted the lack of attention to their mental health, and requested integrating mental health assessment into their care due to its notable impact on their diabetes-related health. They also needed more diabetes knowledge, as well as better access to their providers by having more

time during the clinic visits. Time constraints and the need for better access to health care providers during emerging adulthood was also reported in a systematic review of clinic attendance among EAs with T1D (Hynes et al., 2016).

The needs from the society mainly revolved around decreasing diabetes stigmatization through increasing awareness about T1D, which was reported in prior research (Abdoli et al., 2017; Chiang et al., 2021). Lastly, the EAs requested healthcare support and better access to insulin and diabetes supplies from the government, especially during these challenging times.

Our findings fit well the a-priori framework derived from the Transition and Self-Care theories where the personal factors, the community, and the society affected the ability of the participants to achieve optimal health; and where the self-care abilities were affected by knowledge, social, and healthcare support, and influenced the EAs' physical and mental well-being.

#### ***4. Diabetes-Related Health and Associated Factors***

##### ***a. Glycemic Control and Diabetes-Related Complications***

Our sample had a median HbA1c level of 7.7 %, with 70 % of the participants having HbA1c levels above the recommended target of < 7%. Similar findings were reported in another study, where only around 20% of EAs met the recommendations for glycemic control (Bryden et al., 2003). However, studies reported higher levels of HbA1c among the EAs than our sample with mean values of 8.3% (Hendricks et al., 2013) and 8.2% (Zoffmann et al., 2014). This finding might indicate a better glycemic status in our sample despite not reaching the recommended target. A better indicator of glycemic control than HbA1c would be to measure times-in-range (Beck et al., 2019).

However, this was not feasible to measure since it requires participants to be on continuous glucose monitoring.

Regarding diabetes-related complications, half of the participants reported at least one acute diabetes complication during the past six months. Participants mainly reported experiencing severe hypoglycemia (46.6%) with a median number of three events (range 2-5), and only 4.4% experienced one DKA event during the past six months. Similar prevalence rates of severe hypoglycemia were reported in previous studies (Pedersen-Bjergaard & Thorsteinsson, 2017; Pinés Corrales et al., 2021). However, the prevalence of DKA events in this study were lower than the numbers reported in another study (Bryden et al., 2001), which could be attributed to the better HbA1c levels in our study sample. Contrary to other findings of worse diabetes health among older EAs (Garvey et al., 2012; Tanenbaum et al., 2017; Vallis et al., 2018), none of the health outcomes differed by age between young EAs (18–24 years old) and old EAs (25–29 years old) in this study.

Regression analysis showed that lower HbA1c levels were predicted by using insulin pump therapy, being diagnosed at an older age, and better diabetes self-care. The effect of insulin pump therapy on glycemic control has been well documented in the literature, and was attributed to an increased treatment flexibility and decreased blood glucose variations (Karges et al., 2017; Pickup, 2012). A previous study including a sample of Lebanese youth with T1D showed an association between the use of insulin pump therapy and better glycemic control measured by HbA1c (Bayrakdar et al., 2014). The insulin pump therapy possibly had another indirect effect on HbA1c levels. In the qualitative interviews, participants communicated the effect of technology use on facilitating their self-care practices and reducing the burden of diabetes management, a

finding reported in previous research (Maiorino et al., 2013). It is worth noting that in a study of 1,503 adults with T1D (age between 18 to 80 years old) in USA, EAs had a lower rate of utilization of diabetes technology than older age groups (Tanenbaum et al., 2017). The authors reported that EAs had the lowest rates of insulin pump use, highest diabetes distress levels, and highest HbA1c levels compared with older age groups (Tanenbaum et al., 2017). This finding corroborates the importance of technology use on the health outcomes of the EAs and emphasizes that this age group would particularly benefit from interventions that would increase their acceptance of or access to technology use.

The relationship between age at diagnosis and glycemic control was noted in previous work, and is likely due to the progressive loss of beta cell function over the years (Khadilkar & Oza, 2022). As for diabetes self-care, the predictive association was not surprising since this relationship has been widely documented in previous research (American Diabetes Association, 2020g; Egan et al., 2015; Pyatak et al., 2017). The quantitative results showed a trend for better self-care ( $p = .06$ ) as the age at diagnosis increases in this study, which is probably the result of patients being more mature as they develop the disease, which makes learning and practicing self-care more likely. The participants reported an improvement in self-care practices in the qualitative interviews, and had relatively high diabetes self-care scores, which might explain the lower HbA1c levels reported in our sample compared to other studies.

None of the variables except for level of education of head of household predicted the incidence of acute diabetes complications in our study, which might be explained by an increased ability of educated parents to convey diabetes management to their children. This finding was not reported in previous studies of EAs with T1D. On the

other hand, a study including children with T1D in Saudi Arabia reported a negative association between HbA1c levels and the level of education of mothers, regardless of their socio-economic status (Al-Odayani et al., 2013).

b. Diabetes Distress

The translated Arabic version of the T1-DDS showed an excellent reliability score that was comparable to the original tool results, which reflected the internal consistency of the tool. The majority of the participants (81.1%) reported at least moderate distress levels. A further breakdown of distress categories showing that 34.4% had moderate distress levels, and 46.7% experienced high distress levels related to diabetes. These numbers are higher than what was reported in previous studies, where the prevalence of diabetes distress ranged between 28% and 60% (Downie et al., 2021; Lašaitė et al., 2016; Vallis et al., 2018). The high prevalence of diabetes distress in our sample might be related to the unique circumstances that the EAs were passing through during the timing of the study, namely the Lebanese economic crisis and the COVID-19 pandemic, over and above being and emerging adult. The qualitative findings highlighted the negative psychological effect of the economic crisis when participants reported living in constant fear of not being able to secure their insulin and diabetes supplies. The participants also reported the negative consequences that COVID-19 had on their psychological well-being, a finding that was supported in few recent studies (Joensen et al., 2020; Tejera- Perez et al., 2021).

In this study, diabetes distress was significantly associated with crowding index and diabetes education, and was predicted by diabetes knowledge, blood glucose monitoring type, social support, and self-care. A higher crowding index, which

indicates lower socioeconomic status, was associated with higher distress scores. Only one study examined this association and found that lower diabetes distress was associated with higher socioeconomic status (Stahl-Pehe et al., 2019). In addition, receiving formal diabetes education was negatively associated with diabetes distress in our sample. This was in line with other findings that showed a positive impact of structured education programs on diabetes distress levels in emerging adulthood (Egan et al., 2015).

A predictor of diabetes distress in our study was knowledge of diabetes management, which further compliments the association between receiving formal diabetes education and diabetes distress. L. Fisher et al. (2018) reported that diabetes knowledge had a moderating effect on the association between transition intervention programs and diabetes distress reduction. Additionally, diabetes knowledge may also indirectly affect diabetes distress through its noted influence on diabetes self-care practices (Agarwal et al., 2017).

The literature indicates a significant association between self-care and diabetes distress (Lašaitė et al., 2016). Moreover, the relationship between the two variables is a bidirectional one. Most studies considered self-care as an outcome variable affected by diabetes distress (Chan et al., 2020; Pallayova & Taheri, 2014; Wentzell et al., 2020). In our study, we considered diabetes distress as a diabetes-related outcome affected by behavioral and personal factors. Similar to our findings, few studies reported that self-care predicted diabetes distress (E. Fisher et al., 2018; Mohn et al., 2015; Pallayova & Taheri, 2014; Vallis et al., 2018). The cross sectional design of this study and the qualitative findings allow the possibility of inferring a bi-directional relationship between self-care and diabetes distress.

Continuous glucose monitoring use was another predictor of lower diabetes distress levels. The utilization of continuous glucose monitoring has been associated with better diabetes health outcomes and lower diabetes distress levels (Abdoli et al., 2017; Polonsky et al., 2017). Contrary to these findings, sometimes technology use was associated with some distress related to device malfunctions or some physical barriers to wearing the device (Los et al., 2016; Montali et al., 2022; Tanenbaum et al., 2017). Our study participants experienced only a positive impact of technology use and communicated that it facilitated self-care practices, alleviated the burden of disease management, and reduced diabetes-related anxieties. The timing of data collection for this study during the pandemic could partially explain this positive association since the participants were restricted in their activities during lockdown and later because of the economic crisis.

c. Diabetes Self-Care

The Arabic translated version of the SCI-R scale showed good reliability with Cronbach's alpha coefficient score of .77. This value is lower than the reliability score reported in the original scale development of .87, but is comparable to other translated versions of the scale with scores ranging from .63 to .78 (Jansà et al., 2013; Mumtaz et al., 2016; Teló et al., 2020), indicating its suitability for use in this study.

The study sample showed good levels of diabetes self-care of 69%. This score was compared to other studies conducted in Spain and the USA that used the SCI-R to measure self-care in individuals with T1D, with scores of 69% in 125 people with T1D (mean age =  $36 \pm 18$  years) (Jansà et al., 2013), and 57.9% in 57 people with T1D (mean age =  $30 \pm 8$  years) (Weinger et al., 2005). However, these studies included an older age

group than our sample, which further supports the higher level of self-care practices reported by our EAs, especially in light of the positive association between age at diagnosis and self-care.

Diabetes self-care was predicted by age at diagnosis, diabetes knowledge, and treatment site. These results reflect the claims of the Self-Care Theory where cognitive and functional abilities, knowledge, experience and skills, and access to care are postulated to affect self-care behaviors in individuals with chronic illness (Riegel et al., 2012). Our results suggested that having T1D at an older age predicted better self-care practices. A similar finding was noted by Hendricks et al. (2013), when the authors reported worse self-care behaviors with longer diabetes duration. So, it may be that developing diabetes at an older age is related to a mature person at all levels (cognitive, emotional), thus positively affecting self-care.

Diabetes knowledge did not always predict better self-care among the EAs with T1D (Wong et al., 2020). However, the positive prediction was consistent with other research (Chiang et al., 2020; Kim et al., 2019; Montali et al., 2022), and participants reported in their interviews that they were actively seeking more information about diabetes management during this period from their health care providers and through social media. This would explain their improved self-care practices during this period.

Participants who followed-up at the Chronic Care Center had the highest self-care scores. This finding supports the advantage of having a multidisciplinary team providing the care for the EAs (Joly, 2015). Another factor that differentiates the CCC from other treatment sites is the continuity of care delivery by the same health care team from childhood to adulthood. The effect of this continuity of care was reported in prior studies where EAs who still followed-up with their pediatric clinics had better glycemic

and self-care outcomes than those who transitioned into adult clinics (Garvey et al., 2012; Joly, 2015). The CCC also offers a comprehensive diabetes education program to their patients, as well as periodic encounters with diabetes educators and dieticians during clinic visits. This differentiates this center from other clinics where diabetes education is provided only upon need.

d. Social Support

Social Support was measured by the DCP-SS scale, which had three subscales measuring the Want, Get, and Global Social Support experienced by the participants. Psychometric analysis of the Arabic version showed good reliability score of .72, which is higher than the reliability score reported in the original scale development of .69 (Fitzgerald et al., 1998; Yanover & Sacco, 2008). When compared to other reliability scores of the Arabic version of the scale, our result was better than the reliability score in a Jordanian sample with T1D ( $\alpha=0.65$ ) (Al-Akour, 2003), but less than the Cronbach's alpha coefficient reported in a Lebanese population with T2D ( $\alpha=0.88$ ) (Sukkarieh-Haraty & Howard, 2015).

Originally, the scale score is reported in the literature as a whole score, and not broken down into subscales. However, in this study, we found it important to highlight the scores of each subscale since it gave us insight on the actual support received by the participants versus the support they actually needed. The study sample reported high levels of social support with median scores of the Get and Global subscales of 22 and 27 out of 30 respectively, yielding a median total score of the received support of 48 out of 60. In contrast, the low scores of the Want subscale ( $Mdn = 15$ ) indicated that participants needed less support than what they were actually receiving. The social

support score of our sample was compared with the social support scores reported by a Lebanese sample of T2D (Sukkarieh-Haraty & Howard, 2015). The higher scores of our sample (48 versus 39), indicated that EAs with T1D received exceptionally higher support from family and friends than adults with T2D in Lebanon, which is expected when one compares the age groups in the two studies.

Social support did not correlate or predict any of the main outcome variables. However, it was positively correlated with the Family/ Friends diabetes distress subscale. This indicates an association between social support and experiencing psychological distress caused by family and friends. Our qualitative findings validated this association and the low WANT subscale score, as participants experienced diabetes-related parental conflicts, and wished for less involvement from their parents in their diabetes. The parent-related distress was also noted in other studies where parental controlling relationships had negative emotional impact on the EAs (Celik et al., 2015; Helgeson et al., 2014; Rassart et al., 2015).

We did not detect an association between social support and glycemic control. The findings on this relationship were inconsistent in previous studies (Campbell et al., 2019; Goethals et al., 2017; Rassart et al., 2015). In a study of Lebanese adults with T2D, Sukkarieh-Haraty and Howard (2015) reported a positive relationship between social support and HbA1c. This unexpected relationship was attributed to the characteristics of the Lebanese collectivist culture, where it is a moral obligation to provide support to people in poor health (Sukkarieh-Haraty & Howard, 2015). Although we cannot compare these results to our findings because of the differences in diabetes type and age groups of the samples, their findings corroborate that relationships

between variables differ from the norm across different cultural and ethnic backgrounds.

Finally, it is important to note that the social support scale included some items that measure the level of support that EAs receive from their parents and friends in performing self-care activities. For example, “my family and friends help and support me to take my medicine”, or “to test my sugar”, etc.... This might explain the negative (albeit non-significant) association between social support and self-care on the bivariate level. This association implies that EAs who report high levels of social support are relying more on their parents for their self-care practices than those with low social support levels.

e. The Mediation, Moderation, and Moderated-Mediation Effect of Self-Care and Social Support

The Self-Care in Chronic Illness theory does not consider self-care as an outcome variable, but positions it as a mediator between the predictors and health outcomes (Riegel et al., 2012). In this study, we examined the mediating effect of self-care on HbA1c and diabetes distress. Self-care did not mediate the relationship between age at diagnosis and HbA1c. However, a mediating relationship existed with diabetes knowledge and diabetes distress.

In previous work, some studies reported a mediating effect of self-care on the relationship between predictor variables and HbA1c in emerging and young adults with T1D (Johnston-Brooks et al., 2002; Loseby et al., 2021), while others could not detect such a relationship in adults with T1D and T2D (Sousa et al., 2005). The lack of mediation in our findings suggest that self-reported self-care behavior may not be

sufficient to detect an actual change in glycemic levels. In their attempts to become independent, the EAs might report better self-care practices than what actually is performed. The qualitative interviews also documented instances where participants did not perform adequate self-care for various reasons, reflecting inconsistent performance.

Self-care mediated the association between diabetes knowledge and diabetes distress. Our results indicated a partial mediation effect, meaning that having good diabetes management knowledge still contributed to low feelings of diabetes distress beyond what is accounted for by self-care. This finding signifies that knowledge should be coupled with diabetes care activities to have the most effect on diabetes distress. The mediating effect of self-care on diabetes distress was not directly assessed in previous research. Mohn et al. (2015) investigated the associations of self-management competence and autonomy support from healthcare providers with diabetes distress in adults with T1D. Healthcare autonomy support included providing the individual with the needed knowledge to manage their disease. The authors reported an indirect relationship between autonomy support and diabetes distress via perceived self-management competence (Mohn et al., 2015).

We expected that social support would play a buffering effect on the diabetes-related health outcomes in this study. However, the effect of social support on the health outcomes ran in the opposite direction of our expectations. First, we did not detect a moderating effect of social support on self-care and HbA1c, which may be attributed to the previously mentioned lack of association between the two variables.

Second, despite higher levels of social support predicting lower levels of diabetes distress in the regression analysis, this effect included an interaction term with self-care. This indicated a moderating effect of social support on the association between self-care

and diabetes distress, where the negative effect of self-care on diabetes distress varied according to the levels of social support. The moderation analysis suggested that as social support increased, self-care lost its ability to decrease diabetes distress until it lost its significance at high levels of social support. This finding suggests that with low social support levels, EAs who demonstrate high levels of self-care are the least vulnerable to experiencing diabetes related distress. Therefore, a high social support level in our sample blunted the effect of self-care on the diabetes distress scores of the EAs. The need to control the levels of social support was also reported in a previous study where the benefit of parental support was most prominent when the EAs were able to regulate the level of parental involvement (Wiebe et al., 2018). Some participants communicated in the qualitative interviews that they had to hide having acute complications from their parents in order to limit parental conflicts, a finding that was similarly reported by Chiang et al. (2020). The qualitative interviews showed strained relationships between participants and their parents when it comes to their diabetes. These EAs were striving to take control of their diabetes, and so their parental social support was perceived as frustrating.

To our knowledge, this is the first study to investigate the moderating role of social support on the association between predictor and outcome diabetes variables through diabetes self-care. By using the moderated mediation model, we also found that the indirect effect of diabetes knowledge on diabetes distress through self-care was significant only in individuals with low to middle levels of social support. The moderated mediation effect was not detected at high levels of social support.

The literature described an inconsistent relationship between social support and self-care. A systematic review (Song et al., 2017) reported that in general, social

support improved self-care, but less so in individuals with T1D than T2D. They also noted ethnic differences, with non-Caucasians reporting higher levels of social support and higher effect size on self-care than Caucasians did. However, the review did not analyze the data by age groups, which affects the individuals' need for support according to their developmental needs.

In summary, our findings indicate that caution should be exercised when providing social support to the EAs with T1D in Lebanon. Intrusive involvement by parents or friends may lead to negative associations with self-care behaviors and health outcomes. The influence of social support depends on how it is perceived by the emerging adult.

#### f. COVID-19 and Diabetes

Living with T1D during the COVID-19 pandemic and through the consequent lockdown period affected the daily lives of the study participants. Our study findings indicated an effect on the self-care practices, mental well-being, and glycemic control of the EAs. Similar to other findings, some investigators reported worsening eating habits, decreased physical activity, and decreased blood glucose measurement in EAs with T1D (Tejera- Perez et al., 2021). On the other hand, another study has shown that fear of COVID-19 complications prompted the participants to practice better diabetes self-care practices in order to maintain adequate glycemic control (Fernández et al., 2020). The negative psychological effect was evident in the qualitative interviews, which mainly revolved around fear for one's health and concerns towards accessing diabetes supplies. However, we found a significant improvement in glycemic control during the pandemic with lower HbA1c levels during COVID-19 compared to those before the

pandemic. This finding was in line with other studies that reported improved HbA1c and time-in-range levels during lockdown, which were attributed to improved self-care practices (Bonora et al., 2020; Fernández et al., 2020).

The integrated analysis discussed in the previous and current chapter provided a comprehensive view of the experience and the health status of this understudied population. It further validated the quantitative findings in terms of explaining the mechanisms of interaction between the factors affecting the self-care practices, glycemic control, and psychological impact of diabetes, while integrating the effect of social support.

## **B. Limitations**

Some limitations can be identified in the study. To begin with, the descriptive cross-sectional quantitative study design might not be the best research design to study the effect of emerging adulthood on diabetes outcomes. A prospective longitudinal design that follows adolescents with T1D into their emerging adulthood while examining changes in diabetes-related health outcomes across time might have been a better study design for this research question. However, it will not be feasible to perform a multi-year longitudinal study due to the entailed time constraints of a PhD program. In fact, given the lack of studies on this topic in Lebanon, a baseline data collection with a mixed methods approach is best performed at this stage to understand the transition experience and the variables associated with diabetes-related health outcomes within the Lebanese population as a starting point. The qualitative interviews shed light on the changes over time that the participants went through in their lives and

vis a vis their diabetes, which compensated for the limitation of the cross sectional design.

Conducting the qualitative interviews through virtual meetings instead of face-to-face might be considered a limitation in this study. However, collecting data through online video-conferencing is becoming a commonly accepted technique in qualitative research due to its noted advantages in expanded access to participants, convenience in terms of timing of interviewing, and increased sense of privacy by the part, which prompts additional sharing (Nehls et al., 2015). Our main limitation was experiencing some technology problems like poor connectivity and electricity outage. Nevertheless, the use of virtual interviews was appropriate in our study especially that our population was very familiar with online technology and easily adapted to this interview format, and the fact that the study was conducted during the COVID19 pandemic when face-to-face interviews were not possible.

A sampling limitation includes having a convenience sample with moderately high socioeconomic level, which might affect generalizability of the study findings. The findings of this study need to be validated in future studies on a larger sample of a wider representation of individuals from the lower socioeconomic status.

Another limitation was measuring diabetes knowledge by asking the participant to rate their perceived knowledge of diabetes self-care instead of measuring their actual knowledge. This was done in an attempt to reduce participant burden from a lengthy survey. Future studies can include a more comprehensive objective measurement of this variable due to its important effect on diabetes self-care.

Social desirability is a limitation related to the use of self-report questionnaires, where the participants tend to answer questions in a socially desirable manner. For

instance, participants might have reported better self-care practices than what they actually performed since they were trying to maintain the image of independence and competence in managing their diabetes.

Finally, the study was conducted during the exceptional time of the Lebanese economic crisis, which affected some of the study findings. However, it is very likely that the economic and healthcare repercussions of this crisis will last for few years with a continued effect on the EAs diabetes-related health.

### **C. Implications for Knowledge, Practice, and Research**

Type 1 diabetes is a chronic condition that starts at early ages and can have grave health consequences when not managed properly, especially during emerging adulthood. This study has implications on various areas, including knowledge advancement, practice and policy making, and research.

At a national level, this is the first study that explored the experience of EAs living with T1D in Lebanon. The qualitative and quantitative findings allowed us to understand this experience as the EAs pass through the developmental, situational, and self-care practice changes that characterize emerging adulthood, all through the lens of the Lebanese culture. The results highlighted the key elements at play during this transitional phase from the perspective of the EAs, and identified the variables associated with their diabetes-related health. On a global level, previous investigators were always hesitant to generalize their findings across different cultural and ethnic backgrounds, and found it difficult to predict the effect of those different backgrounds on their findings (Johansen, Rothmann, et al., 2020; Ramchandani et al., 2019). Our findings added to the knowledge of diabetes care for EAs with T1D by proposing a

framework that includes the key elements affecting the health of this population, while highlighting the importance of the cultural effect in this relationship. This framework can be used across different cultural backgrounds and allow for comparison of findings.

At the healthcare system level, the findings may contribute to the development of health policies and clinical practices that are culturally sensitive and cater to the specific needs of the Lebanese EAs with T1D. Acknowledging that emerging adulthood is a unique developmental phase that can negatively affect the health of patients with T1D will mandate a better support from the health policy makers. This support can include health awareness campaigns that target social diabetes stigmatization, screening for the physiological and psychological impact of diabetes in clinics, and providing continuous medical coverage of diabetes treatment for this population.

Moreover, the findings can help health care professionals recognize the uniqueness of the emerging adulthood phase and have a better understanding of the challenges this population faces in managing diabetes. Ultimately, this study can lead to a shift in the management of diabetes towards a developmentally tailored one, aided by the developed framework. In addition, a transition program can be developed to help the EAs achieve optimal health and well-being by addressing their determined needs and challenges during this phase. For instance, the program can include interventions to: 1) improve knowledge and self-care behaviors; 2) focus on reaching a balanced involvement of parents with the care of their children; 3) incorporate a multidisciplinary care approach in the treatment process; and 4) include periodic screening and management of diabetes-related psychological distress in the care of the EAs. We also recommend that health professionals incorporate “peers with diabetes” group support into the care of their patients. This peer support would include providing education,

practical advice, which will help reduce feelings of judgement and stigmatization and positively affect the emotional wellbeing of the EAs.

The Transition Theory distinguishes nursing as the primary facilitator of transition towards optimal health (Meleis et al., 2000). In fact, nurses are the best advocates for the needs of their patients and are often the liaison between the patients and the healthcare system. Our findings highlighted the unique role nurses and diabetes nurse educators play in the care of the participants, and their impact on the EAs' knowledge, health, and psychological well-being.

Implications for future research is wide and varied. This study provided a comprehensive baseline of knowledge about the condition of the EAs living with T1D in Lebanon. Determining the key factors affecting the health of this population can guide the focus of future research.

First, future research should focus on incorporating the perception of other stakeholders involved in the care of the EAs such as parents, significant others, and health care providers. This would allow us to have a comprehensive view of the factors affecting the health outcomes and include these findings in future intervention programs.

Second, tailored intervention programs to improve self-care practices of the EAs can be designed based on the study findings. These programs can be incorporated in the care provided for the EAs and can be tested for effectiveness in terms of improving physical and psychological outcomes.

Third, collaborating with governmental and international sectors to develop a national diabetes registry for patients with T1D is of utmost importance at this point. This will allow us to gather sociodemographic and clinical information about the T1D

diabetes population, as well as link all members of the patient's health team, and provide key information for patients and health care providers. The data obtained from the registry can provide further research questions that can be addressed with longitudinal studies. Ultimately, diabetes registries will improve the quality of care provided to the people with T1D. Along these lines, we recommend future research to include a larger sample from different diabetes clinics at the national level.

Fourth, since this is the first study on this topic in the MENA region, we propose a collaboration with diabetes researchers in other Arab countries to replicate this study at a multi-national level. This will increase the international knowledge about EAs with T1D across different cultures and give us the ability to compare our results across similar cultures.

Finally, the level of advocacy and in-group support noted among the participants was noteworthy. We believe that engaging the EAs with T1D in the research process will empower them to be involved in determining and improving the quality of care they receive. Hence, we recommend the implementation of “participatory action research” in future studies involving the EAs with T1D.

#### **D. Conclusion**

The integrated findings of this mixed methods study promoted the understanding of the complexity and uniqueness of living with T1D during emerging adulthood. The qualitative findings offered an in-depth explanation of the impact of emerging adulthood on the diabetes experience and helped explain the quantitative results that provided a description of diabetes-related health outcomes of the EAs, and the predictors of these outcomes.

During this period, the EAs experience a transformation, which starts by taking ownership of their diabetes and ending by reaching a state of equilibrium. Our qualitative findings highlighted the barriers and facilitators of self-care and identified the gaps in the care offered to this population. It also provided insight into the emotional experience of EAs, with subthemes describing the resilience and strength resulting from having T1D, as well as the frustrations, worries, and fears related to living with T1D in Lebanon. We were also able to describe the EAs' complex relationship with their parents, which involved the EAs still relying on their parents during challenging times, while always striving for more autonomy. Additionally, diabetes social stigmatization emerged as a common experience that negatively affected the self-care practices and emotional well-being of the study participants. Finally, the peers with diabetes support was highlighted as an important factor that needs to be further investigated and integrated in clinical practice and future research.

Our quantitative findings described the suboptimal health status of the study participants and determined the predictors of the outcomes. Diabetes knowledge, the use of diabetes technology, receiving care from a multidisciplinary team, diabetes self-care, and social support were all important predictors of diabetes health. Our results showed that the effect of diabetes knowledge on diabetes distress is mediated by self-care, implying that we need to assess the self-care practices of the EAs even if we provided them with knowledge. We also uncovered the unique relationship between self-care and social support that is specific to our age group and cultural context. Our integrated findings add to the current knowledge on this relationship by implying that the EAs in Lebanon wanted less social support than what they actually received, and

that high levels of social support decreased the buffering effect of self-care on diabetes distress.

The relationship between social support, self-care, and diabetes health is a complex one and is continuously changing with the times and with the new ways of connecting with people. It is even more challenging to determine this relationship when the cultural aspect is added to this mix. To our knowledge, our study framework is the first that recognized this important, often overlooked aspect that affects the health and well-being of the EAs with T1D population.

In conclusion, it is important to acknowledge the complexity of health and illness and the variables that may influence this continuum in such an understudied and vulnerable population, especially while taking into consideration the influence of the developmental characteristics of this population, the Lebanese culture, and healthcare system. This study provides a comprehensive understanding of the condition of the EAs living with T1D in Lebanon, and opens the door to practice and research recommendations.

## APPENDIX A

### *Studies Examining Type 1 Diabetes in Emerging Adulthood*

<b>Study</b>	<b>Purpose</b>	<b>Study design</b>	<b>Sample</b>	<b>Measurement Tools</b>	<b>Outcome Measures</b>	<b>Summary of Relevant Findings</b>
(Abdoli et al., 2017)	To explore and describe perceptions and experiences of young adults with T1D living in Appalachia, Tennessee.	Qualitative descriptive study	9 EAs (18-30 years)	• -	• -	<ul style="list-style-type: none"> <li>• Main themes the struggle toward adulthood, the daily struggle of living with diabetes, the strong desire to live life, the supportive environment, the development of one's identity by diabetes, the disruptiveness of diabetes' demands, and the pros and cons of technological development in diabetes management.</li> </ul>
(Baucom et al., 2015)	To examine whether depressive symptoms are associated with greater perceived daily stress and moderate the link between stress severity and poorer daily adherence in late adolescents with T1D.	Cross-sectional descriptive study	175 late adolescents (17 - 18 years of age) with T1D	<ul style="list-style-type: none"> <li>• Center for Epidemiologic Studies Depression Scale (CES-D)</li> <li>• Daily Inventory of Stressful Events</li> <li>• Self-Care Inventory</li> </ul>	<ul style="list-style-type: none"> <li>• Depressive symptoms</li> <li>• Daily stress severity (DSS)</li> <li>• Diabetes-specific stressful events</li> <li>• Daily adherence</li> <li>• Glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>• Mean depressive symptoms score was above the suggested cutoff for clinically significant depressive symptoms</li> <li>• Greater depressive symptoms were correlated with higher stress, poorer adherence, and poorer glycemic control.</li> <li>• More severe daily DSS was associated with poorer daily adherence, an association moderated by an interaction between mean DSS severity and depressive symptoms</li> </ul>
(Bronner et al., 2020)	To assess HRQOL in a national cohort of young adults with	Secondary data analysis from a	165 young adults (18–25	• Pediatric Quality of Life Inventory	• HRQOL	<ul style="list-style-type: none"> <li>• Young adults with T1D scored significantly worse than did healthy peers on all domains of</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	T1D in the Netherlands, and to compare their HRQOL scores with those of Dutch norm groups of healthy young adults and young adults with different chronic health conditions.	mixed methods study	years of age) with T1D	for young adults (PedsQL-YA).		<p>HRQOL, except social functioning.</p> <ul style="list-style-type: none"> <li>• HRQOL-scores were comparable to scores of young adults with chronic diseases, although the physical and social functioning of young people with T1DM was better.</li> <li>• One quarter (26.1%) of all young adults with T1DM reported fatigue.</li> </ul>
(Bryden et al., 2001)	To determine the clinical and psychological course of diabetes through adolescence and the relationship with glycemic control in young adulthood.	A 10-years longitudinal cohort study	76 individuals with T1D (aged 11-18 years) completed baseline assessments, and 65 were re-interviewed as young adults (20-28 years of age).	<ul style="list-style-type: none"> <li>• Revised Clinical Interview Schedule (adolescents)</li> <li>• Brief Symptom Inventory (adults)</li> </ul>	<ul style="list-style-type: none"> <li>• Glycemic control</li> <li>• Weight gain</li> <li>• Diabetes complications (recurrent DKA, retinopathy, nephropathy)</li> <li>• Psychological state</li> </ul>	<ul style="list-style-type: none"> <li>• Mean HbA1c levels peaked in late adolescence and were worse in female participants.</li> <li>• No difference in HbA1c between baseline and follow-up</li> <li>• By follow-up, 25% of males and 38% females had serious microvascular complications or required treatment for hypertension.</li> <li>• BMI significantly increased over time</li> <li>• Recurrent hospital admission for diabetic ketoacidosis significantly predicted psychological state</li> </ul>
(Butler et al., 2017)	To examine whether race/ethnicity moderates relationships of diabetes stress and general life stressors	Secondary data analysis of the Diabetes Exchange Registry	3440 emerging adults (18-25 years of age) with T1D	<ul style="list-style-type: none"> <li>• Single item assessing diabetes-related stress</li> <li>• Single item assessing general stress</li> </ul>	<ul style="list-style-type: none"> <li>• Glycemic control and complications (HbA1c and DKA)</li> </ul>	<ul style="list-style-type: none"> <li>• Approximately one third of the sample reported experiencing two or more general life stressors during the past 12 months</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	with diabetes outcomes of glycemic control and diabetic ketoacidosis among emerging adults with T1D.					<ul style="list-style-type: none"> <li>• 63% reported often or always experiencing diabetes-related stress</li> <li>• Hispanics had poorer glycemic control when they experienced a relatively fewer number of general life stressors than non-Hispanic Whites.</li> </ul>
(Campbell et al., 2019)	To examine changes in diabetes-specific family conflict, family responsibility for diabetes management tasks, and associations with glycemic control up to 1 year after high school.	One-year longitudinal descriptive study	Seventy-nine emerging adults with T1D (18.1 ± 0.4 years of age) and their parents	<ul style="list-style-type: none"> <li>• Revised Diabetes Family Conflict Scale (DFCS-R)</li> <li>• Diabetes Family Responsibility Questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Diabetes-specific family conflict and family responsibility</li> <li>• glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>• Diabetes-specific family conflict was relatively low and did not change over time.</li> <li>• Parent responsibility for diabetes care decreased over time.</li> <li>• Higher parent- and emerging adult-reported family conflict and higher parent responsibility for diabetes care were associated with worse glycemic control.</li> <li>• Parent-reported family conflict and the interaction between the conflict and parent responsibility predicted HbA1c after 1 year</li> <li>• HbA1c did not predict diabetes-specific family conflict or responsibility 1 year after high school.</li> <li>• Male EAs reported lower diabetes specific family conflict than females.</li> </ul>
(Celik et al., 2015)	To determine the factors associated with	Qualitative descriptive phenomenological study	28 EAs (18-25 years)	• -	• -	<ul style="list-style-type: none"> <li>• Seven themes which affect the diabetes management: negative emotions about the disease, difficulties arising from living</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	mismanagement of diabetes.					condition, difficulties arising from the treatment, treatment process, lack of social support, not solution oriented coping methods, concerns about the future, and issues of developing knowledge and attitude regarding diabetes management.
(Chiang et al., 2020)	To explore the life experiences of patients with T1D transition from adolescence into adulthood in Taiwan	Descriptive phenomenological design	14 EAs (16-25 years)	• -	• -	<ul style="list-style-type: none"> <li>• Six themes emerged: (1) hibernation: awareness of responsibility; (2) emergence: attempts to take responsibility; (3) perseverance: encountering difficulties; (4) anxiety: multiple worries; (5) hesitation: back-and-forth," and (6) exit: finding a way out."</li> </ul>
(Cooper et al., 2017)	To determine the incidence of and risk factors for psychiatric disorders in early adulthood in patients with childhood onset T1D	Retrospective-cohort study	(n= 1302) patients with diabetes compared to age and sex-matched non-diabetics (n=6422), with mean age at end of follow-up 26.4 ( $\pm$ 5.2) years	<ul style="list-style-type: none"> <li>• International Classification of Diseases, Ninth Revision (ICD-9)</li> <li>• International Statistical Classification of Diseases and Related Health Problem</li> </ul>	<ul style="list-style-type: none"> <li>• Psychiatric disorders (anxiety, eating, mood, personality &amp; behavior, schizophrenia &amp; psychosis, and substance dependence)</li> </ul>	<ul style="list-style-type: none"> <li>• The diagnosis of any psychiatric disorder was significantly higher in the T1D cohort than the comparison cohort</li> <li>• Comorbid psychiatric disorders are 2 times more frequent within the T1D cohort</li> <li>• History of poor glycemic control was associated with an increased risk of anxiety, mood, and 'any' disorder</li> </ul>
(Downie et al., 2021)	To examine the impact of psychological	Longitudinal study	287 EAs at T1 (18-35 years) mean age:	• Depression, anxiety, and stress scale 21 (DASS-21)	• Blood glucose monitoring	<ul style="list-style-type: none"> <li>• Attitudes and perceived behavioral control associated with intention</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	distress in the context of T1D		26.7±5.2. 167 completed T2 (1 week later) 27±4.9	<ul style="list-style-type: none"> <li>The problem areas in diabetes (PAID)</li> <li>Diabetes self-management questionnaire (DSMQ)</li> </ul>		<ul style="list-style-type: none"> <li>Intention to monitor predicted blood glucose monitoring</li> <li>Higher scores in psychological distress significantly predicted poorer blood glucose monitoring, but did not moderate the intention-behavior relationship</li> </ul>
(Egan et al., 2015)	To evaluate the effectiveness of a structured transition program by measuring clinical and psychometric properties related to transition and adherence to follow-up.	Mixed-methods study	29 emerging adults (18-26 years of age) with T1D	<ul style="list-style-type: none"> <li>Diabetes Distress Scale (DDS)</li> <li>Diabetes Quality of Life Youth-Short Form (DQOLY-SF)</li> <li>Health Care Climate Questionnaire (HCCQ).</li> </ul>	<ul style="list-style-type: none"> <li>Diabetes-related distress</li> <li>Quality of life</li> <li>Perceived health care provider autonomy support</li> <li>Adherence to follow-up</li> <li>Glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>Adherence to follow-up was 100%.</li> <li>Correlations between DQOLY-SF and DDS and correlations between DDS and A1C were highly significant during the pre-transition and post-transition.</li> <li>There is a statistically significant reduction in diabetes distress from pre- to post-transition evaluations and an increase in HCCQ.</li> <li>Content comparative analysis revealed the following themes: readiness for transition, positive experience of transition program, control of own care, and comfort with new team</li> </ul>
(Goethals et al., 2017)	To examine the role of diabetes-specific parental regulation and general parenting dimensions (responsiveness and	Cross sectional descriptive study	521 patients (aged 14-25 years) with Type 1 diabetes, 407 mothers, and 345 fathers	<ul style="list-style-type: none"> <li>The Self-Care Inventory</li> <li>Child Report of Parent Behavior Inventory</li> </ul>	<ul style="list-style-type: none"> <li>Treatment adherence</li> </ul>	<ul style="list-style-type: none"> <li>Lower psychological control and higher parental responsiveness were associated with better treatment adherence.</li> <li>Diabetes-specific parental regulation was not linked to treatment adherence, except</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	psychological control) in treatment adherence throughout adolescence and emerging adulthood			<ul style="list-style-type: none"> <li>Parental Regulation Scale– Youth Self Report</li> </ul>		<ul style="list-style-type: none"> <li>when combined with high levels of responsiveness.</li> <li>Some effects of psychological control and responsiveness were more pronounced in the older age-group.</li> </ul>
(Habenicht et al., 2018)	To explore the concept of social support in university students and to see how this may be influenced by disclosure.	Qualitative study	14 students (14-28 years of age)	<ul style="list-style-type: none"> <li>Semi structured interviews</li> </ul>	• -	<ul style="list-style-type: none"> <li>Thematic analysis identified three major themes: disclosure as a measured process, the need for lived experience for true understanding and personal growth, and self-awareness.</li> <li>Support from other students with T1D could considerably impact diabetes management.</li> </ul>
(Hanna & Hansen, 2019)	To provide insight into poorly understood diabetes self-management among emerging adults with T1D experiencing transitions.	Qualitative study	25 individuals (19–26 years of age) with T1D	<ul style="list-style-type: none"> <li>Semi-structured individual interviews</li> </ul>	•	<ul style="list-style-type: none"> <li>Transitions disrupt diabetes self-management-related habits, triggers and routines.</li> <li>Social support, stress, conduciveness of environment, stigma, and self-reliance were identified as influential to diabetes management by emerging adults.</li> </ul>
(Hanna, Weaver, Slaven, et al., 2014)	To examine the roles of glycemic control, diabetes management, diabetes care responsibility, living independently of parents, and time since high school	1-year Longitudinal descriptive study	184 emerging adults (17-18 years of age) with T1D	<ul style="list-style-type: none"> <li>Quality-of-life measure for youths</li> <li>Diabetes Self-Management Profile</li> <li>Independent Functioning and Decision-making</li> </ul>	<ul style="list-style-type: none"> <li>Diabetes Quality of life (4 subscales: impact, worry, satisfaction, and health status)</li> </ul>	<ul style="list-style-type: none"> <li>Better diabetes management was associated with more positive responses on all dimensions of DQOL.</li> <li>Impact and worry of DQOL were greater and life satisfaction was lower in the presence of depressive symptoms.</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	graduation in predicting diabetes-related quality of life (DQOL) in emerging adults with T1D			<ul style="list-style-type: none"> <li>in Daily and Non-Daily Diabetes Management Checklist</li> <li>Beck Depression Inventory</li> </ul>		<ul style="list-style-type: none"> <li>Life satisfaction was lower in those living independently of parents.</li> <li>Young women reported poorer diabetes-related health status than young men.</li> <li>Time since graduation was not linked to DQOL.</li> </ul>
(Hanna, Weaver, Stump, et al., 2014)	To examine changes in perceptions of diabetes-specific conflict with parents, parent–youth shared responsibility, parental tangible aid, and parental autonomy support, as well as the moderation effects of living situation, gender, years with diabetes diagnosis, and glycemic control during the year post-high school	One-year longitudinal descriptive study	182 emerging adults (17-19 years of age) with T1D	<ul style="list-style-type: none"> <li>Parent–Adolescent Diabetes Conflict Subscale of the Diabetes Responsibility and Conflict Scale</li> <li>Parental Support for Adolescents’ Autonomy Development Scale</li> <li>Independent Functioning and Decision-making in Daily and Non-Daily Diabetes Management Checklist</li> <li>Support Checklist</li> </ul>	<ul style="list-style-type: none"> <li>Diabetes-specific conflict with parents</li> <li>Parent–youth shared responsibility</li> <li>Parental tangible aid</li> <li>Parental autonomy support</li> </ul>	<ul style="list-style-type: none"> <li>Higher levels of HbA1c, were correlated with more parent–youth conflict</li> <li>Higher levels of parental autonomy support were correlated with more parent–youth conflict and tangible aid</li> <li>Higher levels of parent–youth conflict was correlated with lower levels of parent–youth shared responsibility and higher levels of tangible aid</li> <li>Changes over time in parent–youth conflict were moderated by living independently of parents</li> <li>Autonomy support and shared responsibility were moderated by years with diabetes</li> <li>Tangible aid was moderated by glycemic control</li> </ul>
(Helgeson et al., 2014)	To examine the impact of parent and peer relationships on health behaviors and	One-year longitudinal descriptive study	239 Youth with (n = 117) and without T1D (n = 122)	<ul style="list-style-type: none"> <li>Feeling Controlled by Parents scale</li> <li>Friendship questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>Psychological well-being</li> <li>Diabetes self-care behavior</li> </ul>	<ul style="list-style-type: none"> <li>Friend conflict was a more potent predictor than friend support of changes in health</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	psychological well-being of those with and without T1D over the transition to emerging adulthood.			(intimacy, instrumental support, and emotional support subscales) <ul style="list-style-type: none"> <li>• Test of Negative Social Exchange</li> <li>• Center for Epidemiologic Studies Depression Scale</li> <li>• Perceived Stress Scale</li> <li>• Self-Care Inventory</li> </ul>	<ul style="list-style-type: none"> <li>• Glycemic control</li> </ul>	<p>behaviors and psychological well-being.</p> <ul style="list-style-type: none"> <li>• Parent support was associated with improved psychological well-being and decreases in smoking, whereas parent control was related to increases in smoking and depressive symptoms.</li> <li>• Parent relationships also have the potential to buffer the adverse effects of difficulties with peers</li> <li>• Friend conflict predicted higher likelihood of drinking alcohol and binge drinking</li> <li>• Friend support seems to buffer the negative effects of parent control on alcohol use.</li> <li>• Self-care behavior was related to better glycemic control</li> </ul>
(Hendricks et al., 2013)	To characterize daily diabetes self-care behaviors and to evaluate associations among self-care behaviors, psychosocial adjustment, and glycemic control in an understudied sample of emerging	Cross-sectional descriptive study	49 emerging adults with T1D (18-26 years of age)	<ul style="list-style-type: none"> <li>• 24-hour recall diabetes interview to document frequency of disease self-care behaviors.</li> <li>• Brief Symptom Inventory</li> <li>• The Diabetes Quality of Life</li> </ul>	<ul style="list-style-type: none"> <li>• Self-care</li> <li>• Glycemic control (HbA1c)</li> <li>• Psychosocial adjustment (well-being and quality of life)</li> </ul>	<ul style="list-style-type: none"> <li>• Diabetes self-care behaviors were largely suboptimal</li> <li>• Only a small percentage of participants demonstrated self-care behaviors consistent with national and international recommendations</li> <li>• Psychosocial adjustment was within normal limits and was unrelated to frequency of self-care behaviors.</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	adults with type 1 diabetes.					<ul style="list-style-type: none"> <li>• Mean glycemic control (8.3%) was higher than the recommended A1C level for this age group.</li> </ul>
(Hislop et al., 2008)	To determine the prevalence of psychological distress in young adults with T1D and to explore associated factors.	Cross sectional descriptive study	92 participants (18–28 years of age) with T1D	<ul style="list-style-type: none"> <li>• Centre for Epidemiological Studies– Depression Scale (CES-D)</li> <li>• Adult Self-Report Scale (ASR)</li> </ul>	<ul style="list-style-type: none"> <li>• Psychological distress</li> </ul>	<ul style="list-style-type: none"> <li>• Approximately one-third of participants experience psychological distress, which is associated with poorer glycemic control.</li> <li>• Psychological distress was related to frequency of hypoglycemic episodes.</li> <li>• Greater distress was observed in those using the insulin pump.</li> </ul>
(Kelly et al., 2018)	To examine how 'transition readiness' skills develop from relationship processes with parents, friends, and healthcare providers during their senior year of high school and one year later.	One-year Longitudinal descriptive study	217 participants (17.77 ± 0.4 years of age) with T1D.	<ul style="list-style-type: none"> <li>• Transition Readiness Assessment Questionnaire (TRAQ)</li> <li>• Health Care Climate Questionnaire-Short Form</li> <li>• Parental Monitoring Scale</li> <li>• Diabetes Behavior Rating Scale (DBRS)</li> </ul>	<ul style="list-style-type: none"> <li>• Transition readiness skills (Self-Management; Self-Advocacy)</li> <li>• Adherence</li> <li>• Glycemic control (HbA1c)</li> <li>• Relationships with providers (patient-centered communication)</li> <li>• Parents (monitoring/knowledge)</li> </ul>	<ul style="list-style-type: none"> <li>• Self-Management skills increased across time.</li> <li>• Higher levels of provider communication, parent knowledge/monitoring, and friend knowledge/helpfulness were associated with higher transition readiness skills.</li> <li>• Higher transition readiness was correlated with better adherence, but only greater Self-Advocacy skills were associated with lower HbA1c</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
(Lašaitė et al., 2016)	To explore the gender and age differences in diabetes distress between adolescents and emerging adults with T1D.	Cross sectional descriptive study	255 adolescents (14 to ≤ 18 years of age) and 283 emerging adults (18–25 years of age) with T1D	• Problem Areas in Diabetes scale	<ul style="list-style-type: none"> <li>• Friends (knowledge/helpfulness)</li> <li>• Diabetes distress</li> </ul>	<ul style="list-style-type: none"> <li>• High diabetes distress level was found in 22.8% of participants.</li> <li>• Emerging adults had greater levels of diabetes distress than adolescents.</li> <li>• Negative emotional consequences score was higher in adult females compared to males, when adjusted for age at T1D onset.</li> <li>• Diabetes distress was not related neither to age at diabetes onset nor to HbA1c levels.</li> <li>• Significant correlations between the PAID overall score and diabetes duration</li> </ul>
(Lee Tracy et al., 2019)	Measure associations between health-risk behaviors (smoking, drinking, insulin withholding) and type 1 diabetes outcomes (adherence and HbA1c) during the transition from late adolescence to early emerging adulthood	2-year longitudinal descriptive study	197 high school seniors with T1D (17–18 years old)	<ul style="list-style-type: none"> <li>• One item measuring insulin withholding</li> <li>• Two questions assessing smoking and alcohol consumption</li> <li>• Diabetes Behavior Rating Scale</li> </ul>	<ul style="list-style-type: none"> <li>• Adherence to T1D management</li> <li>• Glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>• Smoking cigarettes, drinking alcohol, and insulin withholding increased during this period.</li> <li>• Smoking negatively predicted adherence; drinking alcohol negatively predicted glycemic control; and insulin withholding negatively predicted adherence and glycemic control during the transition from late adolescence to early emerging adulthood</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
(Levy-Shraga et al., 2016)	To determine whether a dedicated transition clinic for emerging adults with T1D can improve glycemic control and visit attendance.	1-year longitudinal quasi experimental study	53 emerging adults (22.1 ± 2.7 years of age) with T1D	• Diabetes Quality of Life-Youth (DQOLY)	<ul style="list-style-type: none"> <li>• Glycemic control (HbA1c)</li> <li>• Clinic visit attendance</li> <li>• Acute complications</li> <li>• Quality of life</li> </ul>	<ul style="list-style-type: none"> <li>• Mean HbA1c levels decreased from after 1 year post transfer to a transition clinic</li> <li>• 68 % of participants attended ≥ 3 visits during their first year in the transition clinic.</li> <li>• Quality of life, disease-related worries, and life satisfaction did not change significantly during 1-year attendance in the transition clinic.</li> </ul>
(Maiorino et al., 2018)	To describe gender differences in glycemic control, cardiovascular risk factors, diabetic complications, concomitant pathologies, and circulating endothelial progenitor cells, in a population of young adults with type 1 diabetes.	Cross sectional descriptive study	300 patients (168 males and 132 females), aged 18-30 years with T1D	• International Index of Erectile Function (IIEF) for men and the Female Sexual Function Index	<ul style="list-style-type: none"> <li>• Glycemic control (HbA1c)</li> <li>• Diabetes related complications</li> <li>• Cardiovascular risk factors</li> <li>• surrogate markers of the endothelial function as circulating levels of endothelial progenitor cells (EPCs)</li> </ul>	<ul style="list-style-type: none"> <li>• Compared to men, women had a significantly higher HbA1c levels, body mass index, HDL-cholesterol, and a lower count of both CD133+KDR+ and CD34+KDR+CD133+ EPCs.</li> <li>• A higher proportion of women had overweight/obesity, and thyroiditis than men</li> <li>• Smoking and sexual dysfunctions were more prevalent in men than in women.</li> </ul>
(Majumder et al., 2016)	To examine changes in self-management behaviors after high school graduation in a cohort of emerging	One-year longitudinal descriptive study	64 EAs (18-25 years of age) with T1D	• Self-Management of Type 1 Diabetes in Adolescents scale (SMOD-A)	• Diabetes self-management	• Collaboration with parents decreased, diabetes problem-solving and communication increased, and glycemic control

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	adults with type 1 diabetes					worsened during the first year after high school. <ul style="list-style-type: none"> <li>Higher baseline diabetes problem solving significantly predicted better glycemic control at the 1-year follow-up.</li> </ul>
(Markowitz et al., 2016)	To compare the clinical characteristics of individuals who did or did not attend their appointments accompanied by a parent	Cross sectional descriptive study	69 emerging adults (18 – 24 years of age) with T1D	• -	• Glycemic control (HbA1c)	<ul style="list-style-type: none"> <li>A1C levels were significantly higher in those who had attended an appointment with a parent more than once than in those who had never attended an appointment with a parent.</li> </ul>
(Montali et al., 2022)	This study explores the disease experience of adolescents and young adults with T1DM focusing on the barriers and facilitators of disease self-care.	Qualitative Descriptive	22 young adults with T1D	• -	• -	<ul style="list-style-type: none"> <li>Barriers of self-care included disease characteristics and social stigmatization.</li> <li>Facilitators included social support, diabetes education and multi-professional teams in diabetes centers</li> <li>Diabetes technology acted as both a barrier and a facilitator of self-care</li> </ul>
(Palladino et al., 2013)	Compare emerging adults with and without type 1 diabetes on life path decisions, health behaviors, and psychological well-being during the	1-year longitudinal descriptive study	239 EAs (122 without diabetes and 117 with diabetes) (17–18 years old)	<ul style="list-style-type: none"> <li>Center for Epidemiological Studies Depression Scale</li> <li>UCLA Loneliness Scale</li> <li>Purpose in life subscale from</li> </ul>	<ul style="list-style-type: none"> <li>Life Path Decisions</li> <li>Health Behaviors (alcohol consumption, binge drinking, smoking,</li> </ul>	<ul style="list-style-type: none"> <li>Those with and without diabetes engaged in similar levels of risky behaviors.</li> <li>Disturbed sleep increased for males with diabetes only.</li> <li>Having diabetes was not associated with depressive symptoms, loneliness, or bulimic</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	transition out of high school.			<ul style="list-style-type: none"> <li>Psychological Well-Being</li> <li>Eating Disorders Inventory</li> <li>Life Satisfaction Inventory</li> <li>Health behavior outcomes measured by dichotomous questions.</li> </ul>	<ul style="list-style-type: none"> <li>physical activity, sleep,</li> <li>Psychological Well-Being (depressive symptoms, Loneliness, purpose in life, eating disorders, life satisfaction)</li> </ul>	<ul style="list-style-type: none"> <li>symptoms, but was associated with lower life satisfaction and lower life purpose over time.</li> </ul>
(Pierce et al., 2017)	To identify the content domain for developing a multidimensional measure of health care transition (HCT) outcomes in emerging adults with T1D	Qualitative study	46 persons: 10 EAs (18-25 years old) with T1D; 9 parents of young adults with T1D; 10 pediatric T1D care providers; 8 adult T1D providers; 9 health care professionals experts in care for EAs with T1D	<ul style="list-style-type: none"> <li>Semi structured interviews</li> </ul>	<ul style="list-style-type: none"> <li>-</li> </ul>	<ul style="list-style-type: none"> <li>The following constructs were identified for a planned measure of healthcare transition outcomes: biomedical markers of T1D control; T1D knowledge/skills; navigation of a new health care system; integration of T1D into emerging adult roles; balance of parental involvement with autonomy; and “ownership” of T1D self-management</li> </ul>
(Pihlaskari et al., 2018)	To examine longitudinal associations of perceived diabetes-specific peer support	One-year longitudinal descriptive study	211 individuals (17-18 years of age) with T1D	<ul style="list-style-type: none"> <li>Diabetes Behavioral Rating Scale</li> <li>Diabetes Social Support</li> </ul>	<ul style="list-style-type: none"> <li>Treatment adherence</li> <li>Glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>Perceived diabetes-specific peer support in high school predicted better adherence across the subsequent year while</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	with adherence and glycemic control among late adolescents with type 1 diabetes as they transition out of high school and into early emerging adulthood.			Questionnaire–Friends		controlling for initial levels of adherence. <ul style="list-style-type: none"> <li>Those who perceived higher peer support for diabetes during early emerging adulthood (T2) displayed better self-management across this transition year, while controlling for initial levels of perceived peer support.</li> </ul>
(Pyatak et al., 2017)	To report on findings from a prospective, nonrandomized trial which evaluated the efficacy of a structured transition program on two cohorts of youth with type 1 diabetes [one group that had continual access to care (CC) and another that had experienced a lapse in medical care (LC)] during their transfer from pediatric to adult health care.	Prospective nonrandomized trial study	75 individuals with T1D (CC group, n = 51 and LC group, n = 24) Mean age 19.61 ( $\pm$ 1.02) years	<ul style="list-style-type: none"> <li>Diabetes Empowerment Scale–Short Form</li> <li>Diabetes Knowledge Test</li> <li>Perceived Stress Scale</li> <li>Patient Health Questionnaire-9</li> <li>Satisfaction With Life Scale</li> <li>Arizona Integrative Outcomes Scale-24</li> </ul>	<ul style="list-style-type: none"> <li>Number of diabetes care visits during the 12-month study period</li> <li>Glycemic control (HbA1c)</li> <li>Episodes of severe hypoglycemia</li> <li>Diabetes-related emergency department visits and hospitalizations</li> <li>Psychosocial outcomes</li> </ul>	<ul style="list-style-type: none"> <li>The structured transition program was effective in lowering A1C, reducing severe hypoglycemia and emergency department utilization, and improving uptake of routine diabetes care.</li> </ul>
(Ramchandani et al., 2019)	To explore developmental, situational, and	Qualitative study	21 emerging adults (18-29 years old)	Focus groups and single interviews		Four main themes emerged: <ul style="list-style-type: none"> <li>Finding a balance between diabetes and life</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	organizational challenges experienced by emerging adults with T1D.					<ul style="list-style-type: none"> <li>• The desire to be in control of their diabetes</li> <li>• The hidden burden of diabetes</li> <li>• The desire to have a connection with their diabetes provider</li> </ul>
(Rassart et al., 2015)	To examine the longitudinal interplay of depressive symptoms, diabetes-specific perceptions and distress, and glycemic control in emerging adults with T1D.	5-year Longitudinal descriptive study	164 Emerging adults (18–30 years of age) with T1D	<ul style="list-style-type: none"> <li>• Center for Epidemiologic Studies Depression Scale (CES-D)</li> <li>• Problem Areas in Diabetes Scale (PAID)</li> <li>• Illness Perception Questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Depressive symptoms,</li> <li>• Diabetes-specific distress</li> <li>• Illness perceptions</li> <li>• Glycemic control (HbA1c)</li> </ul>	<ul style="list-style-type: none"> <li>• Stronger perceptions of control predicted a relative decrease in treatment-related problems.</li> <li>• Stronger perceptions of consequences predicted a relative increase in depressive symptoms, treatment-related, food-related, emotional, and social support problems over time.</li> <li>• Higher depressive symptoms predicted a relative increase in social support problems.</li> <li>• None of the study variables was related to changes in glycemic control over time.</li> </ul>
(Raymaekers et al., 2017)	To examine how peer support, extreme peer orientation, and parental responsiveness were related to treatment adherence, diabetes-related distress, and glycemic control over a time span of 1 year in adolescents	One-year longitudinal descriptive study	467 adolescents (14-17 years of age) and emerging adults (18-25 years of age) with T1D	<ul style="list-style-type: none"> <li>• Inventory of Parent and Peer Attachment</li> <li>• Child Report of Parent Behavior Inventory</li> <li>• Extreme Peer Orientation questionnaire</li> <li>• Problem Areas in Diabetes (PAID) scale</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment adherence</li> <li>• Diabetes-related distress</li> <li>• Glycemic control</li> </ul>	<ul style="list-style-type: none"> <li>• Peer support negatively predicted diabetes-related distress over time.</li> <li>• Extreme peer orientation positively predicted treatment distress over time.</li> <li>• Parental responsiveness negatively predicted diabetes-related food.</li> <li>• Treatment adherence negatively predicted extreme peer</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
	and emerging adults with type 1 diabetes			<ul style="list-style-type: none"> <li>• Self-Care Inventory (SCI)</li> </ul>		<p>orientation, treatment distress, and HbA1c values over time.</p> <ul style="list-style-type: none"> <li>• For emerging adults, there was a reciprocal positive relationship between HbA1c values and extreme peer orientation.</li> </ul>
(Saylor et al., 2018)	To examine the characteristics and health outcomes of college students with T1D as it relates to membership in a local university-based diabetes student organization.	Cross sectional descriptive study	317 young adults (18 to 30 years of age) with T1D	<ul style="list-style-type: none"> <li>• A self-report tool developed for the study measuring diabetes management and potential barriers to diabetes management, feelings of depression, anxiety, social isolation, hypoglycemia, A1C, and diabetic ketoacidosis</li> </ul>	<ul style="list-style-type: none"> <li>• Glycemic control (HbA1c)</li> <li>• Diabetes management</li> <li>• Self-reported barriers to diabetes management</li> <li>• Hypoglycemia and diabetic ketoacidosis</li> <li>• Psychological health (depression, anxiety, and perceptions of social isolation)</li> </ul>	<ul style="list-style-type: none"> <li>• Students who were affiliated members of a student-led diabetes student organization were less likely than non-members to report increased levels of isolation, depressive symptoms, and anxiety related to their diabetes.</li> <li>• Affiliated participants reported decreased frequency of hypoglycemia events while in college and decreased A1C levels since joining student-led diabetes chapters</li> <li>• No significant differences between the affiliated and non-affiliated members in incidence of DKA.</li> </ul>
(Vallis et al., 2018)	To compare clinical, psychological, education and social variables in emerging adults with T1D with their adult counterparts aged >30 years.	Cross sectional analysis of the Diabetes Attitudes, Wishes and Needs (DAWN2) data	308 emerging adults (18–30 years of age) and 1060 adults (aged >30 years)	<ul style="list-style-type: none"> <li>• EuroQol-5D,</li> <li>• WHOQOL Global Quality of Life</li> <li>• WHO-5 Well-Being Index</li> <li>• Problem Areas in Diabetes (PAID)</li> </ul>	<ul style="list-style-type: none"> <li>• Health impact/quality of life</li> <li>• Beliefs and attitudes</li> <li>• Self-management behaviors</li> </ul>	<ul style="list-style-type: none"> <li>• Emerging adults reported better overall quality of life, social support and support from their healthcare team than adults aged &gt;30 years of age</li> <li>• Emerging adults experienced greater diabetes-specific distress</li> </ul>

Study	Purpose	Study design	Sample	Measurement Tools	Outcome Measures	Summary of Relevant Findings
				<ul style="list-style-type: none"> <li>• Patient Assessment of Chronic Illness Care (PACIC)</li> <li>• Summary of Diabetes Self-Care Activities measure (SDSCA-6)</li> <li>• Diabetes Empowerment Scale- (DES-DSF)</li> <li>• Health Care Climate</li> </ul>	<ul style="list-style-type: none"> <li>• Family and community support</li> <li>• Diabetes education and management support</li> <li>• Perceived future needs for diabetes care</li> </ul>	<p>and were less engaged in self-management.</p> <ul style="list-style-type: none"> <li>• Emerging adults scored lower on several self-management behaviors, and more emerging adults than adults aged &gt;30 years saw the need to improve healthy eating, self-testing and taking medication.</li> </ul>
(Zoffmann et al., 2014)	To describe the level of glycemic control, complications, and psychosocial functioning and the relationships between these variables in a group of young adults with T1D.	Cross-sectional descriptive study	406 young adults (18–35 years of age) with T1D	<ul style="list-style-type: none"> <li>• Problem Areas in Diabetes (PAID)</li> <li>• World Health Organization-5 Well-Being Index (WHO-5)</li> <li>• Rosenberg's Self-Esteem Scale (RSES)</li> </ul>	<ul style="list-style-type: none"> <li>• Glycemic control (HbA1c)</li> <li>• Diabetes complications (retinopathy, nephropathy)</li> <li>• Psychosocial indicators (Diabetes distress, well-being, self-worth)</li> </ul>	<ul style="list-style-type: none"> <li>• Complications were observed among women more than among men (31.6 vs. 18.8%, <math>P &lt; 0.01</math>)</li> <li>• High distress levels were more prevalent among women compared with men (51.2 vs. 31.9%, <math>P &lt; 0.0001</math>)</li> <li>• Except for perceived autonomy support, the psychosocial variables were all associated with HbA1c</li> </ul>

## APPENDIX B

### Study Flyer (English)



**Do you have **Type 1 Diabetes**?**

**Are you between **18 and 29 years old**?**

**We need YOU for a Research Study**  
**Titled: “Type 1 Diabetes in Emerging Adults in Lebanon: A Mixed Methods Study”**

A PhD student at the American University of Beirut, School of Nursing is looking for volunteers to participate in a research study about the Experience of Living with TYPE 1 DIABETES during Young Adulthood  
**THIS STUDY WILL BE DONE ONLINE (through ZOOM or WHATSAPP VIDEO CALL)**

**You Can Participate If You:**

- Have Type 1 Diabetes since you were 17 years old or younger
- Are living in Lebanon since you were 16 years old
- Do not have other chronic diseases requiring frequent medical follow-up
- Are NOT pregnant

**You Will Be Asked To:**

- Fill out a questionnaire about your diabetes self-care and health (around 20-25 minutes)
- If you agree, you might also be asked to participate in an audio-recorded interview on ZOOM or WHATSAPP (around 30-45 minutes)

If you are interested, please contact the researcher **Amani Bayrakdar**,  
Mail: [aab12@mail.edu.aub](mailto:aab12@mail.edu.aub) OR Tel: 70/657693

\*This flyer is approved by the Institutional Review Board at the American University of Beirut

## Study Flyer (Arabic)



هل أنت مريض/ة سكري من النوع الأول؟

هل عمرك بين 18 و 29 سنة؟

### نحن بحاجة لك للمشاركة بهذه الدراسة بعنوان: ”داء السكري من النوع الأول لدى البالغين الناشئين في لبنان: دراسة بطرق مختلطة“

طالبة دكتوراه في الجامعة الأمريكية في بيروت - كلية التمريض، تبحث عن متطوعين للمشاركة في دراسة بحثية حول تجربة التعايش مع مرض السّكري من النوع الأوّل خلال فترة الشباب سيتم إجراء هذه الدراسة عبر الإنترنت (من خلال تطبيق ZOOM or WHATSAPP call)

#### سُيطلب منك:

- أن تملأين استبيانًا حول الرّعاية الدّاتية والصّحة الخاصة بمرض السكري (حوالي 20-25 دقيقة)
- إذا وافقت ، فقد يُطلب منك أيضًا المشاركة في مقابلة صوتية عبر ZOOM or WHATSAPP call (حوالي 30-45 دقيقة)

#### يمكنك المشاركة إذا كنت:

- لديك مرض السكري من النوع الأول منذ أن كان عمرك 17 عامًا أو أقل
- تعيش/ين في لبنان منذ أن كان عمرك 16 عامًا
- ليس لديك أمراض مزمنة أخرى تتطلب متابعة طبية متكررة
- لستِ حاملاً

إذا كنت مهتمًا ، فيرجى الاتصال بالباحثة أماني بيرقدار ،

عبر البريد الإلكتروني: [aab12@mail.edu.aub](mailto:aab12@mail.edu.aub) أو عبر الهاتف: 70/657693

تمت الموافقة على هذا المنشور من قبل لجنة الأخلاقيات في الجامعة الأمريكية في بيروت

## APPENDIX C

### Script for “Initial Contact by the Clinic Staff”

“You are invited to participate in a study titled “Type 1 Diabetes in Emerging Adults in Lebanon: A Mixed Methods Study”, that is conducted by Amani Bayrakdar, a Nursing PhD student at the American University of Beirut. The study examines the experiences of people aged 18 to 29 years who are living with type 1 diabetes in Lebanon. Participating in the study is done remotely (by interview-through Zoom or WhatsApp video call). If you agree to participate, you will be asked questions, which will take around 20-25 minutes of your time. At the same time, you might also be asked to participate in a second audio-recorded interview to talk about your experience with diabetes during this phase of your life, which will take around 30-40 minutes. Upon participation, you will receive (... Lebanese Liras) for your time. This study is very important because it will help health care providers understand the needs of young adults with type 1 diabetes so they can provide them with better care.

If you are interested in knowing more about the study, I can put you in contact with the investigator; and she will explain the study and what is required from you. I can either share her contact information with you, or you can give me permission to give her your contact information. Your participation is totally voluntary and if you refuse to participate this will not affect the care you are receiving”.

If you are interested to participate in the study or have any questions about it, you may contact Amani Bayrakdar at email: [aab12@mail.aub.edu](mailto:aab12@mail.aub.edu) or Tel: 70-657693.

أنت مدعوة للمشاركة في دراسة بعنوان "داء السكري من النوع الأول لدى البالغين الناشئين في لبنان: دراسة بطرق مختلطة"، تجريها أماني بيرقدار، طالبة دكتوراه في التمريض في الجامعة الأمريكية في بيروت. تبحث الدراسة في تجارب الأشخاص الذين تتراوح أعمارهم بين 18 و 29 عامًا مع مرض السكري من النوع 1 في لبنان. تتم المشاركة في الدراسة عن بُعد عبر مقابلة من خلال WhatsApp أو Zoom. إذا وافقت على المشاركة، فسُطرح عليك أسئلة، والذي سيستغرق حوالي 20-25 دقيقة من وقتك. في الوقت نفسه، قد يُطلب منك أيضًا المشاركة في مقابلة ثانية مسجلة بالصوت للحديث عن تجربتك مع مرض السكري خلال هذه المرحلة من حياتك، والتي ستستغرق حوالي 30-40 دقيقة. عند المشاركة، ستحصل على (... ليرة لبنانية) مقابل وقتك. هذه الدراسة مهمة للغاية لأنها ستساعد مقدمي الرعاية الصحية على فهم احتياجات الشباب المصابين بداء السكري من النوع 1 في لبنان حتى يتمكنوا من توفير رعاية أفضل لهم. إذا كنت مهتمًا بمعرفة المزيد عن الدراسة، فيمكنني توصيلك بالباحث؛ وهي سوف تشرح لك الدراسة وما هو مطلوب منك. يمكنني إما مشاركتها بطريقة الإتصال بك، أو يمكنك منحي الإذن لإعطائها معلومات حول كيفية الإتصال بك. مشاركتك طوعية تمامًا وإذا رفضت المشاركة فلن يؤثر ذلك على الرعاية التي تتلقاها".

إذا كنت مهتمًا بالمشاركة في الدراسة أو لديك أي أسئلة حول ذلك، يمكنك الإتصال بالباحثة أماني بيرقدار على البريد: [aab12@mail.aub.edu](mailto:aab12@mail.aub.edu) أو الهاتف: 70-657693

## APPENDIX D

### Oral Consent Form (English)

Primary Investigator: Dr. Samar Nouredine  
Study coordinator: Ms. Amani Bayrakdar  
Place of the research: American University of Beirut, Bliss Street, Beirut, Lebanon  
Title of the study: "Type 1 Diabetes in Emerging Adults in Lebanon: A Mixed Methods Study"

Hello. My name is Amani Bayrakdar. I am a doctoral student in the Hariri School of Nursing at AUB. I would like to invite you to participate in a research study about the experience of living with type 1 diabetes in individuals aged 18 to 29 years. My focus will be to examine the effect of your illness on your health and life in general, how you are managing it. I am doing this study as part of my doctoral studies at AUB. The only way to achieve this goal is by interviewing patients.

We are targeting for this research study 90 patients with type 1 diabetes who are between 18 and 29 years, were diagnosed with diabetes at least one year before turning 18, and who have been living in Lebanon for at least two years before turning 18 years. We recruited participants from the diabetes clinic through their health care providers, as well as AUB students by email invitation.

If you agree to participate in this study, I will interview you, through Zoom or video call, where I will ask you questions about your demographic characteristics and health status related to your diabetes, as well as about your self-care for diabetes, your feelings about diabetes, and the support you get from your family and friends regarding your diabetes. This interview is expected to take around 20 minutes of your time. If you agree, you may also be one of 20 persons with type 1 diabetes who will be invited to participate in a second interview to discuss your experience with diabetes during this phase of your life, including what challenges you face and what are the factors that can help you during this time. The second interview will be audio-recorded and expected to take around 30-40 minutes. After we reach 20 participants, we will stop requesting from individuals to participate in the second interview. Please stop me at any time if you have questions about the study.

Your privacy and confidentiality of the information you provide will be protected. The virtual interview will take place in a private place with no one around. Your name and other identifying information will never be attached to your answers and they will not be used in our reports or published papers. All data will be kept in a locked drawer in a locked room at the School of Nursing at AUB, or saved in a password-protected computer. Data access is limited to the Principal Investigator and myself. All data will be destroyed three years after the study is completed.

Your participation in this study is entirely voluntary and you have the right to withdraw your participation at any time. Refusal or withdrawal from the study will involve no loss of benefits to which you are otherwise entitled nor will it affect your relationship with AUB/AUBMC. You can also skip any question that you do not want to answer during the interview.

We do not expect any risk to you from participating in the study beyond the risks of daily life. The main risk is the inconvenience due to the time spent in the interview. There is also a minimal risk of experiencing signs of distress/anxiety during data collection when answering the social support and distress scales. In case this happens, I will stop the interview and ask you if you would like to take a break or stop the interview altogether. In case you need further

support, you can contact the Outpatient Department (OPD) Psychiatry clinics at AUB-MC located in ACC Building (Halim & Aida Daniel Academic & Clinical Center), 4th floor. Tel: 01350000 ext. 5650. These clinics provide low-cost psychological assistance.

If you participate in the study, you will receive a sum of (... Lebanese Liras), which is a compensation for your time, at a time and place of your choosing. Withdrawal from the study at any point will not affect you receiving this amount of money. Your participation in the study will also have an indirect benefit since the information you provide will help researchers better understand the needs of the young adults with T1D so that they can provide better care to them.

In case you will be interviewed for the open ended questions, I would need your permission to audio record the interview in order not to miss any information you provide. You cannot participate in the open-ended interview if you refuse to be audio-recorded. The recordings will be stored on a password-protected computer in the office of the primary investigator at the Hariri School of Nursing at AUB and will only be used by me and the primary investigator. I will destroy/delete all the recordings after completion of the study.

If you have any questions, you are free to ask them now. If you have further questions about the study, you may contact the primary investigator Dr. Samar Nouredine, Hariri School of Nursing, American University of Beirut, Tel: +961-03-579451; Email: sn00@aub.edu.lb. You will be provided with a copy of the consent form. If you have questions about your rights as a participant in this research, you can contact the Institutional Review Board office at AUB: American University of Beirut, Phone: +961-1-350000, Ext: 5444/5455, Email: irb@aub.edu.lb

### Oral Consent Form (Arabic)

#### إقرار الموافقة الشفهية على المشاركة في البحث

الباحث الرئيسي: د. سمر نور الدين

منسق الدراسة: السيدة أماني بيرقدار

مكان البحث: الجامعة الأمريكية في بيروت ، شارع بليس ، بيروت ، لبنان

عنوان البحث العلمي: "داء السكري من النوع الأول لدى البالغين الناشئين في لبنان: دراسة بطرق مختلطة"

مرحباً. اسمي أماني بيرقدار. أنا طالبة دكتوراه في مدرسة الحريري للتمريض في الجامعة الأميركية في بيروت. أود أن أدعوك للمشاركة في دراسة بحثية حول تجربة التعايش مع مرض السكري من النوع 1 لدى الأفراد الذين تتراوح أعمارهم بين 18 و 29 عامًا. سينصب تركيزي على دراسة تأثير مرضك على صحتك وحياتك بشكل عام ، وكيفية إدارتك له. أقوم بهذه الدراسة كجزء من دراسات الدكتوراه في الجامعة الأميركية في بيروت. الطريقة الوحيدة لتحقيق هذا الهدف هي عبر إجراء مقابلات مع المرضى.

نستهدف في هذه الدراسة البحثية 90 مريضاً يعانون من مرض السكري من النوع الأول تتراوح أعمارهم بين 18 و 29 عامًا، والذين تم تشخيص إصابتهم بمرض السكري لمدة عام على الأقل قبل بلوغ سن 18 عامًا، والذين يعيشون في لبنان لمدة عامين على الأقل قبل بلوغ 18 عامًا. قمنا باستقطاب مشاركين من عيادة السكري من خلال مقدمي الرعاية الصحية ، وكذلك طلاب من الجامعة الأمريكية في بيروت عن طريق دعوة عبر البريد الإلكتروني.

إذا وافقت على المشاركة في هذه الدراسة ، فسوف أقوم بإجراء مقابلة معك ، من خلال Zoom أو مكالمة فيديو ، حيث سأطرح عليك أسئلة حول خصائصك الديموغرافية وحالتك الصحية المتعلقة بمرض السكري لديك ، بالإضافة إلى بعض الأسئلة حول رعايتك الذاتية لمرض السكري ، ومشاعرك حول مرض السكري ، والدعم الذي تحصل عليه من عائلتك وأصدقائك فيما يتعلق بمرض السكري الخاص بك. من المتوقع أن تستغرق هذه المقابلة حوالي 20 دقيقة من وقتك. إذا كنت توافق ، فقد تكون أيضاً واحداً من 20 شخصاً مصاباً بداء السكري من النوع 1 الذين سنتم دعوتهم للمشاركة في مقابلة ثانية لمناقشة تجربتك مع مرض السكري خلال هذه المرحلة

من حياتك ، بما في ذلك التحديات التي تواجهها وما هي العوامل التي يمكن أن تساعدك خلال هذا الوقت. سيتم تسجيل المقابلة الثانية صوتيًا ومن المتوقع أن تستغرق حوالي 30-40 دقيقة. بعد أن نصل إلى 20 مشاركًا ، سنتوقف عن طلب المشاركة في المقابلة الثانية. من فضلك أوقفني في أي وقت إذا كانت لديك أسئلة حول الدراسة.

ستتم حماية خصوصيتك وسرية المعلومات التي تقدمها. ستتم المقابلة الافتراضية في مكان خاص خالي من الناس. لن يتم إرفاق اسمك ومعلومات التعريف الأخرى بإجاباتك ولن يتم استخدامها في تقاريرنا أو أوراقنا المنشورة. سيتم الاحتفاظ بجميع البيانات في درج مغلق في غرفة مغلقة في مدرسة التمريض في الجامعة الأمريكية في بيروت ، أو حفظها في جهاز كمبيوتر محمي بكلمة مرور. يقتصر الوصول إلى البيانات على الباحث الرئيسي وأنا. سيتم إتلاف جميع البيانات بعد ثلاث سنوات من اكتمال الدراسة.

يرجى تفهم أن مشاركتك في هذه الدراسة طوعية تمامًا ولديك الحق في سحب مشاركتك في أي وقت. لن يترتب على رفض الدراسة أو الانسحاب منها خسارة الفوائد التي يحق لك الحصول عليها ولن يؤثر ذلك على علاقتك مع الجامعة الأمريكية في بيروت/ و المركز الطبي في الجامعة الأمريكية في بيروت. يمكنك أيضًا تخطي أي سؤال لا تريد الإجابة عليه أثناء المقابلة.

لا يُتوقع أن تنطوي مشاركتك في هذه الدراسة على أي مخاطر عليك تتجاوز مخاطر الحياة اليومية. الخطر الرئيسي هو الإزعاج بسبب الوقت الذي تستغرقه المقابلة. هناك أيضًا خطر ضئيل من التعرض لعلامات الضيق / القلق أثناء جمع البيانات عند الرد على مقياس الدعم الاجتماعي و مشاعرك حول مرض السكري. في حالة حدوث ذلك ، سأوقف المقابلة وأسألك عما إذا كنت ترغب في أخذ استراحة أو إيقاف المقابلة تمامًا. في حال احتجت إلى مزيد من الدعم ، يمكنك الاتصال بعيادات الطب النفسي في قسم العيادات الخارجية (OPD) في مستشفى الجامعة الأمريكية في بيروت الموجودة في مبنى ACC (مركز حلیم و عابدة دانيال الأكاديمي و السريري) ، الطابق الرابع. هاتف: 01350000 تحويلة. 5650- تقدم هذه العيادات مساعدة نفسية منخفضة التكلفة.

إذا شاركت في الدراسة ، فستتلقى مبلغ ( ... ليرة لبنانية) وهو تعويض عن وقتك، في مكان و زمان تحدده انت. لن يؤثر الانسحاب من الدراسة في أي وقت على تلقي هذا المبلغ من المال. سيكون لمشاركتك في الدراسة أيضًا فائدة غير مباشرة لأن المعلومات التي تقدمها ستساعد الباحثين على فهم أفضل لاحتياجات الشباب الذين يعانون من T1D حتى يتمكنوا من تقديم رعاية أفضل لهم.

في حالة إجراء المقابلة الثانية معك والتي تشمل الأسئلة المفتوحة ، سأحتاج إلى إيداعك للتسجيل الصوتي للمقابلة حتى لا تفوتني أي معلومات تقدمها. لا يمكنك المشاركة في المقابلة المفتوحة إذا رفضت التسجيل الصوتي. سيتم تخزين هذه التسجيلات على جهاز كمبيوتر محمي بكلمة مرور في مكتب الباحث الرئيسي في مدرسة الحريري للتمريض في الجامعة الأمريكية في بيروت ولن يتم استخدامها إلا من قبلي أنا والباحث الرئيسي. سوف أتلّف / أهدف جميع التسجيلات بعد الانتهاء من الدراسة.

سيتم تزويدك بنسخة من نموذج الموافقة. إذا كان لديك أي أسئلة ، فأنت حر في طرحها الآن. إذا كان لديك المزيد من الأسئلة حول الدراسة ، يمكنك الاتصال بالباحثة الرئيسية د. سمر نور الدين ، مدرسة الحريري للتمريض ، الجامعة الأمريكية في بيروت ، هاتف: + 961-03-579451؛ البريد الإلكتروني: sn00@aub.edu.lb. إذا كانت لديك أسئلة حول حقوقك كمشارك في هذا البحث ، فيمكنك الاتصال بمكتب مراجعة المؤسسة في الجامعة الأمريكية في بيروت: الجامعة الأمريكية في بيروت ، هاتف: + 961-1-350000 ، تحويلة: 5455/5444irb@aub.edu.lb ، البريد الإلكتروني:

## APPENDIX E

### Invitation to Participate in a Research Study

**This notice is for an AUB-IRB Approved Research Study**  
**Primary investigator: Dr. Samar Nouredine (Hariri School of Nursing, AUB)**  
**\*It is not an Official Message from AUB\***

We are inviting you to participate in a remotely conducted research study titled: "Type 1 Diabetes in Emerging Adults in Lebanon: A Mixed Methods Study", about the experience of living with type 1 diabetes in Lebanon in individuals aged between 18 and 29 years.

The study involves conducting an interview with you that includes questions about you and your health. If you agree, you may also be asked to participate in an open-ended audio-recorded interview (through Zoom or WhatsApp video call) where you will discuss your experience with diabetes during this phase of your life, including what challenges you face and what are the factors that can help you care for your diabetes during this time of your life.

You are invited because we are targeting patients with type 1 diabetes who are between 18 and 29 years, who have had diabetes at least one year before turning 18, and who have been living in Lebanon for at least two years before turning 18 years.

The estimated time to complete the interview is approximately 20 minutes. If you were invited to participate in the interview and accept, this second interview is expected to last 30-40 minutes.

If you participate in the study, you will receive a sum of (... Lebanese Liras) which is a compensation for your time.

If you are interested to participate in the study or have any questions about it, you may contact Dr. Samar Nouredine; email [sn00@aub.edu.lb](mailto:sn00@aub.edu.lb); cell phone 03-579451 or the study coordinator Amani Bayrakdar Mail: [aab12@mail.aub.edu](mailto:aab12@mail.aub.edu) or Tel: 70-657693.

#### دعوة للمشاركة في دراسة بحثية

هذا الإشعار مخصص لدراسة بحثية معتمدة من-لجنة الأخلاقيات في الجامعة الأمريكية في بيروت  
الباحثة الرئيسية سمر نور الدين في كلية الحريري للتمريض ، الجامعة الأمريكية في بيروت  
\*هذه ليست رسالة رسمية من الجامعة الأمريكية في بيروت\*

ندعوكم للمشاركة في دراسة بحثية سينتم إجراؤها عن بعد بعنوان: "مرض السكري من النوع الأول لدى البالغين الناشئين في لبنان: دراسة بطرق مختلطة"، حول تجربة التعايش مع مرض السكري من النوع 1 في لبنان لدى الأفراد الذين تتراوح أعمارهم بين 18 و 29 عامًا.

تتضمن الدراسة معك تتضمن أسئلة عنك وعن صحتك. إذا وافقت ، فقد يُطلب منك أيضًا المشاركة في مقابلة مع أسئلة مفتوحة تسجيل صوتي (من خلال Zoom أو WhatsApp video call) حيث ستناقش تجربتك مع مرض السكري خلال هذه المرحلة من حياتك ، بما في ذلك التحديات التي تواجهها وماذا هي العوامل التي يمكن أن تساعدك على رعاية مرض السكري الخاص بك خلال هذا الوقت من حياتك.

أنت مدعو لأننا نستهدف مرضى السكري من النوع الأول الذين تتراوح أعمارهم بين 18 و 29 عامًا ، والذين أصيبوا بالسكري لمدة عام على الأقل قبل بلوغ 18 عامًا ، والذين يعيشون في لبنان لمدة عامين على الأقل قبل بلوغ 18 عامًا. الوقت المقدر لإكمال هو حوالي 20 دقيقة. إذا تمت دعوتك للمشاركة في المقابلة والقبول ، فمن المتوقع أن تستغرق هذه المقابلة الثانية 30-40 دقيقة.

إذا شاركت في الدراسة ، فستتلقى مبلغ (... ليرة لبنانية) وهو تعويض عن وقتك. إذا كنت مهتمًا بالمشاركة في الدراسة أو لديك أي أسئلة حول ذلك ، يمكنك الاتصال بالدكتورة سمر نور الدين ؛ البريد الإلكتروني [sn00@aub.edu.lb](mailto:sn00@aub.edu.lb) ؛ الهاتف الخليوي 03-579451 أو منسقة الدراسة أمانى بيرقدار البريد: [aab12@mail.aub.edu](mailto:aab12@mail.aub.edu) أو الهاتف: 657693

# APPENDIX F

## Study Questionnaire

### I. Section 1: Demographic/socioeconomic data:

1. How old are you?
2. Gender: a) Male b) Female
3. Where do you manage your diabetes? (If you follow-up at more than one place, check all that applies)?
  - a) At a pediatric diabetes clinic
  - b) At an adult diabetes clinic
  - c) At a family medicine clinic
  - d) At the Chronic Care Center
4. Are you still following-up with the same physician since you were 17 years old?
  - a) Yes
  - b) No
5. What is your marital status?
  - a) Single
  - b) Married
  - c) Divorced
  - d) Other: (please specify) \_\_\_\_\_
6. Do you have any children?
  - a) Yes
  - b) No
7. How old were you when you were diagnosed with diabetes? \_\_\_\_\_ years old
8. Are you on insulin treatment through:
  - a) NPH and short acting insulin
  - b) Lantus/ Levemir/ Toujeo/ Tresiba and short acting insulin
  - c) Insulin pump therapy
9. How do you monitor your glucose?
  - a) You use a Glucometer
  - b) You use a Freestyle Libre
  - c) You use a continuous glucose monitor (CGM)
10. Do you have any other chronic health problems? a) Yes b) No  
If yes, what illness:
  - i. High blood pressure
  - ii. High blood lipids
  - iii. Kidney problems
  - iv. Eye problems
  - v. other problems, please specify:
11. What is the highest level of education that you have completed?
  - a) Did not complete high school
  - b) Currently in high school
  - c) High school graduate
  - d) Currently in university or college
  - e) University graduate
  - f) Other, please specify: \_\_\_\_\_
12. What is your employment status?
  - a) Currently working full time
  - b) Currently working part time
  - c) Unemployed

- d) Student  
e) Other, please specify: \_\_\_\_\_
13. Who do you live with?  
a) Live alone  
b) Live with my parents  
c) Live with my spouse  
d) Live with friends  
e) Other, please specify: \_\_\_\_\_
14. How many rooms are where you live (excluding the kitchen and bathrooms)? \_\_\_\_\_
15. How many people live with you? \_\_\_\_\_
16. What is the educational level of the head of your household?  
a) Less than high school  
b) High school diploma or equivalent  
c) Bachelor's degree  
d) Master's degree or higher  
e) I am the head of my household
17. Do you currently have health coverage? a) Yes      b) No
18. What aspects of diabetes care does your health insurance cover? (Choose all that applies).  
a) None  
b) Hospital admissions  
c) Laboratory tests  
d) Insulin  
e) Testing strips  
f) Sensor  
g) Insulin pump and supplies
19. Have you received a formal education about how to manage your diabetes?  
a) Yes  
b) No
20. How would you rate your knowledge about managing your diabetes on a scale from 1 to 5?  
(1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent)
21. How many times did you visit the diabetes clinic during the last year?  
a) Less than two visits in the last year  
b) Two visits or more in the last year
22. Which of the following check-ups did you have over the last two years? (Choose all that applies).  
a) An eye exam  
b) A blood test for lipids/ cholesterol  
c) A test for your kidneys (urine for microalbumin)  
d) A blood pressure check  
e) A foot exam
23. Do you do any of the following (choose all that apply):  
a) Smoke cigarettes. If yes, at what age did you start? \_\_\_\_\_ years old  
b) Smoke Hubble Bubble. If yes, at what age did you start? \_\_\_\_\_ years old  
c) Drink alcohol. If yes, at what age did you start? \_\_\_\_\_ years old
24. What is your most recent HbA1c level: \_\_\_\_\_  
Verified by medical records: a) Yes      b) No
25. How many episodes of diabetic ketoacidosis (DKA) did you have during the past 6 months - where you had your blood glucose so high that you had to go to the hospital and receive IV fluids and insulin therapy? \_\_\_\_\_
26. How many times during the past 6 months did your blood sugar get so low where you were unable to treat yourself and needed someone's help? \_\_\_\_\_
27. Do you have a glucagon hypoglycemia emergency kit?

- a) Yes
- b) No

**II. Section 2: DCP Social Support**

**Each of the 2 questions below include a number of statements. Please rate the extent of your agreement with each statement by stating whether you strongly agree, agree, neither agree nor disagree, agree or strongly agree. If the item does not apply to you, let me know.**

1. I want a lot of help and support from my family or friends in: (circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a) following my meal plan	1	2	3	4	5	N/A
b) taking my medicine	1	2	3	4	5	N/A
c) taking care of my feet	1	2	3	4	5	N/A
d) getting enough physical activity	1	2	3	4	5	N/A
e) testing my sugar	1	2	3	4	5	N/A
f) handling my feelings about diabetes	1	2	3	4	5	N/A

2. My family or friends help and support me a lot to: (circle one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a) follow my meal plan	1	2	3	4	5	N/A
b) take my medicine	1	2	3	4	5	N/A
c) take care of my feet	1	2	3	4	5	N/A
d) get enough physical activity	1	2	3	4	5	N/A
e) test my sugar	1	2	3	4	5	N/A
f) handle my feelings about diabetes	1	2	3	4	5	N/A

3. My family or friends: (one answer for each line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
a) accept me and my diabetes	1	2	3	4	5
b) feel uncomfortable about me because of my diabetes	1	2	3	4	5
c) encourage or reassure me about my diabetes	1	2	3	4	5
d) discourage or upset me about my diabetes	1	2	3	4	5
e) listen to me when I want to talk about my diabetes	1	2	3	4	5
f) nag me about diabetes	1	2	3	4	5

4. Who helps you the **most** in caring for your diabetes? (check only one box)

- 1.  Spouse
- 2.  Parents

3.  Other family members
4.  Friends
5.  Paid helper
6.  Doctor
7.  Nurse
8.  Other health care professional
9.  No one

### III. Section 3: Self-Care Inventory-Revised tool (SCI-R)

This survey measures what you actually do, not what you are advised to do. How often have you followed your diabetes treatment plan in the past 1-2 months? There is one choice for each item.

	Never	Rarely	Sometimes	Usually	Always
1. Check blood glucose with monitor	1	2	3	4	5
2. Record blood glucose results	1	2	3	4	5
3. Check ketones when glucose level is high	1	2	3	4	5
4. Take the correct dose of diabetes pills or insulin	1	2	3	4	5
5. Take diabetes pills or insulin at the right time	1	2	3	4	5
6. Eat the correct food portions	1	2	3	4	5
7. Eat meals/snacks on time	1	2	3	4	5
8. Keep food records	1	2	3	4	5
9. Read food labels	1	2	3	4	5
10. Treat low blood glucose with just the recommended amount of carbohydrate	1	2	3	4	5
11. Carry quick acting sugar to treat low blood glucose	1	2	3	4	5
12. Come in for clinic appointments	1	2	3	4	5
13. Wear a Medic Alert ID	1	2	3	4	5
14. Exercise	1	2	3	4	5
15. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	1	2	3	4	5

### IV. Section 4: Type 1 Diabetes Distress Scale (T1-DDS)

Instructions: Living with type 1 diabetes can be tough. Listed are a variety of distressing things that many people with type 1 diabetes experience. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you: is it not a problem, a slight problem, a moderate problem, a somewhat serious problem, a serious problem or a very serious problem.

	Not A Problem	A Slight Problem	A Moderate Problem	A Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that I am not as skilled at managing diabetes as I should be.	1	2	3	4	5	6
2. Feeling that I don't eat as carefully as I probably should.	1	2	3	4	5	6

3. Feeling that I don't notice the warning signs of hypoglycemia as well as I used to.	1	2	3	4	5	6
4. Feeling that people treat me differently when they find out I have diabetes.	1	2	3	4	5	6
5. Feeling discouraged when I see high blood glucose numbers that I can't explain.	1	2	3	4	5	6
6. Feeling that my family and friends make a bigger deal out of diabetes than they should.	1	2	3	4	5	6
7. Feeling that I can't tell my diabetes doctor what is really on my mind.	1	2	3	4	5	6
8. Feeling that I am not taking as much insulin as I should.	1	2	3	4	5	6
9. Feeling that there is too much diabetes equipment and stuff I must always have with me	1	2	3	4	5	6
10. Feeling like I have to hide my diabetes from other people.	1	2	3	4	5	6
11. Feeling that my friends and family worry more about hypoglycemia than I want them to.	1	2	3	4	5	6
12. Feeling that I don't check my blood glucose level as often as I probably should.	1	2	3	4	5	6
13. Feeling worried that I will develop serious long-term complications, no matter how hard I try.	1	2	3	4	5	6
14. Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.	1	2	3	4	5	6
15. Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.	1	2	3	4	5	6
16. Feeling that thoughts about food and eating control my life.	1	2	3	4	5	6
17. Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.	1	2	3	4	5	6
18. Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	1	2	3	4	5	6
19. Feeling concerned that diabetes may make me less attractive to employers.	1	2	3	4	5	6

20. Feeling that my friends or family act like “diabetes police” (bother me too much)	1	2	3	4	5	6
21. Feeling that I’ve got to be perfect with my diabetes management.	1	2	3	4	5	6
22. Feeling frightened that I could have a serious hypoglycemic event while driving	1	2	3	4	5	6
23. Feeling that my eating is out of control.	1	2	3	4	5	6
24. Feeling that people will think less of me if they knew I had diabetes.	1	2	3	4	5	6
25. Feeling that no matter how hard I try with my diabetes, it will never be good enough.	1	2	3	4	5	6
26. Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
27. Feeling that I can't ever be safe from the possibility of a serious hypoglycemic event.	1	2	3	4	5	6
28. Feeling that I don't give my diabetes as much attention as I probably should.	1	2	3	4	5	6

### استبيان الدراسة

1. القسم الأول: البيانات السكانية/ الاجتماعية الاقتصادية:

1. العمر: \_\_\_\_\_
2. الجنس: (a) ذكر (b) أنثى
3. أين تعالج/ين مرض السكري؟ إذا قمت بالمتابعة في أكثر من مكان ، حدد كل ما ينطبق:
  - (a) في عيادة السكري الخاصة بالأطفال
  - (b) في عيادة السكري الخاصة بالكبار
  - (c) في عيادة طبيب الأسرة
  - (d) في مركز رعاية الأمراض الدائمة
4. هل ما زلت تتابع/ين مع نفس الطبيب منذ أن كان عمرك 17 عامًا؟ (a) نعم (b) لا
5. الحالة الاجتماعية:
  - (a) أعزب/ عزباء
  - (b) متزوج/ة
  - (c) مطلق/ة
  - (d) وضع آخر، يرجى التحديد: \_\_\_\_\_
6. هل لديك أطفال؟ (a) نعم (b) لا
7. كم كان عمرك عندما تم تشخيصك بمرض السكري؟ \_\_\_\_\_ سنة

8. هل تتناول/ين علاج الإنسولين من خلال:
- (a) Humilin N و إنسولين سريع
- (b) Lantus/ Levemir/ Toujeo/ Tresiba و إنسولين سريع
- (c) مضخة الأنسولين (Insulin Pump)
9. كيف تراقب نسبة الجلوكوز لديك؟
- (a) عبر إستخدام جهاز قياس السكر المنزلي (Glucometer)
- (b) عبر إستخدام جهاز Freestyle Libre
- (c) عبر إستخدام جهاز مراقبة دائمة (CGM (continuous glucose monitor)
10. هل لديك أي مشاكل صحية مزمنة أخرى؟ (a) نعم (b) لا
- إذا كانت الإجابة نعم، فما هو المرض:
- i. ضغط الدّم المرتفع
- ii. ارتفاع نسبة الدهون في الدم
- iii. مشاكل في الكلى
- iv. مشاكل في العين
- v. مشاكل أخرى، يرجى التحديد: \_\_\_\_\_
11. ما هو أعلى مستوى تعليمي أتممته؟
- (a) لم أكمل المدرسة الثانوية
- (b) حاليا في المدرسة الثانوية
- (c) خريج/ة الثانوية
- (d) حاليا في الجامعة أو الكلية
- (e) خريج/ة جامعي/ة
- (f) وضع آخر، يرجى التحديد: \_\_\_\_\_
12. ما هو وضعك الوظيفي؟
- (a) أعمل حاليا بدوام كامل
- (b) أعمل حاليا بدوام جزئي
- (c) عاطل/ة عن العمل
- (d) طالب/ة
- (e) غير ذلك، يرجى التحديد: \_\_\_\_\_
13. مع من تعيش؟
- (a) أعيش بمفردي
- (b) أعيش مع والديّ
- (c) أعيش مع زوجتي/ زوجي
- (d) أعيش مع الأصدقاء
- (e) غير ذلك، يرجى التحديد: \_\_\_\_\_
14. كم عدد الغرف حيث تسكن (باستثناء المطبخ والحمامات)؟ \_\_\_\_\_
15. كم عدد الأشخاص الذين يعيشون معك؟ \_\_\_\_\_

16. ما هو المستوى التعليمي لرب أسرتك؟
- (a) أقل من الثانوية العامة  
(b) شهادة الثانوية العامة أو ما يعادلها  
(c) درجة البكالوريوس  
(d) درجة الماجستير أو أعلى  
(e) لا ينطبق
17. هل لديك حالياً تغطية صحيّة؟ (a) نعم (b) لا
18. ما هي جوانب رعاية مرض السكري التي يغطيها التأمين الصحي الخاص بك؟ (اختر كل ما ينطبق).
- (a) لا شيء  
(b) دخول المستشفى  
(c) الفحوصات المخبرية  
(d) علاج الإنسولين  
(e) شرائط فحص سكر الدم  
(f) جهاز استشعار السكر (sensor)  
(g) مضخة الإنسولين و لوازمها
19. هل تلقيت تعليماً مفضلاً حول كيفية إدارة مرض السكري لديك؟ (a) نعم (b) لا
20. كيف تقيم معرفتك حول إدارة مرض السكري الخاص بك على مقياس من 1 إلى 5؟  
(1 = ضعيف ، 2 = مقبول ، 3 = جيد ، 4 = جيد جدًا ، 5 = ممتاز)
21. كم مرة قمت بزيارة عيادة السكري خلال العام الماضي؟
- (a) أقل من زيارتين في العام الماضي  
(b) زيارتان أو أكثر في العام الماضي
22. أي من الفحوصات التالية أجريتها على مدار العامين الماضيين؟ (اختر كل ما ينطبق)
- (a) فحص العين  
(b) فحص الدم للدهون / الكوليسترول  
(c) فحص الكلى (البول للألبومين الميكروي - Micro albumin)  
(d) فحص ضغط الدم  
(e) فحص القدم
23. هل أنت (حدد كل ما ينطبق):
- (a) تدخن/بين السجائر؟ إذا كانت الإجابة بنعم ، في أي سن بدأت؟ \_\_\_\_\_ سنة  
(b) تدخن/بين النرجيلة؟ إذا كانت الإجابة بنعم ، في أي سن بدأت؟ \_\_\_\_\_ سنة  
(c) تشرب/ين الكحول؟ إذا كانت الإجابة بنعم ، في أي سن بدأت؟ \_\_\_\_\_ سنة
24. ما هو أحدث مستوى تخزين سكر الدم (HbA1c) لديك: \_\_\_\_\_
- موثق عبر السجلات الطبية؟ (a) نعم (b) لا
25. ما كان مستوى تخزين سكر الدم (HbA1c) لديك قبل بدء جائحة كورونا (قبل شباط 2020): \_\_\_\_\_
- موثق عبر السجلات الطبية؟ (a) نعم (b) لا

26. كم عدد نوبات الحامض الكيتوني السكري (Ketones or DKA) تعرضت لها خلال الستة أشهر الماضية (حيث كان مستوى الجلوكوز في الدم لديك مرتفعاً لدرجة أنه كان عليك الذهاب إلى المستشفى وتلقي السوائل الوريدية والعلاج بالأنسولين؟) : \_\_\_\_\_
27. كم مرة خلال الأشهر الستة الماضية انخفض فيها السكر في الدم عندك لدرجة أنك لم تتمكن من علاج نفسك و احتجت إلى مساعدة أحدهم؟ \_\_\_\_\_
28. هل لديك حقيبة جلوكاجون (glucagon hypoglycemia emergency kit) لمعالجة نقص السكر الحاد في الدم ؟
- (a) نعم  
(b) لا

## II. القسم الثاني: قياس الدعم العائلي و دعم الأصدقاء

- بالنسبة للأسئلة 1 و 2 و 3 أدناه ، هناك عدد من العبارات. يرجى تقييم مدى اتفاقك مع كل عبارة عن طريق وضع دائرة حول الرقم الذي يتوافق مع اختيارك. إذا كان العنصر لا ينطبق عليك ، ضع دائرة على "غير مطابق".
1. أريد الكثير من المساعدة والدعم من عائلتي أو أصدقائي في: (ضع دائرة حول إجابة واحدة لكل سطر)

غير مطابق	موافق بشدة	موافق بعض الشيء	متردد	أعراض بعض الشيء	أعراض بشدة	
6	5	4	3	2	1	1. إتباع خطة الطعام
6	5	4	3	2	1	2. تناول الأدوية
6	5	4	3	2	1	3. العناية بالقدمين
6	5	4	3	2	1	4. القيام بالتمارين الرياضية
6	5	4	3	2	1	5. القيام بفحص السكر
6	5	4	3	2	1	6. التعامل مع مشاعري تجاه مرض السكري

2. تساعدني عائلتي أو أصدقائي ويدعموني كثيراً من أجل: (ضع دائرة حول إجابة واحدة لكل سطر)

غير مطابق	موافق بشدة	موافق بعض الشيء	متردد	أعراض بعض الشيء	أعراض بشدة	
6	5	4	3	2	1	1. إتباع خطة الطعام
6	5	4	3	2	1	2. تناول الأدوية
6	5	4	3	2	1	3. العناية بالقدمين
6	5	4	3	2	1	4. القيام بالتمارين الرياضية
6	5	4	3	2	1	5. القيام بفحص السكر
6	5	4	3	2	1	6. التعامل مع مشاعري تجاه مرض السكري

3. عائلتي و اصدقائي: (ضع دائرة حول إجابة واحدة لكل سطر)

موافق بشدة	موافق بعض الشيء	متردد	أعراض بعض الشيء	أعراض بشدة	
5	4	3	2	1	1. يتقبلوني و يتقبلون مرض السكري
5	4	3	2	1	2. يشعرون بعدم الارتياح تجاهي بسبب مرض السكري
5	4	3	2	1	3. يشجعونني أو يطمئنونني عن مرض السكري
5	4	3	2	1	4. لا يشجعونني و يحبطونني نحو مرض السكري
5	4	3	2	1	5. يستمعون إلي عندما أريد التحدث عن مرض السكري.
5	4	3	2	1	6. إنهم يزعمونني بشأن مرض السكري.

4. من أكثر شخص يساعدك في رعاية مرض السكري لديك؟ (ضع علامة في خانة واحدة فقط)

(a) الزوج/ة	(f) الدكتور
(b) الأب و الأم	(g) الممرضة
(c) أفراد الأسرة الآخرين	(h) غيرهم من أخصائيي الرعاية الصحية
(d) الأصدقاء	(i) لا أحد
(e) مساعد مدفوع الأجر	

### III. القسم الثالث: مقياس الرعاية الذاتية لمرضى السكري (SCI-R)

يقيس هذا الاستطلاع ما تقوم به فعلياً، وليس ما يُنصح بفعله. كم مرة اتبعت خطة علاج مرض السكري خلال الشهر أو الشهرين الماضيين؟ يرجى وضع دائرة حول الرقم الذي يتوافق مع اختيارك لكل عنصر أدناه.

أبداً	نادراً	أحياناً	عادةً	دائماً	
1	2	3	4	5	1. أفحص السكر في الدم بجهاز الفحص
1	2	3	4	5	2. أسجل نتائج فحص السكر في الدم
1	2	3	4	5	3. أفحص الحمض الكيتوني السكري (الكيتونات) عندما يكون مستوى السكر في الدم مرتفعاً
1	2	3	4	5	4. أتناول الجرعة الصحيحة من حبوب علاج السكري أو الإنسولين

5	4	3	2	1	5. أتناول حبوب علاج السكري أو الإنسولين في الوقت المحدد/ الصحيح
5	4	3	2	1	6. أتناول حصص الطعام الصحيحة
5	4	3	2	1	7. أتناول وجبات الطعام / الوجبات الأساسية والخفيفة في الوقت المحدد
5	4	3	2	1	8. أحتفظ بسجلات الغذاء (food records)
5	4	3	2	1	9. اقرأ ملصقات الطعام (food labels)
5	4	3	2	1	10. أعالج انخفاض نسبة السكر في الدم بالكمية الموصى بها من الكربوهيدرات/ النشويات
5	4	3	2	1	11. أحمل معي سكر سريع المفعول لمعالجة انخفاض السكر في الدم
5	4	3	2	1	12. آتي إلى مواعيد العيادة
5	4	3	2	1	13. أرثدي معرف التنبيه الطبي لمرض السكري (مثل بطاقة أو اسوارة تعريف).
5	4	3	2	1	14. أمارس الرياضة
5	4	3	2	1	15. أضبط جرعة الأنسولين بناءً على مستوى السكر في الدم والطعام والتمارين الرياضية

#### IV. القسم الرابع: مقياس الضيق/ الإنزعاج عند مريض السكري

قد يكون التعايش مع مرض السكري من النوع الأول صعباً. المدرجة أدناه مجموعة متنوعة من الأشياء المزعجة التي يعاني منها العديد من الأشخاص المصابين بداء السكري من النوع 1. بالعودة إلى الشهر الماضي ، يرجى الإشارة إلى الدرجة التي قد يمثل فيها كل مما يلي مشكلة بالنسبة لك عن طريق إختيار الرقم المناسب. على سبيل المثال ، إذا شعرت أن عنصرًا معينًا لم يكن يمثل مشكلة بالنسبة لك خلال الشهر الماضي ، فيمكنك وضع دائرة على "1". إذا كان الأمر صعبًا جدًا عليك خلال الشهر الماضي ، يمكنك وضع دائرة على الرقم "6".

مشكلة خطيرة جدًا	مشكلة خطيرة	مشكلة خطيرة نوعًا ما	مشكلة متوسطة	مشكلة بسيطة	ليست مشكلة	
6	5	4	3	2	1	1. الشعور بأنني لست ماهرًا في معالجة مرض السكري كما ينبغي.
6	5	4	3	2	1	2. الشعور بأنني لا أكل بعناية كما ينبغي
6	5	4	3	2	1	3. الشعور بأنني لا ألاحظ علامات تدل على انخفاض السكر في الدم كما كنت ألاحظها من قبل
6	5	4	3	2	1	4. الشعور بأن الناس يعاملونني بشكل مختلف عندما يكتشفون أنني مصاب/ة بداء السكري.

6	5	4	3	2	1	5. الشعور بالإحباط عندما أرى ارتفاعاً في معدلات السكر في الدم التي لا يمكنني تفسيرها
6	5	4	3	2	1	6. الشعور بأن عائلتي وأصدقائي يعطون أهمية أكثر مما ينبغي لمرض السكري.
6	5	4	3	2	1	7. الشعور بأنني لا أستطيع إخبار طبيب السكري بما يدور فعلياً في ذهني.
6	5	4	3	2	1	8. الشعور بأنني لا أخذ الأنسولين بقدر ما ينبغي.
6	5	4	3	2	1	9. الشعور بوجود الكثير من المعدات والأشياء المتعلقة بمرض السكري التي يجب أن أحملها معي دائماً
6	5	4	3	2	1	10. الشعور بأن علي إخفاء مرض السكري عن الآخرين.
6	5	4	3	2	1	11. الشعور بأن أصدقائي وعائلتي قلقون بشأن نقص السكر في الدم أكثر مما أريدهم.
6	5	4	3	2	1	12. الشعور بأنني لا أقوم بفحص مستوى السكر في الدم بقدر ما ينبغي.
6	5	4	3	2	1	13. الشعور بالقلق من أنني سأصاب بمضاعفات خطيرة طويلة الأمد ، مهما حاولت.
6	5	4	3	2	1	14. الشعور بأنني لا أحصل على المساعدة التي أحتاجها حقاً من طبيب السكري الخاص بي حول معالجة مرض السكري.
6	5	4	3	2	1	15. الشعور بالخوف من احتمال تعرضي لإنخفاض خطير في سكر الدم عندما أكون نائماً.
6	5	4	3	2	1	16. الشعور بأن الأفكار عن الطعام والأكل تتحكم في حياتي.
6	5	4	3	2	1	17. الشعور بأن أصدقائي أو عائلتي يعاملونني كما لو كنت أكثر ضعفاً أو مرضاً مما أنا عليه فعلياً.
6	5	4	3	2	1	18. الشعور بأن طبيبي السكري لا يفهم حقاً ما يعنيه أن يكون الإنسان مصاباً بمرض السكري.
6	5	4	3	2	1	19. الشعور بالقلق من أن مرض السكري قد يجعل أصحاب العمل أقل إعجاباً بي.

6	5	4	3	2	1	20. الشعور بأن أصدقائي أو عائلتي يتصرفون مثل "شرطة السكري" (بزعجني كثيرًا)
6	5	4	3	2	1	21. الشعور بضرورة أن أكون مثالًا في إدارة مرض السكري لدي.
6	5	4	3	2	1	22. الشعور بالخوف من التعرض لهبوط حاد لسكر الدم أثناء القيادة
6	5	4	3	2	1	23. الشعور بأن أكلني خارج عن السيطرة.
6	5	4	3	2	1	24. الشعور بأن الناس سيقولون من قيمتي إذا عرفوا أنني مصاب/ة بداء السكري.
6	5	4	3	2	1	25. الشعور بأنه مهما حاولت جاهداً مع مرض السكري، لن يكون ذلك جيدًا بما فيه الكفاية.
6	5	4	3	2	1	26. الشعور بأن طبيبي السكري لا يعرف ما يكفي عن مرض السكري و العناية بمرضى السكري.
6	5	4	3	2	1	27. الشعور بأنني لا أستطيع أن أكون في مأمن من احتمال تعرضي لهبوط حاد في سكر الدم.
6	5	4	3	2	1	28. الشعور بأنني لا أعطي مرض السكري القدر اللازم من الاهتمام الذي يجب أن اعطيه.

## APPENDIX G

### **Semi-Structured Interview Guide**

The following questions will be used to guide the qualitative interview:

1. Tell me how your diabetes self-care practices changed from late adolescence until now.
2. Who is helping you now with your diabetes care and how?
  - a. Probe: parents, peers, health care providers
3. What are the things that make it harder/easier for you to perform diabetes self-care practices by yourself?
  - a. Probe: How does COVID19 and the economic crisis in Lebanon affect your diabetes self management?
4. How do you think your diabetes affects your life?
  - a. Probe: academic/work life; family/social life?
5. How does your current relationship with others (your parents, peers, and healthcare team) affect how you care for your diabetes?
  - a. Probe: If you could change anything about how you are cared for by your healthcare team, what would you change?
  - b. If you could change anything about your relationship with your parents and peers with regards to diabetes, what would you change?
6. How is the COVID and the recent unstable economic situation in Lebanon affecting your ability to perform diabetes care?
7. Is there anything else you would like to discuss?

Follow up cues to keep the flow of the description will be used along with probes such as: “tell me a little more about that?” and “what do you mean by...”



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